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Anorexia: Illuminating Impairment or Dishonourable Disability?

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Abstract

Since its evolution in the 1960s the social model of disability, forged as an alternative to the medical model, has become increasingly established and influential. Consequently, supporters of this way of thinking have felt able to criticise it. Anorexia, not generally included in Disability Studies, will be used below to address perceived flaws in the social model, for instance its neglect of impairment and experience. While not providing answers to these disagreements, this article hopes to promote further discussion and raise issues of concern to those who are familiar with the social model and to those with an interest in anorexia.

Introduction

Anorexia is not considered a conventional disability, although for various bureaucratic and financial purposes it is regarded as thus. For example, in Britain, 'anorexics'[1] are entitled to Disability Living Allowance (DLA) and at university, people with this condition can claim extra financial support as disabled students. However, 'disabled' is a label that 'anorexics' interviewed for this article declined from adopting[2] even though the oppression they face mirrors that which disadvantages disabled people, such as medical hostility, media misrepresentation and the onerous power of the cultural 'norm'.

This similarity in experience suggests that the social model of disability could be used to aid discussion on anorexia, an impairment associated with teenage girls or 'superwaif' models, but which, in fact, affects both genders and people of all ages, social and ethnic groups (Abraham and Llewellyn-Jones, 1997). In addition to moving away from stereotypical depiction's of anorexia, looking at this condition from a social model perspective may also raises issues of interest to disability theorists.

The social model of disability has liberated people from the individualising tendency of the medical model, removing self-blame and calls for self-alteration, because instead of seeing the environment as static and the disabled person as alterable, the social model reverses this understanding. However, this model has been criticised for taking a narrow approach towards disability based on structural barriers neglecting the issues of impairment and experience which isolates those with impairments like anorexia from fitting into it. These areas, along with the division between mental and physical disabilities and the specific problems faced by those with invisible impairments, will be discussed below using the voices of nine interviewees to animate points made. All interviewees came from a support group for students with problems around food at which I act as facilitator having experienced anorexia firsthand. Their words "are not intended to be representative...rather their words give expression to some of the issues which concern us" (Morris, 1991: 11). They make theoretical discussion more engaging and, above all, enable the personal voice to become political.

Anorexia and Debates in Disability Studies

The growing credibility and influence of the social model has enabled proponents to criticise aspects of it. Therefore, I shall look at current debates within Disability Studies linking them with the investigation of anorexia; namely arguments for bringing impairment and experience into the model, the division between mental and physical disabilities and the difficulties faced by people with invisible impairments.

Impairment and experience

The heavy emphasis placed on impairment by the medical model has meant that, traditionally, the social model focused attention away from this area in its work (Begum, 1996: 170). However, some disability activists state that the social model can no longer centre on institutional or physical barriers and call for its reformulation to acknowledge that people are disabled by society and their bodies (Hermeston, 1999: 15). Paterson and Hughes have staunchly advocated a need to incorporate impairment and the body into the model (Hughes and Paterson 1997), declaring that disablism makes people constantly aware of their somatic selves (Paterson and Hughes, 1999: 608). Likewise, Crow suggests that bodily experiences are an inherent part of disabled people's lives (Crow, 1996: 59) and that although impairment may not cause disability, it is a precondition for this form of oppression (Crow, 1996: 69). She also implies that the traditional social model has failed some individuals by making it hard for them to talk about the difficulty and discomfort arising from impairment itself (Crow, 1996). Hence, to centre debate on disabling barriers, it is argued, is as limited as the previous tendency to regard disability as bodies-to-be-rehabilitated because "[s]uch a focus represents only part of a much more complex, multi-layered picture" (Pinder, 1996: 137).

Reluctance to incorporate impairment into the social model leaves certain conditions and their consequences misunderstood by both lay people and medics (e.g. sickle-cell anaemia; see Kraemer, 1994) and may mean that inappropriate or oppressive services go unchallenged (Crow, 1996). This can be seen in the case of anorexia whereby misconstruction of the nature of this impairment leads to prejudice and inhumane treatment such as force-feeding and Electro-Convulsive Therapy (ECT). If impairment were incorporated into the social model it might allow for an exposition of the physical effects of anorexia, often overlooked in society. As one interviewee declared: -

> ...anorexia is far too glamorised. I think somebody should go out there and tell [people] what it's like to...not to be able to control your bowels, or have hair growing all over your body, or to lose hair in handfuls from your head and all the horrible things that go along with it. But nobody ever talks about these things in the newspapers, do they. (Fiona)

Highlighting the true nature of anorexia may mean it ceases to be trivialised as a 'slimmer's disease'. Its physical consequences include muscle wastage and extreme stomach cramps (Menzies-Welham, 1997), stunted growth, low blood pressure, bad circulation, neurological disturbances, impaired immune system, irregular heartbeat, great mal fits, kidney function problems and cardiac arrest (Orbach, 1993). Infertility, a primary complication of anorexia (EDA, 2000), can have a long-term effect on someone's personal and social status. People in relationships without children may be socially regarded as selfish and only thought of as a 'real couple' when part of a larger family. Paradoxically, if people have fertility treatment to become 'normal' they may face negative reactions from certain sectors of the public, especially religious groups, for interfering with nature. Therefore, as a secondary impairment deriving from anorexia, infertility can further stigmatise an 'anorexic's' sense of self.

It is illogical to suggest that people with impairments experience oppression and discrimination in the same way. As Shakespeare suggests: "Can I, as a person with restricted growth, effectively speak for or write about someone with cerebral palsy..." (Shakespeare, 1993: 255). The type of impairment someone has, and the way it is socially constructed, influences how others treat and interrelate with her/him. Individuals with mental disabilities may be regarded as a threat or as morally weak whereas those with physical impairments may be pitied as unfortunate 'victims'. Such disablist stereotypes can detrimentally affect people's "psycho-emotional well-being" (Thomas, 1999: 3). Disability

Studies, while continuing to look at barriers to activity and at what disabled people are prevented from 'doing', should also examine how disablism and impairment shape the way people act and think about themselves, at barriers to their 'being' (Thomas, 1999). For instance, a continual problem for 'anorexics' is that their impairment makes them feel 'odd' as this comment illustrates:

> I worry about how people will react if they know I've had anorexia because I feel like it's a...tainted part of me and that they'll judge me for it. People just don't know how to act around you when tell them and they end up treating you differently. (Petra)

Thus, the nature of an impairment impacts on how someone feels, on how a disabling condition is encountered. As a mental impairment, anorexia is disabling in different ways to physical disabilities and, because it fluctuates like other impairments such as Crohn's disease, how disabled an individual feels will vary at different moments in time. When an 'anorexic's' weight is very low the physical environment may be felt to be most hostile, for example, when muscle wastage makes walking up stairs difficult. Yet, if the condition is not so visible, but still dominates individual's mental functioning and behaviour, she/he may feel that attitudinal barriers are more disabling because others cannot accept 'difference'.

It is not only the type of impairment that influences people's experience of a disabling society. Factors like gender, ethnic status and sexuality also play a part, but these issues tend to be overlooked by materialist approaches (Barnes, 1991; Oliver, 1990) towards the social model (Thomas, 1999: 101). Anorexia illustrates that how an individual encounters disability is influenced by these areas. For example, because it is regarded as a 'female condition', men may be ridiculed or rejected when they self-starve, experiencing greater oppression than women with anorexia as a result.

In addition, anorexia highlights the fact that people experience disability differently when they acquire a stigmatising impairment rather than being born with it. People can easily become disabled at any stage of life, suddenly finding themselves moving from a socially dominant to an oppressed group. This change of status, on top of social and physical limitations, can prove hard to cope with. Disabled people who have had a 'former life' as 'normal' will probably have internalised culturally produced, negative views associated with disability making the reality of their circumstances and union with other disabled people difficult. As Tepper recalls: "The meaning of the cognitive category of disability I learned prior to my disability did not allow me to accept myself as part of that population" (Tepper, 1999: 105). One interviewee made a similar comment:

> The image I had of people with anorexia before I got ill was completely different to how it is. I remember seeing a programme on the subject and thinking how stupid the girls were and thinking that their parents should make them eat...When you've actually been through it you realise it's a lot different to what you see on TV, but what you see means you don't want to be branded as 'anorexic'. (Marie)

People impaired in later life may find that characteristics and roles they used to posses, like mother, teacher, 'enthusiastic', are submerged by a 'disabled identity' as they come to be defined by their particular impairment and associated with stereotypical 'disabled qualities' such as passivity or dependency. Friends may also alter how they act towards the individual, in some cases disappearing altogether:

> I think people can treat you differently if they know. I mean that's what I remember with my old school friends they sort of...I felt they were treating me differently...like I'd see them and they'd ask me how I was feeling and you don't say that to someone who's just a friend. I was always made to feel like an invalid'. (Jayne)

> I lost a lot of my friends through this. I mean my school friends were great. They visited me when I was in hospital and when I was at home they would visit me to check I was OK. But we were bound to grow apart because I was locked in my own narrow world which centred around food and exercise while they were out there learning how to be adults'. (Marie)

New networks of friends have to be sought and tentative steps may be taken towards meeting others with similar impairments. This is often what happens when 'anorexics' join self-help groups from which companionship, as well as support, is sought. However, meeting with others is not only comforting, it can also be empowering. Support groups offer people an alternative way of expressing themselves in the world and give the opportunity to challenge issues, leading to activism in some cases.

Experiences of disability have started to be explored through a recent surge in personal narratives (Bauby, 1997; Grealy, 1994; Murphy, 1987). The same is true with anorexia (MacLeod, 1981; Shelley, 1997). Such accounts enable people to depict their own situation, rather than having it (mis)represented by others. They "tell us not simply about the particular, the micro-environments in which individuals live...but also about the general, the macro-environments which make up the broader social context of these lives..." (Thomas, 1999: 84). Personal accounts can unify people through "pride and shame, pleasure and pain" (Marks, 1999b: 614), educating them about their impairment, making them aware that other people share similar experiences and diluting personal blame (Morris, 1991: 164).

Nasa Begum, an active member of the Disability Movement, recalls how she was conditioned into denying her body as a youngster. It was only when she read the book *Images of Ourselves* (Campling, 1981) which gave disabled women the opportunity to express their personal thoughts about impairment that she was able to accept her own body (Campbell and Oliver, 1996: 101). Interviewees also remarked on how reading others' experiences of anorexia helped them manage their condition, although drawbacks of engaging with such accounts were mentioned:

> I found it really useful at the start because I could relate to what they were describing. But now that I'm coming out the other side, I'm looking for accounts of people who have completely 'got over' their anorexia because so many of the accounts seem to say that people are coping rather than recovered. But I don't want to be like that. I want to be able to say I've got rid of it...Maybe I should use that to spur me on to getting better, so that I can write an account like that. (Kitty)

> I suppose in a way it helped to feel that someone else was going through the same thing...But at the same time, it's sometimes hard because the people who write them seem so 'sorted', they seem to know exactly why they are as they are...With me, there are so many different causes. I just feel completely bewildered by the whole thing. (Louise)

> There was a time when I'd actively seek them out...Sometimes they boosted my determination, other times they made me feel I'd never get better. Often I'd compare myself, my feelings, actions and, of course, weight, with those described and I admit feeling almost triumphant if I'd been better than them at it, you know if I'd lost more weight. This is a side of anorexia I still find difficult, comparing myself to others all the time. (Fiona)

Some social modellists have criticised narrative accounts for detracting attention away from the fight to change society. Finkelstein asserts that "finding insight in the experiences of discrimination is just a return to the old case file approach to oppression, dressed up in the social model jargon" (Finkelstein, 1996: 11). Such theorists tend to be males who have adopted a dualistic mode of thinking dividing the public/political from the private/personal, a division feminists have been striving to demolish by arguing that 'the personal is political' based on the notion that "public policies can be crafted on private experience" (Peters, 1996:

227).

Feminists declare that the personal realm has been devalued because it is seen as 'feminine' and they have attempted to reverse this trend by giving women the opportunity to voice their experiences through qualitative, emancipatory research undoing the notion that some areas of life are private (Thomas, 1999: 69). It is argued that Disability Studies must do likewise (Morris, 1991) because taking a stance of the 'personal as political' calls for individuals' voices to be heard. This will result in their subjective experiences and, consequently, their lives being given value (Morris, 1991: 183).

Similarly, 'anorexics' need to delineate their situation, giving realistic accounts of the condition. Too often professionals have a stereotyped idea of an 'anorexic' as being childish and stubborn, which influences their treatment and approach towards a patient, denying her/his subjectivity as the individual comes to be constituted by her/his condition. Differences in the experience of anorexia need to be emphasised because how it is encountered and dealt with depends on someone's personal, psychological and social circumstances. In addition, it is vital to recognise how the impairment itself can affect people's image of themselves[3], especially since it is classed as a 'mental illness'.

Mental/Physical Divide

The Disability Movement urges people to celebrate their difference, but mental disabilities, including anorexia, are so steeped in sinister or negative connotations that it can be hard to be open about such impairments, as the following quote demonstrates:

> ...when I told my mum I was going to St George's for help I remember she was shocked and my brother looked up from his newspaper and said 'What, St George's for nutters?' This made me realise that eating disorders could have negative associations and might be misunderstood. So it made me a bit weary of telling other people. I mean it was OK for me to see a dietician and the GP, but when I had to see a psychologist, people thought I must be a bit weird.

The social model needs to acknowledge the personal experiences of people with mental disabilities as they struggle against attitudinal rather than structural barriers. This calls for an element of compassion within the model for those unable to deal with an impairment, which is often seen as a sign of weakness and a threat to the Disability Movement's campaign for independence and acceptability.

Social model literature fails to clearly define whether people with mental disabilities ('survivors') are part of the general discussion giving little recognition to such individuals or their organisations (Beresford, 2000: 168). Beresford suggests that disabled people and survivors are united in some ways. For instance they are forced together for bureaucratic purposes, individuals may be positioned as mentally and physically disabled, and both groups endure oppression and discrimination (Beresford, 2000: 169). However, many survivors reject being included in the social model because they do not see themselves as disabled (Beresford and Wallcraft, 1997: 69) associating this "with the medicalisation of their distress and experience" (Beresford et al., 1996: 209). Likewise, people with physical impairments may not wish to be associated with the 'mentally ill' whose behaviour is frequently painted as bizarre or violent (McNamara, 1996).

People with mental disabilities tend to come at the bottom of the hierarchy of impairments, below those with physical and learning disabilities, because they are constructed as deviant and dangerous (Beresford, 1993: 21), as possessing a spoiled identity and lacking rationality (Beresford and Wallcraft, 1997: 77). The media plays a fundamental role in this portrayal focusing on the strange or aggressive behaviour of people categorised as 'mentally ill'. This has real consequences for individuals living with such disabilities because politicians are affected by what is reported and shape policies around mental health accordingly.

Recent scare stories have lead to calls for 'compulsory treatment orders' so that individuals can be treated against their will in their own home (Brindle, 1999: 12). In addition, there have been moves to institutionalise people with 'personality disorders' even if they have never committed an offence (Beresford, 2000: 168). As Beresford and Wallcraft comment, the Disability Movement "has campaigned against the arbitrary abuse of disabled people's human and civil rights, [but] the restriction of survivors' rights...is enshrined in law as part of the provisions established to maintain and 'treat' them" (Beresford and Wallcraft, 1997: 76).

Despite the differences between survivors and disabled people, links have been established. They campaigned together in Trafalgar Square for a Civil Rights Bill which lead to the establishment of the Disability Discrimination Act and survivors have attended and addressed the British Council of Disabled People's AGM (Gifford et al., 1995/96). Forging further links between survivor and disability organisations would be beneficial because they can "learn from each other's different experiences; work and campaign more effectively for...rights; and resist outside attempts to divide and play [them] off against each other" (Beresford, 1993: 21). Although some survivors have rejected the social model, it unites people with different impairments by emphasising that society rather than an impairment is disabling liberating people from personal blame experienced especially by those labelled as 'mentally ill'.

'Anorexics' may face hostility and be regarded as strange or unreliable because they are classed as having a 'mental illness'. Their impairment may also be judged as self-inflicted preventing other disabled people from accepting them into the Disability Movement and influencing the way professionals care for them. They may be treated less compassionately, regarded as less worthy of attention because their situation is thought to be self-induced. The stigmatisation attached to this mental disability therefore forces many 'anorexics' to deny the reality of their condition to themselves as well as to others. They strive to keep their impairment invisible.

Invisible Impairments

Impairments can be visible or invisible. Unless an 'anorexic' is seriously underweight, it falls into the latter and, like other invisible impairments, is only exposed in specific circumstances such as mealtimes. Someone with an invisible impairment may try to appear 'normal' by adopting certain tactics to 'pass' in society (Goffman, 1963). 'Anorexics' are no exception. They devise ways of hiding their impairment while still carrying out 'anorexic' behaviours:

> I'm an expert at making excuses for not eating. Saying I'm allergic to things is a good way of avoiding food, and becoming a vegetarian has helped. (Marie)

> I only eat when people can see me, so they think that I eat more than I do. Like if my housemates go out and get some chocolate I'll get some too, but that one bar will be all I eat all day, although my friends don't know that. (Kitty)

People with invisible impairments are left with the dilemma of whether to 'come out' or not as disabled. This has links with gays and lesbians whose 'Otherness' is also invisible, allowing them to pass as 'normal'. Defined as the 'discreditable' by Goffman (1963), someone with an invisible impairment will often live in fear of it being 'found out' making social interaction awkward as she/he tries in vain to hide the impairment because of the social stigma associated with it, as suggested by the following statement:

> I still find it's something about myself that I try and hide. I'm always petrified that I'll be found out. I do tell some people, and I'm finding it easier to be more open, but I choose who I tell very carefully. (Marie)

Paradoxically, people with invisible impairments may also feel as though they are colluding with their own oppression by denying their condition. 'Coming out' may remove this uncertainty and guilt and it allows for identification with others so that feelings of isolation are reduced. A fundamental aspect of 'coming out' is saying, "'This is who I am and I align myself with this group of people'" (Corbett, 1997: 95). However, taking this stance may leave individuals open to negative reactions, not only about their impairment per se, but about its reality. For example, Kraemer (1994) exposes the discrimination people with sickle-cell anaemia can encounter if they demand morphine when in a state of 'crisis'. The intensity of pain expressed is non-measurable leading some professionals to question their patient's distress. In certain cases, patients are thought to be 'putting it on' to gain access to a potent drug. This doubt is increased when the nature of the impairment means that only a short time after the drug is administered the individual is able to carry on with life as if nothing has happened. Similarly, others cannot appreciate the true extent of the mental anguish that food, size and weight causes the 'anorexic' who is often told, simplistically, to 'just eat':

> People say 'I'll take you to McDonalds, that will sort you out'. They don't understand that they can't just put food in you to make you better. It's much harder than that. And that's when it gets frustrating because people think it's so easy to get over because eating is such an ordinary thing - but not to an anorexic. Eating takes on a whole different meaning, with rules and rituals and fears associated with it. It's annoying that people think recovering is just about eating - if that's all it was about I'd be better now. (Louise)

As a consequence, people with anorexia may come to be dismissed as attention seeking and selfish:

> I think at the back of most people's minds there's an idea that all she needs is a good kick up the backside basically. (Shauna)

> I sometimes feel that, I mean it's obviously still a big problem for me, but I feel that people think I'm just down or depressed, that I'm attention-seeking, that I'm not really anorexic, that I'm just trying to make out that I've got an eating disorder. (Crissy)

If those with invisible impairments decide to self-define as disabled, their claim may be rejected because they do not 'look the part'. The Disability Movement may not welcome or accept these individuals judged to be "far too symmetrical in physique to be included" (McNamara, 1996: 198). Such a reaction may stop people accepting the proposal contained in this article, that is, examining anorexia, an invisible impairment, using the social model of disability regarding it as a misuse of the model, an affront to 'truly' disabled people. But if disability is conceived of as a flexible and fluctuating social construct there is no reason why such a proposal should be rejected since a 'real', or 'false', disability does not exist. As Thomson asserts, disability unites a "collection of embodiments whose only commonality is being considered abnormal" (Thomson, 1997: 283). However, whether 'anorexics' would self-define as disabled is debatable. In fact, most of the interviewees seemed more content and concerned with hiding what they felt was a stigmatising aspect of themselves, even though doing thus can prove wearing:

> The secrecy of it, trying to keep it to yourself is awful...I was really embarrassed about it so I just couldn't tell anybody. It was like I was living a double, secret life and this got really tiring... I think people just don't know how much you're going through. I don't think there's enough said about it, which makes you keep secret about it. (Crissy)

More discussion on anorexia is therefore needed that does not pathologise or blame the individual to remove the burden that an individual may feel at not being able to disclose this aspect of her/his life.

Conclusion

Crow warns that just because concerns about impairment are excluded from the social model, they do not disappear. Impairment can not be ignored because it plays such a big part in disabled people's lives (Crow, 1996). Yet social modellists often focus on structural barriers of disability ignoring somatic and emotional aspects of disablism. Thomas warns that failing to incorporate personal experience into the social model means areas of disabled people's social lives, such as relationships, will be hijacked and framed by those taking an individual/personal tragedy approach towards disability (Thomas, 1999: 74), those who, often, are not disabled. Hence, incorporating impairment and experience into the social model is essential because it allows disabled people to define disability for themselves.

In addition, including these areas may make the model more relevant to those diverging from the 'disabled norm' - that is, those who are not white, heterosexual, physically and visibly disabled males, such as 'anorexics'. If the social model were applicable to a wider range of people, who might, consequently, identify as disabled, the political power of the Disability Movement would be strengthened because of a growth in numbers, a growth that would also be aided by the convergence of disability and 'survivors' movements.

Individuals from both groups experience oppression as a result of society's obsession with the 'norm', be that aesthetic, functional or behavioural and, therefore, they should unite in their demand to be heard. Oppression deriving from a perceived 'difference' is unacceptable in a country like Britain which proclaims to be developed and tolerant. The limiting, artificial 'norm', that is a white, heterosexual, able-bodied male, needs to be eradicated so that all people, be they female, black, gay or disabled are treated with the dignity and respect they deserve as citizens and human beings.

Unfortunately, while divergence from the 'norm' is still stigmatised, those with invisible impairments will continue to hide their condition. This can lead to a lifetime of secrecy.

Many of the interviewees stated how having anorexia meant they lead a double life and were in constant fear of being 'found out', which affected their ability to form relationships and feel at ease in others' company:

> I find it hard to make new friends because I'm always worried about how they'll react when they know I've got anorexia. I don't think the majority of people really understand what it's all about. They just see it as something to do with wanting to look thin and think you must be vain or strange'. (Heather)

Anorexia shows how fragile and artificial an identity can be, how easy it is to cross the line between 'normal' and 'abnormal'. Like other people who lose weight, 'anorexics' may at first receive positive reinforcements of their behaviour with people admiring their altered appearance and the will power thought to accompany it. Yet, almost overnight, these comments change from being appreciative to being condemnatory, leaving 'anorexics' confused as to when and why reactions reversed. There is a shift in how their actions are perceived, from 'normal' dieting to behaviour considered odd, 'mental', impaired, a transformation accompanied by prejudice and oppression. Others will change the way they interact with an 'anorexic' and medical professionals may come to play a significant role in and wield power over their lives. In this sense, 'anorexics' unexpectedly become 'disabled'.

Therefore, anorexia, a mental and often invisible impairment, is an important topic for Disability Studies to include in its work. It highlights the fact that impairment and experience are crucial areas for the social model to investigate because how people encounter disability is influenced by a variety of factors. Disabled people's lives can not be considered as a homogenous entity. Incorporating anorexia into this discipline will expand and ameliorate understanding of this condition and could also benefit Disability Studies widening its scholarly remit which needs to be broadened if it is to move out of the ghetto it presently finds itself in (Davis, 1995; Marks, 1999a) to become a more mainstream, accessible field of academia.

Endnotes

1. Some theorists (e.g. Hepworth, 1999) suggest the term 'anorexic' confines people to a medical label. However, because 'anorexic' is a recognised term it will be used here, but in inverted commas, indicating that it is not linked to narrow medical definitions. People labelled thus may come to construct the term for themselves, an example of conscious raising, similar to disabled people's redefinition of 'disability' through the social model.

2. They felt that to do so implied they were dependent or intimated that their impairment was permanent.

3. For example, putting on just a few pounds or losing some weight may change and influence an 'anorexic's' whole persona and ability to participate in the world.

4. A 'Survivors Movement' for people with mental disabilities exists which dates back to 1985 when, at an international conference, it was realised how underdeveloped this movement was (Campbell, 1996: 219). It is continuing to develop, but lacks the same political and social power as the Disability Movement (Beresford, 2000).

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