

Disability: What Loss and Whose Loss?

Bob Sapey

Lecturer in Applied Social Science, Lancaster

University

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Introduction

About four years ago, I was asked to write a chapter about disability for a book on loss and grief for social workers (Sapey, 2002). I was very hesitant. Loss is an issue on which there has been a great deal of clarity within disability studies – traditional psychological theories of loss have been firmly rejected. Whilst the original UPIAS definitions recognised that impairment involved a physiological or functional loss, and that disablement as a form of social oppression would certainly involve a loss of inclusion, what was being rejected was the notion that people would necessarily be psychologically affected by impairment or disability in such ways as to require an individual adjustment via set stages of recovery. This approach usually consists of five stages; denial, anger, fear and bargaining before finally reaching a recovered

stage of acceptance. It is widespread enough to even be featured in an episode of the Simpsons.

My hesitancy to get involved with loss and disability was also due to an experience in 1988, when I was chair of the editorial board of *Social Work Today*. The editor had published a paper by a US academic, Professor Raymond Berger, on loss and disability which was quite a thorough review of some psychological literature. This paper sought to demonstrate that impairment should be conceptualised as a loss and to promote social work practice based on the need for psychological adjustment. Berger did not distinguish between impairment and disability and used the latter interchangeably with the phrase 'traumatic loss'. Mike Oliver (1983), in his book *Social Work with Disabled People*, had already pointed to social workers' practice being based on a stages approach to loss and grief as the most prominent example of how social work was based upon an individual model of disability. In response to the publication of Berger's paper, Oliver wrote to the magazine. He compared the magazine's decision to publish this paper with having,

topless social workers on page three as a means of combating sexism in social work, or a pictorial history of the black-and-white minstrel show as a guide to antiracist practice. (Oliver, 1988, p. 12).

Personally I agreed with this criticism of Berger's paper as I had witnessed social workers being quite unhelpful because of their faith in the stages approach. One young man I remember, who was living in a residential home in the 1970s, had asked for support in his application for council housing. The then assistant director of social services refused to provide this on the basis that he had not yet gone through the stage of anger. Fortunately he was determined and left without her support and eventually did get his home by turning up at the council offices one afternoon just before 5 o'clock, and when told once again that the housing officer would not see him, he settled down with a flask of coffee, sandwiches and a pack of cards – he was housed within a month!

What disabled people were up against in social work is quite well illustrated by this excerpt from a book published in 1970, *Psycho-Analytic Insights and Relationships: A Kleinian Approach*. It is also the only passage on disability in the whole book.

Illness and accidents at any age may confront us with slow or sudden loss of abilities. Denial of the limitations imposed can only lead to a superficial adjustment, which hides underlying persecution and depression. It is only when the work of mourning has been done and the anger, despair, and depression are eventually mitigated by love and courage, that the individual can go forward. If anger and despair

predominate permanently, the individual regresses to an earlier stage of development, becoming self-centred, self-pitying, with a chip on his shoulder and begrudging others their freedom, or infinitely demanding of their time and attention. If the loss can be admitted, mourned and accepted with courageous resignation, a heightened appreciation of the remaining gifts and opportunities can lead to development in a different direction. (Salzberger-Wittenberg, 1970, p.106)

This clearly illustrates the uncritical move from loss of ability to psychological disturbance. Whilst the promotion of these ideas was clearly damaging, I also believe that one of the effects of the strong criticism that Oliver and others were levelling at the association of loss and disability was to inhibit further exploration of the relationship between disability, impairment and other approaches to loss.

Having said that, it is also true that Oliver himself has provided some useful insights into the way in which acquired impairment might be conceptualised as a significant life event. In his own research on the social implications of spinal cord injury he had cited Silver and Wortman who concluded,

Our review of the available literature suggests that a great deal of variability exists in individual reactions to negative life events, both within a particular life crisis and across different crises. We have found little reliable evidence to indicate that people go through

stages of emotional responses following an undesirable life event. We have also reviewed a substantial body of evidence suggesting that a large minority of victims of aversive life events experience distress or disorganization long after recovery might be expected. Current theoretical models of reactions to aversive outcomes cannot account for the variety of responses that appear. (Silver and Wortman, cited in Creek *et al.*, 1987, pp. 20-21)

Oliver certainly did not wish to deny that people's experience of life changing injuries might include loss, but he argued that it was entirely inappropriate to assume that all people would necessarily go through the same stages, or indeed that such stages would lead to recovery without attention being paid to the material and social environment.

Clearly, breaking one's back or neck may have tragic consequences for some individuals but as most people appear to cope with such a happening, such coping can thus only be explained by reference to such unscientific notions as the indomitable nature of human spirit. This gives rise to the 'super cripple' phenomenon where those who cope are ascribed with heroic characteristics and flies in the face of the everyday realities of people with spinal cord injury who see themselves as ordinary people coping with extra-ordinary circumstances. (Creek *et al.*, 1987, p. 19)

This rejection of a stages approach is not just about acquired impairment. Speaking as the mother of a son born with impairments, Dona Avery described how she

fought the medical staff who wanted her to respond to these stages of grief after her child was born. She said,

I have seen a 5th stage, and it is not Acceptance or Hope of a Cure. It is learning that an unborn perfect child was one conceived by society, not me, and that the actual child I was gifted with is perfectly fine.
(Avery 1997)

Paul Abberley has also studied the psychological impact of impairment, but from a different perspective. He accounts for the dominance of theories of loss in the psychology of disablement by the fear of non-disabled people and their perception of impairment as a form of death. He argues that this fear runs so deep that it is almost impossible for disabled people to convince non-disabled people that this is not the case and, as such, the scientific credentials of traditional loss theories must be questioned. He concludes that:

IF disabled people display psychological abnormalities it is because they have been socialised into such traits ... Disabled people do not need to deny the individual psychological costs they pay, rather [they] need to identify them as a most directly experienced aspect of oppression, and dispute not the existence of psychological distress in disabled people but the kinds of causal account that are produced. (Abberley, 1991, p. 4)

This clearly has resonance with the work of Carol Thomas (1999) and Donna Reeve (2002) at Lancaster who have been exploring the psycho-emotional effects of disablism

and they certainly help to create an environment in which I have been able to undertake some study, albeit limited, of these issues.

So what we are left with is a very clear message that a stages approach is often inappropriate to understanding impairment and that it is also incapable of dealing with the problems of disablement that are socially constructed. Drawing on Abberley's ideas, I would suggest that the Kleinian approach mentioned earlier is actually a transference of the fears of the therapist onto their disabled client or patient.

New ideas

Getting back to the request to write a chapter, I was persuaded by the editor, Neil Thompson, that there were new developments in theorising practice in relation to loss and grief and that it would be useful to begin to explore how these related to disability. There were three particular ideas that were being introduced to social work at that time. These were,

1. The dual-process model, attributed to Stroebe and Schut
2. Meaning reconstruction, attributed to Neimeyer

3. Disenfranchised grief, attributed to Doka (Thompson 2002).

In different ways each of these have an impact on the arguments surrounding loss and disability which is what I now wish to explore.

As opposed to viewing grief as stages to be passed through, the dual-process approach argues that people shift between a loss and a restoration orientation, with either one being dominant at any point in time. Rather than acceptance being the end stage of a process, this idea recognizes that these fluctuations may go on for a long time, typically illustrated by the way anniversaries of events may trigger grief that had long been absent. The balance will shift from periods when our emotions may be dominated by loss to others when we are engaged in the activities of a new life without the person who has died. In the case of impairment these fluctuations could be related to responses to disabling and non-disabling situations. Thompson (2002) argues that the advantages of this approach are that it,

moves us away from the narrow, psychologistic approach which presents grieving as a (largely biologically-based) natural process and alerts us to the complex web of psychological, cultural and socio-political factors which interact to make loss

experiences far more complex than traditional approaches would have us believe. (p. 7)

The acknowledgement of the restoration orientation certainly helps to explain and include the experiences of disabled people who have rejected the stages approach. Instead of seeking conformity to a particular model, restoration is seen very much an individual activity and it may draw on collective action and the use of cultures of resistance as well as personal strengths and material resources. This is an approach which recognises the complexity of the lives that people lead both before and after the onset of impairment.

In Oliver's 1987 research on the social implications of spinal chord injury, (Creech *et al.*, 1987) he and his colleagues sought to measure the levels of dissatisfaction people had with their disablement. They found that this diminished after a period of time (about 6-8 years), but they could not explain this by a stages of recovery process as this did not fit with people's experience. What the dual-process model allows us to do is to rethink this as periods of different orientations with restoration becoming more dominant over time, but never absent and certainly influenced by other social and environmental factors.

The second of the developments, meaning reconstruction, is explained by Thompson as being,

premised on the fundamental argument that, when we experience a profound loss, we also experience a loss of meaning, a potentially deep-going disruption of our lifestory. Accordingly, the process of grieving can therefore be seen as one of making sense of the loss – answering to our own satisfaction the practical, existential and perhaps spiritual question of why it happened and reconstructing what our life means, particularly those aspects of our life directly affected by the loss. In effect, through grieving we are struggling to integrate the significance of the loss into our lives after our previous meaning system has been disturbed. (Thompson 2002, p. 7)

This is clearly similar to Bury's ideas on biographical disruption, but it also has some resonance with Oliver's (1983) argument for an interactionist approach to understanding the effect of impairment and disability, and the subsequent need for intervention. Although there are certain effects that may be triggered by loss, the actual impact of this on any individual will vary from person to person according to their own emotional, social and material resources, as will the ways in which different people choose to make sense of their present and future lives.

Neimeyer and Anderson (2002) describe three important aspects to reconstructing meaning after a loss: sense making; benefit finding and; identity reconstruction. In terms of making sense, while most people might ask "why?", the ways in which we answer this question varies

according to our individual psychological dispositions, our spiritual beliefs and our social support systems.

In terms of both benefit finding and identity reconstruction it may be helpful to consider Swain and French's (2000) work on an affirmation model of disability. They reviewed a range of literature in which disabled people point to benefits they have derived from being disabled and contrast this to the dominant view that conceptualises disability as a personal tragedy. We might try to understand the range of conceptualisations as rational reconstructions of meaning due to the previous experiences and beliefs of individuals and their current resources.

In developing the idea of an affirmation model, Swain and French draw on the way some people, within disability arts in particular, have not only incorporated disability and impairment within their lives, but have overtly asserted the value of its inclusion within a positive identity. Meaning reconstruction acknowledges the need people have to establish a positive identity when aspects of their being which contributed to that identity have been lost. Whereas traditional individual model approaches to disablement suggest that individuals need to come to terms with change and in particular with a diminished social role and hence to accept an inferior identity, the social model

emphasizes the need for attitudes of others towards impairment to change. Meaning reconstruction appears compatible with this insofar as it does not impose any specific mode of change, and the new meanings that people construct to make sense of their lives are recognized as being varied.

Whatever the reason, as Abberley (1991) points out, people with impairments do experience distress. This may be the result of impairment effects, especially pain, or the effects of being treated in oppressive ways, but as Morris (1991) has argued the social model of disability has the potential to deny disabled people the legitimacy of their own feelings if it becomes too rigid itself. Meaning reconstruction may offer an opportunity to include psychological and sociological ideas that acknowledge individual difference and choice without weakening the validity of the political argument about the causes of disability.

The final idea entering social work is that of disenfranchised grief, and in relation to death, one of the clearest examples of this is that of people with learning difficulties who may be thought of as unable to experience loss in quite the same way as others. It may be the griever who is disenfranchised in this way or it may be the loss that is not recognized, such as with pets or devalued

relationships. Interestingly here, in the disability studies arguments it can be that the loss associated with impairment is disenfranchised by the political project. Corker and French (1999) draw attention to the difficulty that disabled people have writing about their personal experiences because those working from an individual model approach are likely to say, 'We told you so!' (p. 10) and this may be viewed as too great a risk within the disabled people's movement.

However, disenfranchised grief is also a concept that could be used differently to describe the way in which psychologists and others have attempted to exclude the experience of disabled people from the development of their own individual model theories of disablement (Finkelstein, 1980). Here, traditional theories of loss and their imposition on disabled people are a prime example of disabled people's experience being disenfranchised. I am aware that this is not exactly what Doka may have been referring to as disenfranchised grief, but it is the way in which people experience impairment and disability that is ignored, and this may include grief, or lack of grief.

How some disabled people describe loss

Over the past three years, along with two colleagues, John Stewart and Glenis Donaldson, we have been

undertaking a study¹ in the north west which is intended to explore the social impact of a 100% increase in wheelchair use between 1986 and 1995. The early part of this involved in-depth interviews with wheelchair users about their experiences and as part of the analysis of that data, I looked at the issue of loss. I have not attempted to analyse the data in a framework of any of the theories I've just described as the data was not collected in a way that would lend itself to such an analysis. Rather, I have tried to construct a story from what people actually said.

I started with two questions. First, is impairment necessarily experienced as an emotionally troubling loss, and second, how do negative views of impairment impact on the lives of disabled people? The response that is expected if disablement is thought of as a psychological loss was present in the data.

I knew when I was on the floor. I couldn't move. I think your brain like locks out a bit and stops you from taking too much in at once and I think that's the power of the brain, so that you only absorb so much at once so that you can only realise and it takes time as to the realisation ... so in my head I sort of had it that yes, I was paralysed on the floor and

¹ *The Social Implications of the Increase in Wheelchair Use* is funded by the NHS Executive North West R & D Directorate.

yet ... you still think you're going to walk. You know for quite a while and then gradually it sinks in that it isn't going to happen and you know, so gradually I've come to terms with it that way.

And this parent certainly explains feelings which conform to a traditional psychological approach.

I didn't know about Cerebral Palsy but perhaps he assumed that I did and so really, it was quite a body blow because all I thought of, as lay people do, is wheelchair! That's it, what does the future hold and any hope that you might have had is dashed again.

I don't know that you would have gone through, or any parent would have gone through, a sort of a grieving process, is that true? Yes definitely true.

I think when we first had [our daughter], when we found out we wished she was dead. Definitely, I'll be honest about that, we wished that she wasn't around any more, we didn't want this child and why was it us? What had we ever done wrong and why couldn't it happen to somebody else?

There are clearly elements of 'sense making' in this second quotation and the respondent very honestly refers to a lay model of disability which Swain and French (2000)

sum up in the phrase 'better dead than disabled'.
 However, this next man felt that he had gained from becoming disabled and probably fits into the affirmation model.

My CV has really grown. I've actually gained more out of life since I've been in a wheelchair than I did before my accident. I've certainly achieved so much.

He has found benefits and incorporated his impairments into a new and positive identity. We found many people who valued the way they are and for some of them, those who devalue impairment may cause resentment.

I think they're [people like Christopher Reeves] living in a fantasy world. I think being such a high profile person like he is, he could do more good for disabled people. I didn't like the advert where it showed him walking cause it made it like, well if you want to be normal ... you've got to be walking. ... I thought, well what you're stating is it's not acceptable to be paralysed...

This man described how he responded to being offered to partake in experimental therapies.

I've been asked to go down that route, but I would never go down that route simply because I think about

life now and before I had my accident. One day I woke up and I had nothing, and I've coped with nothing, and I've learnt to deal with nothing, and I've got on with nothing and that helped. That nothing has brought everything. Now to be given a chance of having it back is scary for.

For him, remaining in a restoration orientation could be seen as being dependent on incorporating his impairment. Whilst he uses the word 'scary', he goes on to argue that life is not a dress rehearsal and that rehabilitation with no definite outcome is very distracting.

Just to be a Guinea Pig and to try out stuff and that, but they don't tell you the ins and outs, and you've got to bear in mind that it's so many, that so many months or years is going to be taken away from your life; because you're going to be involved in occupational therapy, physiotherapy, back and forth to the hospital and I don't want that. I've got a life.

But for others it is different. One man who quite recently had been paralysed in an accident said.

Well I'm 110% behind them, yes I'm very hopeful and very confident that something will happen. I don't suppose I'll ever play football again, but if I could just get out the chair for part of the day I'd be

so much better off, and if just other things like bowels and bladder, if they were improved...

Even though this man has a different attitude, he is seeking physiological gain rather than being in a state of psychological denial. For him there may be few benefits, but nevertheless he is actively getting on with many aspects of his life.

Although some respondents with acquired impairments did think that maybe people with congenital impairments would have a different experience of loss because they would not have experienced a sudden realisation of being disabled, this woman who has a congenital impairment disagrees.

I'll tell you when I realised for the first time that being disabled wasn't necessarily a good thing, it was, believe it or not, when I was 11. And it was the last year of junior school; the kids went on a holiday. I just assumed that I'd go and I was absolutely devastated when my Mum and Dad said "no" and I said, "well why not" and they said, "because the teachers will have to help". By that time as far as I was concerned I was physically independent, ... Up to that point it had not been a problem. If I needed carrying an adult lifted me up and carried me so I didn't see it as

somebody doing anything that they shouldn't do, or extraordinary.

She went on to explain how this was the first time she experienced disability as a negative.

...that was the first time it dawned on me that I was any different really, or more importantly that my difference went against me. I'd perceived myself as being different in terms of when I was at school. The teachers were still allowed to smack the children and for some reason I always knew that I would never be smacked, ... perhaps it would be frowned upon if a teacher smacked me at school, but that was OK to be different in that way. I didn't like the idea that being disabled would stop me from going or doing anything and that was the real first time when it really hit home.

Again, if we relate this to the dual-process model, as a child this woman moved from an orientation in which she was aware of an advantage to one where she experienced disability as a negative, yet the advantages remained.

This illustrates the way in which a simple stages approach is inappropriate due to its temporal and unidirectional nature.

There are aspects of being disabled, other than impairment, which may be experienced as loss. One man identifies the loss of friends.

My friends now are friends that I've built up relationships with since I've been back home. Friends before my accident have nothing to do with me, are embarrassed to see me when I'm in town. ... I even see them in town and they look at me, and I don't know if they're embarrassed or anything or whether they think I've changed, I don't know. Out of all my friends that I used to know before my accident, I've only got two that I keep in contact with.

But the question he asks is whose loss is this?

At first I was upset, I was gutted but now it's a case of I look back and it's their loss, it's not mine. OK I have changed, but I've changed for the better and my personality is a lot stronger. I feel a lot stronger myself, physically and mentally, but I don't hate them or anything, but I think it's their loss.

In addition to friends, respondents identified loss of home, loss of job, loss of confidence, and loss of role. Another common issue was losing control of what happened after the onset of an impairment and we had several people describe the ways in which they were excluded from

fundamental decisions about how their homes were adapted. Some described how the professionals involved contributed to this exclusion by keeping them in the dark and infantilising them.

I was sat in the kitchen and they were wandering round the house, and upstairs, deciding on what they were going to do, and I'd no say in it, and it was like they were the adults and I was the child.

Having decision making taken away by professionals is clearly frustrating and constituted an important area of loss of control for several of our respondents. The disabled person's expertise was being disenfranchised by the social workers and OTs. Although these professionals were practising from a knowledge base, it is questionable as to whether they were consistent. Whilst one respondent might report not being allowed home until alterations were complete, another would tell of how she had to go home before they could be started. This kind of treatment by professionals is disabling and as I suggested earlier, achieving a restoration orientation may be dependent on living in a non-disabling environment, not simply the physical environment the OT may be trying to construct, but also the environment of the process through which the adaptations are achieved.

Loss of control was also a feature when respondents discussed their wheelchairs and their care arrangements. Some were given very little choice in either of these areas, but in addition, some respondents described other people's reactions as the cause of grief for them. This man with an acquired impairment talked about how his wheelchair is symbolically negative and this has the potential to impact on his ability to be positive.

There's still a huge stigma about being in a wheelchair like 'oh he must be retarded or whatever', and you know you get people talking to the person who's with you rather than you but yes some people definitely don't treat you as an equal.

For this person however, her childhood friends were fine, but it was her mother who could not accept her wheelchair.

Right from the word go I was included. My wheelchair was a good cop car and we used to play cops and robbers and the kids especially the boys used to love chasing up and down with me. ... [Some] people are afraid of using a wheelchair and I know that my Mum, and I've never really understood her for this, my Mum hates my wheelchair.

It is difficult to imagine how a child reconciles such mixed messages and even as an adult in her 30s, this woman

says that she's never really understood her mother's dislike of her wheelchair. In the process of developing a positive identity it must be harder to cope with these disabling responses from such a close relative than from the professionals. However, what we must also remember is that as most disabled people acquire their impairments and have been non-disabled themselves, they will also have to deal with their own prejudices.

I said "I don't want a wheelchair, what do I want a wheelchair for?" and the stupid thing was that I'd spent a lifetime working with older people and people with disabilities and that was for somebody else. You see I was the carer, it doesn't happen to me, absolutely no way, I don't need a wheelchair.

One area of loss that goes unrecognised by professionals is the price people have to pay in terms of loss of privacy and increased vulnerability in order to receive care services.

I think with the carer's job, we as the elderly or the disabled we're in a very vulnerable situation, because once I'm in bed I can't move. So OK you've got to trust some people, but I don't trust them totally. They are very good I must admit but I had a bad experience with my last care

company, so that's why I'm a bit dubious.

This person went on to describe one awful night during which she dare not sleep out of fear of what her carer was doing, yet also she dare not say anything directly to her because of her dependence. The same person described how her father thought she was 'terrible' for making a complaint to the care agency.

I'd set my own questions, my Dad say's "you're terrible you" 'cause I've had to get, well not rid of them, but I've had to phone the office and say "don't send that carer again" because, I don't know, they just weren't there. I know you should give everyone a chance but they just drive me mad.

The feeling of vulnerability, the loss of control and the emotional price of taking action – whilst I am a bit wary of labelling this as grief, nevertheless this person certainly appeared to be disenfranchised in these matters. Perhaps being disenfranchised is also a key reason why this next respondent told us that gaining control always seemed to involve fighting.

I did get much say, but only because of me and because of the way I am. But I had to fight like you always do, like you always do have to fight for everything, always.

Conclusions

I think it is clear that applying a traditional psychological approach to loss and grief to impairment or disability is not very helpful. Whilst we can see all the stages as being present – denial, anger, fear, bargaining and acceptance – they do not necessarily follow an order and the expectation that anger should give way to acceptance would be to deny disabled people social justice – it is only anger and fighting back that helps some people to gain control over important aspects of their autonomy that others are all too willing to take away.

I think there is a very clear message for social workers and other care workers in this data that the regimes they might establish to support independent living may lead to a real loss of control. This is not a new idea, but conceptualising it as the construction of a disenfranchised grief may help to strengthen the argument for professionals to show more respect to service users.

Biographical disruption may be quite a well established idea in medical sociology, but whether it has penetrated professional practice in a positive way is another matter. There appears to be evidence that practitioners such as OTs, physiotherapists and social workers are tending to take over decision making and this is probably linked to their belief that someone who has a physical impairment is

in some way incapable of making their own decisions. Yet, clearly they would not have thought this had they not been dealing with people with impairments, so it raises the question of what type of psychological difference they think this makes. This tendency to exclude points to a understanding of disability as a form of disruption, but certainly in a negative way. It may be that with the linguistically more positive idea of meaning reconstruction rather than the more negative idea of disruption, professionals could themselves develop more positive practices and begin to work in collaboration and as allies to disabled people.

Finally, I do think the dual-process model offers the most of these three ideas. This is such a clear challenge to the psychological stages theory of loss and it helps makes sense of the experiential ways in which disabled people have been challenging the notion of disability and impairment as a loss. Those experiences, as we know, do not deny the feelings of loss, or of impairment having tragic consequences, but they seldom match the expectations of a stages approach. Most people do not put their lives on hold while they adjust to a sick-role, rather they take control as they can and incorporate their new self into an existing life. For professionals,

recognising the co-existence of loss and restoration orientations, could make a big difference to practice.

So to end, I want to return briefly to the title of this paper, *What Loss? Whose Loss?* In terms of the *what*, I can identify two main losses: loss of control over ones life; and the loss of opportunities to make sense, find benefit, develop a positive identity and to occupy a restoration orientation. Certainly there is evidence that at any point in time we could find people who appear to exhibit the features of a more traditional approach to loss, but I must concur with Silver and Wortman (cited above) that there is little evidence in my reading of the literature to suggest that these features are part of a stages model.

In terms of *whose loss*, it is clear that these issues directly and adversely affect disabled people, but it is also clear from some of the data I have examined that they also affect parents and that sometimes, it is others who are seen as losing something. Beyond this I want to be more hesitant and merely suggest some ideas for further study as I think any conclusions I might draw should be more complex than I am able to state at present.

Perhaps the question is not simply one of who is affected, but who constructs the loss. If most loss is associated with disabling environments – material, social or emotional –

then it may be more pertinent to look for the causes. Often these lie outside the impaired individual, but they may also lie inside when that person holds on to a range of negative perceptions of disability acquired before the onset of their impairment. I think that both the meaning reconstruction and the dual-process models give us frameworks which are helpful to understanding these issues in ways that can also improve practice in the welfare field.

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