Beyond 'vulnerability': An ecological model approach to conceptualising risk of sexual violence against people with learning difficulties

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Abstract

This paper presents an ecological model approach to conceptualising risk of sexual violence against people with learning difficulties, which takes account of the complex social processes involved in the creation of risk. The concept 'vulnerability', often assumed to be a risk creating characteristic of people with learning difficulties, is too simplistic to take account of all the processes involved in the formation of risk of sexual violence. Risk is influenced by personal attributes, self-defence-skills, environments and socio-cultural factors. These risk factors are closely interlinked and constantly interact with one another. The ecological model provides a tool for examining the impact that interactions between individuals and social environments have on an individual's learning and the development opportunities that have the potential to increase self-defence skills.

Introduction

People with learning difficulties in the UK are considerably more likely to experience sexual violence than non-disabled people. Mencap *et al.* (2001) estimate that the likelihood of serious sexual attack is four times higher than amongst non-disabled people. Explanations of the high incidence of sexual violence against people with leaning difficulties tend to be sought within the individual and in the immediate environment: It has been suggested that there is a causal link between learning difficulties and the likelihood of experiencing sexual violence (e.g. Mencap *et al.*, 2001; Department of Health (DoH), 2000; Fairbairn *et al.*, 1995). This is implied in the label 'vulnerability', a concept that is

commonly used to describe the increased risk of people with learning difficulties of experiencing sexual violence. However, the conceptualisation of risk of sexual violence through individual 'vulnerability' focuses analysis on the individual. An ecological model approach demonstrates that such a focus is too simplistic. This paper presents a tool for examining risk of sexual violence that adopts a social model philosophy.

Theoretical underpinnings and terminology

This paper is based on the social model of disability, which makes a distinction between disability and impairment. This distinction was first suggested by the Union of the Physically Impaired Against Segregation (UPIAS) in 1976:

Impairment: lacking part of or all of a limb, or having a defective limb, organism or mechanism of the body;

Disability: the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities. (page 3-4)

When Michael Oliver (1983), however, adapted these definitions and termed them a social model approach to disability, he was explicit that the social model applies to people with intellectual impairments too. The inability to understand complex words would then be an impairment, but being excluded from gaining knowledge because information is not provided in an accessible format; for example via plain language and pictures to aid understanding, is a disability.

The importance of this social model of disability is that it no longer sees disabled people as having something wrong with them – it rejects the individual pathology model" (Oliver, 1983:27).

Disability activists such as Morris (1991) promote the view that impairment should be celebrated as individual difference in a diverse society. Why should we all understand and respond to new information in the same way? Learning styles of non-disabled people differ and so do those of people with learning difficulties. People with learning difficulties add human diversity to human

diversity. There are many kinds of intellectual functioning; each has its strengths and weaknesses. If we would accept intellectual impairments as adding to diversity, we could benefit from each other's strengths and also support each other through our weaknesses. Hence a social model approach suggests that the problems people with learning difficulties encounter in their daily lives are not caused by their impairments, but by society.

The level and form of prejudice against disabled people amounts to being 'oppressed'. It is illustrated by the discrimination widely practiced in the built environment, employment, leisure and personal relationships (Barnes & Mercer, 2002:10).

Learning Disabilities or Learning difficulties

In the UK there are currently two terms in use to refer to people with intellectual impairments: people with learning difficulties and people with learning disabilities. 'Learning disabilities' is used by the UK government and professionals, while 'learning difficulties' is used by the UK self-advocacy movement. The relevance, use and meaning of these terms are discussed below.

The White Paper Valuing People (DoH 2001) defines 'learning disability' as a lasting condition that started before adulthood that may include the presence of a "reduced ability to cope independently" or "a significantly reduced ability to understand new or complex information and to learn new skills" (page14, section 1.5).

In this paper 'learning difficulties' refers solely to individuals with intellectual impairments and not to individuals with the educational label of 'specific learning difficulties' (Department for Education and Skills, 2005). 'Learning difficulties' is not a new term. The self-advocacy movement has used it for more than ten years (see for example Central England People First 2000, Goodley 2000, Harris 1995). As far back as 1969, Morris suggested 'learning difficulty' as an alternative way of referring to people with intellectual impairments. She describes 'learning difficulty' as a social phenomenon, a creation of culture, politics and society (Morris 1969). 'Learning difficulties' emphasises that people are able to learn once difficulties in the learning process are overcome (Harris 1995). The term fully embraces social model terminology. Oliver and Barnes (1998) assert that

"the use of the phrase 'people with disabilities' is unacceptable because it blurs the crucial distinction between impairment and disability" (page 18).

According to the social model, the phrase 'people with learning disabilities' translates as 'people with social barriers to learning'. This makes little grammatical sense. In contrast to impairment, disability is not part of the individual experiencing it, as the words 'with disabilities' would suggest. Disability happens when a person with impairments is disadvantaged by social and attitudinal barriers. We may talk about disadvantaged people, but not about 'people with disadvantages'. We may talk about oppressed people, but not about 'people with oppression'. In the same way UK social model advocates are adamant that we should use the phrase 'disabled people', but not the phrase 'people with disabilities' (e.g. Oliver & Barnes 1998). Nonetheless, many individuals with learning difficulties would prefer not to be labelled at all (Central England People First, 2000; Goodley, 2000; Harris, 1995; Finnegan, 1995). In this paper 'individual' rather than 'person with learning difficulties' is used as

Sexual Violence

A further note must be made on the use of the term 'sexual violence'. Professionals may be more familiar with the term 'sexual abuse', which is widely used in government publications, for example by the current national framework for adult protection 'Safeguarding Adults' (Association of Directors of Social Services (ADSS) 2005).

much as possible, to avoid an excessive use of the label.

We commonly use the term 'sexual abuse' to describe experiences of sexual violation of adults with learning difficulties (e.g. Mencap et. al., 2001; McCarthy & Thompson, 1996) older adults (e.g. DoH, 2000) and young people (e.g. Westcott & Cross, 1996; Kennedy, 1996), but 'harassment', 'assault' and 'rape' to describe the experiences of non-disabled adults (e.g. The London Rape Crisis Centre, 1999; Holland et. al., 1992; Kelly, 1988). This differing terminology emphasises the perceived differences between individuals who are accredited with adult social status and those who are not. Adults with learning difficulties are often viewed as underdeveloped or incomplete adults. Adult social status is characterised by an individual's inclusion in social, political,

economic and family life. Adults are expected to be self-sufficient and those who are assumed not to fit this criterion, such as young people, older people and disabled people, are defined by their perceived dependence on non-disabled adults. Such social groups are often excluded from exercising full citizen rights and responsibilities (Priestley, 2003). The differing terminology, 'sexual abuse' and 'sexual violence', distorts the fact that sexual violence is a similar experience for disabled and non-disabled adults and for working aged adults, young people and older adults. In this paper the more commonly used term 'sexual abuse' is replaced by the term 'sexual violence' against adults with learning difficulties.

This paper adopts a broad feminist definition of sexual violence: The term refers to unsought or unwanted contact and non-contact sexual experiences, including sexual harassment, sexual assault, pressurised and coercive sexual intercourse and rape (Kelly, 1988). According to the Sexual Offences Act 2003, a sexual experience is unwanted if a person did not consent to the experience (e.g. section 1(1)b, 2(1)c, 3(1)c, 4(1)c). Consent means that a person 'agrees by choice, and has the freedom and capacity to make that choice' (section 74). A person with learning difficulties who has no or little knowledge on sex and sexuality, sexual conduct and the consequences of sexual behaviour is deemed to be lacking the 'capacity' to consent to sexual behaviour (Foundation for People with Learning Disabilities, 2001, para 4.5.13). A person who did not exercise resistance to a sexual act has been violated if they feared the consequences of noncooperation, due to use of actual violence (section 75(2)a) or fear of violence (section 75(2)b). A person may have been asleep or unconscious (section 75(2)d), under the influence of a substance that disabled their defences (section 75(2)f) or they may have been physically unable to exercise resistance due to an impairment (section 75(2)e). Survivors of sexual violence often experience difficulties in naming their experiences as harassment, assault or rape (The London Rape Crisis Centre, 1999; Holland et. al., 1992; Kelly, 1988). Kelly (1988) places sexual violence on a continuum. She argues that the boundaries between categories of sexual violence are blurred and that a person's conceptualisations of what has happened to them change over time. The broad term 'sexual violence' enables survivors to identify that they have been harmed, without having to give their experience a name they feel uncomfortable with (Kelly, 1988).

The UK policy context

Within a five year period the UK government published two adult protection policies, with No Secrets (DoH, 2000) being replaced by Safeguarding Adults (ADSS 2005). The systematic protection of 'vulnerable' adults through Central Records Bureau (CRB) checks of the staff who are working with them has become compulsory with the Care Standards Act 2000 (part 7). Recently there have been high profile investigations into services for people with learning difficulties at the Cornwall Partnership National Health Service (NHS) Trust (Healthcare Commission 2006) and at the Sutton and Merton Primary Care Trust (Healthcare Commission) 2007a). The inspections revealed poor health care practice, dehumanising treatment of the residents and incidents of physical and sexual violence. As a response to the Cornwall enquiry, a national audit of NHS and private healthcare services for people with learning difficulties has been carried out (Healthcare Commission, 2007b). The enquiry not only looked at issues of protection, it also assessed whether people with learning difficulties using services are able to live dignified lives. It also examined how well services comply with the Disability Discrimination Act 1995 and Valuing People (DoH, 2001). Adult protection and the evaluation of services for people with learning difficulties are important processes. The fact that we are now considering these issues with such great care indicates that there is an increased public commitment to enforce the right of people with learning difficulties to protection from dehumanising treatment and violence.

Central government practice guidance to UK professionals working with people with learning difficulties explains risk of sexual violence through the concept of 'vulnerability'. Practice guidance often conveys the impression that there is a causal link between learning difficulties and 'vulnerability', thus being labelled with learning difficulties inevitably means that an individual is 'vulnerable' as well (e.g. ADSS, 2005; DoH, 2000; Lord Chancellor's Department, 1997). The most commonly used definition amongst UK professionals describes a 'vulnerable' adult to be someone who:

is or may be in need of community care services by reason of mental or other disability, age or illness; and who

Is or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation. (Lord Chancellor's Department, 1997:68)

The new adult protection policy *Safeguarding Adults* (ADSS, 2005), however, replaces the term 'vulnerable adult', because it is recognised that the label 'vulnerability' may lead to the assumption that the cause for violence is located within the individual experiencing it. 'Vulnerable adults' are now termed 'adults who may be eligible for community care services'. This group is defined as:

those whose independence and wellbeing would be at risk if they did not receive appropriate health and social care support. They include adults with physical, sensory and mental impairments and learning disabilities (ADSS 2005:4).

Nevertheless, despite revised linguistics, the focus remains on individuals who are defined through their assumed dependency on non-disabled adults. The focus on impairment as the main risk factor to sexual violence entails elements of an individual model approach to disability. This is too narrow a focus, which an ecological approach addresses, enabling us to take account of both, individual and social causes of risk and of the interactions between them.

The origin of risk factors to sexual violence within an ecological model

When Sobsey (1994) examined the pattern of known sexual offences against people with learning difficulties, he explained them by applying an ecological model of sexual abuse (p.104). He analysed actual incidents of sexual violence, however, while the model put forward by this paper is concerned with identifying risk factors, in order to examine opportunities for risk prevention work with people with learning difficulties. While Sobsey (1994) posed the question why sexual violence had happened, this paper asks how sexual violence can be prevented. Thompson (2006) puts forward an ecological model that illustrates the formation of inequalities and discrimination in the social circumstances surrounding individuals, the PCS model. The structure of the ecological model of the origin of risk to sexual violence differs significantly from the PCS model. However there are also some commonalities, which will be explored below.

In Figure 1 an ecological model is utilised to explain the origin of risk. It should be noted that the language and format of the model have been changed in comparison to Sobsey's (1994) model, to create a model that incorporates five groups of risk factors to sexual violence.

Exosystem

Microsystem

Individual (personal attributes) (self-defense skills social networks)

Environment

Society and culture

Figure 1: Ecological model of the origin of risk to sexual violence

The individual's *personal attributes* are at the centre of the ecological model. Personal attributes include age, gender, intellectual and physical impairments, ethnicity, sexuality, culture, religion, economic status, social class and so on. Secondary analysis of data from the British Crime Surveys (BCS) 1998 and 2000 (Myhill & Allen, 2002) found that age and gender were major risk factors for experiencing sexual violence. However, this analysis did not take account of impairment as a risk factor. Intellectual and physical impairments are known to have a significant impact on risk (ADSS, 2005; Sexual Offences Act 2003, Mencap *et. al.*, 2001; DoH, 2000; Kennedy, 1996, Westcott & Cross, 1996; Westcott, 1993). The BCS found little variation in the

occurrence of sexual violence amongst differing ethnic groups. Ethnicity is consequently not viewed as a particular risk factor (Home Office, 2004). Economic status on the other hand has a high impact and those from less affluent households are at an increased risk to experience sexual violence (Home Office, 2004).

Self-defence skills are a flexible part of the individual. They are shaped and developed through life and learning experiences. The term self-defence skills describes those characteristics that would determine whether an individual has 'capacity' to consent to sexual activity under the Sexual Offences Act 2003. 'Capacity' to consent is not defined by the Act, but it is assumed that an individual must possess a range of skills to be able to give informed consent to sexual activity and to effectively resist unwanted sexual approaches. The literature suggests that such self-defence skills may include:

- Knowledge about sex and sexuality (e.g. Foundation for People with Learning Disabilities, 2001; Fairbairn *et. al.*, 1995; Hingsburger, 1995);
- The vocabulary needed to report sexual violence (e.g. Westcott, 1993);
- Social awareness to detect or anticipate sexually violating situations (e.g. Mencap *et. al.*, 2001; Fairbairn *et. al.*, 1995);
- The ability to distinguish sexual behaviours from personal care (e.g. Foundation for People with Learning Disabilities, 2001; Milligan & Neufeldt, 2001);
- Awareness of one's right to resist sexual contact (e.g. Hingsburger, 1995);
- Self-esteem needed to effectively resist an unwanted sexual approach (e.g. Hingsburger, 1995; Westcott, 1993);
- Feeling in control over what is happening to one's body (e.g. Hingsburger, 1995; Westcott, 1993);
- Ability to make decisions (Hingsburger, 1995).

A focus on individual attributes and self-defence skills in explaining the origin of risk to sexual violence could reflect an individual model approach to disability, unless care is taken to include the social factors. The argument presented in this paper challenges individualising approaches to explaining sexual violence and demonstrates how self-defence skills result from social processes. They are neither fixed capacities nor inherent to the individual.

The individual, protected by self-defence skills, is situated within a *microsystem*, the 'home' environment. This consists of an individual's immediate social network, typically family members or paid carers and fellow residents within a residential group. Research suggests that most incidents of sexual violence take place within this system (e.g. Mencap *et. al.*, 2001; McCarthy, 1999; McCarthy & Thompson, 1996; Sobsey, 1994). Consequently it has been suggested that isolation and over-protection within a microsystem are not effective mechanisms to prevent sexual violence (McCarthy, 1999; McCarthy & Thompson, 1996; Sobsey, 1994).

The microsystem is embedded within an *exosystem*, the environment within which the 'home' is situated. This consists of the neighbourhood and communities within it. All community activities, such as education, leisure, employment and day care, are part of the exosystem.

Finally, the exosystem is embedded in the *macrosystem*, the wider society and culture. Thompson's (2006) C- (cultural) and S- (structural) level are located within the macrosystem. Culture refers to

shared ways of seeing, thinking and doing. It relates to the commonalities – values and patterns of thought and behaviour, an assumed consensus about what is right and what is normal; it produces conformity to social norms (Thompson, 2006:27 [original italics]).

The structural element in the macrosystem consists of social forces and socio-political dimensions. Law and social policies are located at this level.

Interactions between different domains of the ecological model

Five areas of risk to sexual violence are introduced above. Now the interactions between them are examined with a particular focus on the interactions between an individual's personal attributes and the micro-, exo- and macrosystem and on the formation of an individual's self-defence skills in response to interactions with the three systems. Personal attributes are known to impact upon level of risk: Adults with learning difficulties are more likely to experience sexual violence than non-disabled adults. As outlined above, the assumed causal relationship between learning difficulties and risk has been conceptualised as 'vulnerability'. The ecological model adds a new dimension to our understanding of the formation of risk by enabling us to take account of additional *social* risk creating factors and to see beyond individual 'vulnerability'. The ecological model illustrates how the micro-, exo- and macrosystem react to the personal attribute 'learning difficulties'. This is best demonstrated with specific examples:

Example 1: The parents of an adult with learning difficulties may be more involved in giving advice and support with his or her (sexual) relationship than they are with the relationship of a non-disabled peer (microsystem).

<u>Example 2:</u> A young person with learning difficulties may receive a different quality of sex education to his or her non-disabled peers (exosystem).

<u>Example 3:</u> The Sexual Offences Act 2003 offers particular protection to adults who are deemed to have no 'capacity' to consent to sexual activity (macrosystem).

These inputs from the micro-, exo- and macrosystem impact upon the specific experience of individuals. The inputs are reactions to the personal attribute 'learning difficulties'. Families, communities and the law respond to people with learning difficulties differently than to non-disabled people. This is not necessarily negative. Equal opportunities can only be created if we accommodate for the particular needs of each individual. Not accommodating an individual's needs arising from impairment would be oppression (Barnes & Mercer 2003). We must, however, be aware that different treatment of people with learning difficulties has implications for the formation of an individual's level of risk to sexual violence. Not only do inputs influence an individual's experience, they also provoke further change in the environment. Let us return to one of the above examples:

Example 1: Parents (microsystem) might not allow their disabled son or daughter to go to a night club (exosystem). This might be provisionally protective and reduce risk posed by the exosystem, but the increased involvement of the parents might also disable the individual from acquiring

some of the skills needed to defend against sexual violence (individual: self-defence skills), for example independent decision making skills.

An ecological model approach helps us to understand that events in the social world do not happen in isolation. Any one event will change the course of subsequent events. Particular treatment of a person with learning difficulties will have consequences. This is of particular importance in the formation of self-defence skills, which are developed through learning and development opportunities, and which are determined by complex processes within the individual's immediate social networks (microsystem), within the environment (exosystem) and by culture and the wider society (macrosystem).

To illustrate this process it is useful to envisage the formation of a specific self-defence skill; the ability to make decisions. Many people with learning difficulties live in environments where decisions are often made for them by their families or carers (microsystem) and by other people within the exosystem, such as teachers and professionals. A resulting lack of practice in independent decision-making in everyday life makes it more difficult for a person to make the decision whether they welcome an unsought sexual approach or not. Hingsburger (1995) asserts that: "[t]he ability to make up your own mind is the first step on the way to autonomy and the ability to say, 'No!" (page 23).

The new Mental Capacity Act 2005 is a macrosystem input on an individual's ability to make decisions, which has the potential to change decision making interactions with people with learning difficulties on all levels of the ecological model: The Act stipulates that people with learning difficulties must be assumed to have capacity to make a decision unless it is established that a person lacks capacity to make a particular decision (section 1(2)). Changes within the macrosystem will, over time, interact with and produce change in the exosystem and microsystem. Under the new law, for example, professionals (exosystem), families and carers (microsystem) should encourage people with learning difficulties to make their own decisions or at least to be as involved as possible in the decision making process. This will shape the individual experiences of people with learning difficulties. Increasing practice in decision-making will enhance an individual's self-defences.

By applying an ecological model to the origin of risk factors to sexual violence of people with learning difficulties, it becomes apparent that risk does not just originate within the individual. It is instead composed of complex social processes. Change to any domain of the ecological model will cause change to other domains and reshape the formation of risk factors. The next section explores how an ecological model understanding of risk may guide preventative work that is underpinned by social model values.

Suggestions for anti-oppressive preventative work with individuals

Thompson (1992a, cited in Thompson, 2006) argues that [t]here is no middle ground; intervention either adds to oppression (or at least condones it) or goes some small way towards easing or breaking such oppression (page 15).

Preventative work with people with learning difficulties that focuses on an individual's inherent 'vulnerability' can become oppressive. If a person is assumed to be at risk because of who they are, then nothing can be done to alter that state of being than to protect them (Hingsburger, 1995). While protection by an outside body is of importance to all of us at some points in our lives, expecting people with learning difficulties to rely solely on protection by others would be disempowering. A focus on individual 'vulnerability' as the cause of risk would lead to exceptionalistic solutions which conceptualise the individual as the cause of risk (Westcott & Cross, 1996).

Anti-oppressive preventative work must reject the concept of 'vulnerability'. Instead of focussing just on the individual, we must also aim to find universalistic solutions to reduce risk to sexual violence. Universalistic solutions focus on changing the environment and conditions that surround a person (Westcott & Cross, 1996). They are situated on the macro-, exo- and microsystem. Universalistic solutions take the pressure for change off the individual and re-focus it on the environment. Examples of universalistic solutions that work to reduce risk to sexual violence are the additional protection offered to people with learning difficulties by the Sexual Offences Act 2003 and the compulsory

CRB checks of staff working with this group of people that were introduced by the Care Standards Act 2000.

In addition to universalistic change, risk preventative work with individuals remains important. As part of this process an individual's particular level of risk to sexual violence needs to be measured. Generally this task must be approached with great care, because it focuses on the individual and can easily lead to the belief that the individual's status causes the risk. Identifying individual risk factors should therefore always be accompanied by an analysis of social factors as well, as suggested by the ecological model. If these precautions are taken, the concepts assertiveness and resistance could be applied to measure an individual's potential for self-defence against sexual violence. Assertiveness and resistance are positive self-defence skills, which must be learned by all humans. To be assertive is to be confident, to believe in oneself and one's right to resist unwanted sexual approaches. Resistance is the skill by which an individual defends against an unwanted sexual approach. It is the ability to exercise control over what is happening to one's body. In order to exercise effective resistance an individual must be aware of the social implications of sexual behaviour and be able to make his or her own decisions. If an individual is found to lack these skills, we must provide learning and development opportunities that enable the individual to acquire them. Our response is therefore enabling. We seek solutions in the circumstances surrounding a person (micro-, exo- and macrosystem). Changing the environment in order to enable change in the individual provides a universalistic tool for an exceptionalistic solution.

In order to provoke further universalistic change that benefits all social groups who are at risk to experience sexual violence, we must challenge the existence of unequal power relations in our society. Inequality occurs in response to age, gender, impairment, ethnicity, class and other personal attributes (Thompson, 2006). Feminist writers have conceptualised sexual violence as the exercise of power and control (e.g. Holland *et. al.,* 1992; Kelly, 1988). Consequently, if we challenge unequal power relations, we challenge conditions that create opportunities for sexual violence. Universalistic questions must furthermore ask why some individuals in our society become perpetrators of sexual violence. Investigations into incidents of sexual violence must focus on the motivations of the violator and on the conditions that allowed an

unwanted sexual approach to succeed. Such an analysis is however beyond the scope of this paper.

Conclusion

This paper suggests an ecological model approach to conceptualising risk to sexual violence, which is underpinned by the social model. It outlines how the high risk of sexual violence against people with learning difficulties is socially created. The concept of 'vulnerability' is criticised, because it focuses analysis of the origin of risk onto the individual. Individual 'vulnerability' assumes that a certain set of personal attributes and low selfdefence skills combined create risk. The ecological model, in contrast, demonstrates that 'vulnerability' takes insufficient account of the social formation of self-defence skills and of the impact of environmental, cultural and social factors on the formation of risk. Explaining risk through 'vulnerability' calls for exceptionalistic solutions, namely for the protection of the 'vulnerable' individual. Findings from research suggest that protection by confining individuals to environments that are considered to be safe, such as residential care homes or specialist day care settings, does not stop sexual violence (e.g. McCarthy, 1999; McCarthy & Thompson, 1996; Sobsey, 1994). Perpetrators of sexual violence can be found in any environment. Many researchers suggest that the safest way of protecting people with learning difficulties is to enable them to increase their individual self-defences (e.g. McCarthy, 1999; McCarthy & Thompson, 1996; Hingsburger, 1995). The ecological model explains how self-defence skills are shaped and provides a tool for identifying areas for effective risk prevention interventions.

To sum up, if we are committed to reduce risk to sexual violence, we must refrain from individualistic conceptualisations of risk through the concept 'vulnerability'. Instead of focussing solely on the protection of 'vulnerable' individuals, we must see beyond 'vulnerability' and aim to eliminate conditions that create risk. Interventions should be empowering and universalistic, targeting social processes that are responsible for the formation of risk.

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