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## CHAPTER 12

### The Social Model, the Emancipatory Paradigm and User Involvement

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#### **Introduction**

It is only the disabled person who can satisfactorily define his or her needs in terms of the enabling of equal opportunity. This is the basis of demanding consultation and it is the purpose of consultation (HCIL 1990: unpagged)

Since this statement was made in 1990, there has been a mushrooming in the number and type of user/consumer consultation and research exercises carried out by service providers and policy makers, often in response to legislation. In 2002, I carried out a study which was prompted by concerns that service user involvement (UI), instead of providing a voice for disabled people, had served instead to legitimise the aims of service providers and policy makers. In addition, it was suggested, UI had distracted people's attention and energies from the main disability agenda - the emancipation of disabled people through full human and civil rights including the right to participate in society on equal terms with others. But were

these fair criticisms? In broad terms, I attempted to examine whether UI is a worthwhile exercise, that is, were there any tangible signs of change as a result of disabled people's participation, how people involved perceived it and finally, had it had an empowering effect? Put another way, does UI as it is currently practiced sit comfortably with the struggle for equality implicit in the social model, does it fulfil or dissipate the vision of those disability rights campaigners who originally called for disabled people to have a real and effective voice in service provision?

This chapter is based on that study and will review the methods used, provide an analysis of the key findings and emerging themes, and conclude by reflecting on my research practices within the emancipatory paradigm.

### **The social model**

Although the first stirrings of disability protest had begun in the 19th century, it was not until the 1960s that disabled people started to come together collectively and to challenge the role of paternalistic impairment-specific charities like the RNID and SCOPE (formerly the Spastics Society) who, together with the growing body of welfare professionals, sought to speak on behalf of and had significant influence over the lives of disabled people (Campbell and Oliver 1996). By breaking away from these traditional charities and forming new pressure groups, disabled people were able to question their position in society, how they wished to be perceived and to develop the roles they would play in the wider struggle against their oppression.

The social model is accredited as originating from within UPIAS in the 1970s (Campbell and Oliver 1996), and later formalised by Oliver (1983:23). It redefines disabled people's position and status, by framing the causes of disability in social terms rather than viewing the person's impairment or pathology as the problem: that is, the ways

in which the physical, cultural and social environments exclude or disadvantage those labeled as disabled. In this way disabled people have been able to express their situation in terms of human rights and as an issue of equality, aligning themselves with other oppressed groups. However, for disabled people the biggest obstacles to their inclusion in society are negative public attitudes and material considerations such as the economy and the way it is organised by the mode of production (Barnes 1991; Oliver 1996). Furthermore, for disabled people, the dynamics of oppression are deeply rooted in the social and welfare policies of the state: they are evident in the power relationships present in UI for example, which include issues of control and the roles assigned to users in research formulation (Fisher 2002). Notwithstanding these differences, alignment with other oppressed groups has allowed disabled people to draw on the experience and thinking of feminist and anti-racist theorists in many areas, including that of research.

### **The emancipatory research paradigm**

There has been much examination of the role of disabled people in research (for example, Hunt 1981; Oliver 1987; Barnes, 1996; Stone and Priestley 1996). Since the 1960s, as the 'business' of disability research has continued to grow, there have been calls by disabled people and disability theorists for the social and material relationships of research production to change (Barton 1992; Oliver 1992; Barnes 1996). Central to the criticisms of disability research projects is that they have been carried out in a non-partisan and objective manner using empirical methodologies, which is said to have compounded disabled people's oppression through:

The misunderstanding of the nature of disability, the [projects'] distortion of the experience of disability, their failure to involve disabled people and the lack of any real improvements in the

lives of disabled people (Barton 1992:99).

To provide an alternative to the empirical research model, the emancipatory paradigm has been put forward by Oliver (1992) and others (Barnes 1992; Finkelstein 1992). This approach seeks to advance the interests of 'subordinate' or oppressed groups in society (Guba 1990), in line with feminist and anti-racist research methods. Its key feature is the rebuttal of positivist and interpretative claims to objectivity and assertions about the political positions of the researcher (Stone and Priestley 1996). Moreover, emancipatory disability research must be located within the social model of disability and should aim to change the world, not just describe it, if it is to provide a radical alternative to mainstream theory and methods (Oliver 1992). Furthermore, it is argued, that unless disabled people are involved in determining the aims, methods and use of research, then clearly such research neither empowers nor has transformative potential (Zarb 1992). However, this emphasis on the importance of disabled people's central role within a project is very different, I believe, from the assumption that only disabled people should carry out such research. As Barnes (1992) has argued, emancipatory disability research is not about biology but about commitment and researchers (with or without impairments) putting their knowledge and skills at the disposal of disabled people and their organisations, and the 'generation and production of accessible and useable knowledge' (Barnes 2003:6). There are now a number of academics who do much to promote disabled people's interests.

Within critical or emancipatory social research it is necessary for the researcher to see beyond the dominant ideologies in order for the truth to be revealed (Harvey 1990). Through this approach feminists, for example, have been able to demonstrate that housework is real work, that it has been devalued by a male dominated society

and consequently by revealing oppressive structures, have encouraged social change in the roles of women (Oakley 1974). Emancipatory disability research then, whilst seeking new hypothesis, bases itself upon the methods and methodologies used within the feminist paradigm of 'reciprocity', 'gain' and 'empowerment' (Lather 1987; Ribbens 1990) and more recently, from within disability studies itself, the requirement of the researchers for 'reflexivity' (Oliver 1992).

Of course, the emancipatory paradigm has not been without its critics. For example, it has been argued that by focusing on one oppressed group the research may conflict with the interests of other oppressed groups who have not been considered legitimate objects for study (Hammersley 1992; Silverman 1998). Other academics, (Stone and Priestley 1996; Stone 1997; Barnes and Mercer 1997; Oliver 1997; Shakespeare 1997), who are in the main supportive of the principles of emancipatory research, have raised questions about the practicality and effectiveness of doing emancipatory disability research.

Nevertheless, it is the emancipatory paradigm that has informed much of disability research in recent years. The integrating theme running through this application of social model thinking is its transformative aim: that is 'the removal of barriers and the promotion of disabled people's individual and collective empowerment' (Barnes 2003: 5). For Oliver (1992, 1996), the value of research can be gauged by asking how far the process of participation has made a contribution to individual or collective empowerment and whether improvements in the lives of disabled people have been achieved in any measure as a result. From this perspective the role of the researcher is to help facilitate these goals through the research process. It is this standpoint and these principles, which I attempted to use as a yardstick in studying user involvement projects, and also to apply to my own research in carrying

out that study.

### **Recent developments in user involvement and associated research**

In response to disabled people's campaigning for improved representation (and also to the wider development of consumer and citizens rights), over the past two decades there have been major changes to the way health, social services and the benefits system have developed policies which focus on the housing and support needs of disabled people (Means and Smith 1998; Cameron et al. 2001). Legislation and policy statements now stress the importance of enabling those who are in receipt of services to have their say in how those services are run (Beresford and Campbell, 1994; Barnes, Mercer and Morgan 2002) and during the 1990s consultation exercises became an increasingly common element of policy reviews affecting services for disabled people.

The form and quality of these exercises varied widely: for example, some involved only the occasional input while others were on a much larger scale. Some initiatives, indeed, have appeared to be going further towards giving control over research to disabled people who are service users through the development of 'user-led' reviews (Evans and Carmichael 2002). Notwithstanding these general advances, the question of involving people with learning difficulties in the process of research (and in user consultations) has invariably been viewed as too complex to resolve, and until recently they have tended to remain on the periphery (Richards 1984; Aspis 1997).

Within the past few years, however, a small number of projects have aimed to address these issues, for example (Baines et al. 2001; Gramilch et al. 2002).

User or consumer involvement then, is now seen as an

essential part of the policy making process and lends credibility to the decisions made as a result of policy review. In essence, for disabled people, UI has become the process whereby they contribute in some way to the decisions made within the statutory and voluntary service sectors to provision that may have a profound effect on their lives. Indeed, thousands of disabled people are now participating in a range of such activities.

The focus of my study (which was carried out for an MA dissertation at the University of Leeds) was to evaluate disabled people's experiences of being involved (as service users) in research and consultation projects and to assess from their perspective, the impact of UI practices over the past two decades by identifying tangible signs of change. A literature review was undertaken and data were collected using methods appropriate to both emancipatory and participatory research.

### **The research project**

In order to maximise the validity of the data, it was decided to use both qualitative and quantitative methods. The qualitative part of the study involved in depth interviews of participants in two research projects and a focus group discussion. The quantitative part consisted of a questionnaire-based survey of disability organisations regarding their experience of UI over the past five years.

### ***Qualitative methods***

Two recent projects, which were viewed as originating from disabled people and/or as 'user led', were identified as case studies: the first was a local authority best value review of the Direct Payments scheme and its support service, while the second project aimed to map the current and future use of services provided for people with learning difficulties across a rural county. Both studies had involved disabled people in a variety of ways (principally as researchers and contributors) and findings

from these had been disseminated through public launches to their constituents and interested agencies, and by the circulation of summary reports.

In line with the principles of emancipatory methods and to avoid the research being viewed as oppressive, participants were asked how they preferred to be interviewed: individually, in pairs or as a focus group. Those who opted for individual interviews were then offered a choice of face-to-face, telephone or email interviews. As a result, data was collected by means of three semistructured telephone interviews and a small focus group discussion. In order to facilitate the meaningful participation of people with learning difficulties (who had conducted the majority of the fieldwork in the second sample project under review) participants were asked how they would like to be involved and by whom (if anyone) they would like to be supported. Following a brief discussion among the potential group, it was agreed that participants would be most at their ease if the meeting were held in their organisation's office over lunch. Supporters were chosen by the participants and were people with whom they were familiar (a paid worker and an advisor to the organisation).

The researcher recognises that it is accepted practice to acknowledge the value of disabled people's participation in research by offering a nominal fee. However, all of those involved in the focus group and individual interviews stated they were happy to assist without payment as the study was funded by the researcher and was for academic rather than commercial purposes. The members of the focus group agreed to accept payment for a sandwich lunch, as this enabled people to attend who would usually have been elsewhere at this time.

After an initial informal discussion with the researcher, during which the aims and objectives of the study were

outlined, participants were given the opportunity to ask questions and clarify their roles within this exercise. The researcher gave assurances that all information received would be treated with confidence and sensitivity and would not be attributable to any individuals or organisations. An information sheet was provided setting out the aims and objectives and a copy of the proposed interview questions (in plain text and pictures) was circulated in advance to the focus group and their supporters, to enable participants to be prepared for the meeting.

A time convenient to the interviewees was arranged and consent was given either verbally or in writing before the interviews/group discussion took place, and again at the start of interview, with an opportunity to withdraw at any time. The interviews and the surveys were structured around the key themes of previous experiences of UI, current experiences of a specific research project including access issues, training, ownership, influence and outcomes. The focus group discussion was less structured but followed a similar pattern to the individual interviews as well as providing an opportunity to talk about emerging issues and concerns.

### ***Quantitative methods***

In order to survey the experiences of both established groups as well as those that have emerged over the last ten years, nine organisations that had participated in similar, recent research (Barnes, Morgan and Mercer 2001) were selected for inclusion, the sampling criteria was according to that report, based on the year of establishment, size of membership, geographic location, and range of services offered. However, as the response to this first survey attempt was low, further organisations were included, in order to provide a wider collection of data to be analysed. The second tranche were all members of BCODP and, as far as possible, fulfilled the

same sampling criteria as the first group. Initial contact was made with organisations by telephone and email, to explain the study and enquire if they would be willing to participate. After receiving agreement, surveys and covering letters were sent out either by email or mail, according to the organisations' preferences. In total, 22 organisations were contacted and eleven surveys returned, providing data on 44 projects.

### **Research findings and analysis**

The following sections highlight a number of significant issues and themes that emerged from the analysis of both the results of the fieldwork exercises and the literature and policy review that was undertaken regarding the impact of user involvement.

#### ***A means of changing policies?***

This admittedly small-scale study revealed that, over the past five years, organisations of disabled people and their members have been involved in a wide variety of UI activities, with a number of different agencies (for example, health authorities, community trading exchange schemes, national care standards commission, research projects) and at varying levels of participation. However, the primary focus of UI activity remains on disabled people's relationships with Social Services Departments and the provision of essential support arrangements.

As observers of the disability movement have acknowledged (Campbell and Oliver 1996; Drake 1999), it is difficult to quantify the impact that disabled people's involvement has had on changing policy, particularly where there is sparse evidence on which to base any assessment. Marx and Adam's (1994) criteria for gauging the progress of (new) social movements put an emphasis on concrete change: political, economic, legislative, attitudinal and behavioural. Although this study found that only a minority of projects resulted in visible outcomes, the

significance of these changes should not be underestimated. As noted by survey respondents:

We now have a CIL, run by disabled people, providing a range of services. A Day Centre 'warehouse' run by a large charity under contract will close, the service will re-tender with a new specification to more appropriately reflect the varying needs of service users.

In a wider context, UI can be seen as part of an increasing ability to influence policy. As a result of disabled people's redefinition of their situation in terms of human rights and equality, together with their increased visibility in society, it has been possible for disabled people and their organisations to effect changes, particularly in local health and social services policies. Although some of these have been relatively small changes at local levels, others have been more visible. For example, as a consequence of the success of the Direct Payments legislation and the growth of the Independent Living Movement, disabled people once regarded simply as the passive recipients of services now have greater choice and control over how their support needs are met (Begum and Fletcher 1995; Wood 1991).

### **Contributing to empowerment?**

Campbell and Oliver (1996) specify other standards that may be used as a measure of the success of UI. These include raising the consciousness and supporting the empowerment of disabled people and the promotion of disability as a civil and human rights issue. These aspects are fundamental to the emancipation of disabled people, and empowerment in particular proved to be an aspect of UI about which participants in the study tended to be most enthusiastic:

Participating users gain confidence, new skills and

knowledge.

(survey respondent)

I personally got a lot from it (the research project). I felt much

more confident both in myself and what I could do.

(interviewee)

Sometimes this empowerment took the form of knowing better how to play the game next time:

We will be better prepared and know what questions to ask before we do anything like this again! (focus group participant) Although some have questioned the reach of UI into the community, it seems undeniable that UI draws in those who were previously unpoliticised and raises their consciousness of inequality:

I have become more aware that Direct Payment users and disabled people who rely on services, are expected to be accountable in all things, all of the time.... which wouldn't be accepted by non disabled people. (interviewee)

With regard to raising disability issues, this study looked primarily at local initiatives. At this level most organisations felt that their efforts had been effective, reporting 'increased Social Services awareness of disability issues' but most found it difficult to quantify any benefit from their UI activities in terms of civil rights or the wider agenda. In summary, while the large majority of participants in this study perceived UI to be beneficial, they also highlighted some less positive aspects of the process.

### ***Consultation fatigue, disillusionment and setting priorities***

Consultation fatigue was also raised as an issue by the majority of participants in the study. As noted elsewhere,

(Barnes, Mercer and Morgan 2002) disabled people have become tired of being asked for their views in all sorts of surveys, especially when there appears to be few improvements arising from it. Again, in this study, survey respondents commented that:

Lack of resources and inaccessible structures most often mean that consultation becomes ineffective.

We are asked regularly to 'supply' disabled people for research, UI etc.... people have their own lives and do not just get involved in UI unless it's going to make a difference to them. A significant cause for concern noted by participants in both of the research projects examined during this study, was the feeling that their work had been to some extent misused, distorted or even ignored if it challenged the status quo.

It's disappointing as we were very strong ... Seems like they have cherry picked and have taken up some of the recommendations which they could do without too much hassle or cost.

(interviewee)

As a result of consultation fatigue and a (healthy) degree of scepticism regarding agencies' motivation, it appears that disabled people (as service users) are becoming much more selective than in the past in deciding to whom they will give their views and in which activities they will participate. There was evidence that organisations and individuals are beginning to set priorities that reflect perceptions of which project is likely to be of most benefit to them or their cause. When disabled people's experience is that the value of UI is doubtful and that the outcomes have the potential to become distorted or the findings to be manipulated to fulfill another party's agenda, it is not surprising that they tend

to be more reluctant to enter into dialogue, or will even refuse to take part.

As UI is still a relatively recent activity, certainly in the amount that is currently being practiced, disabled people are understandably starting to re-examine the role they play within it. Accountability and control of projects were the key determinants of satisfaction levels expressed by organisations of disabled people: they gave noticeably higher ratings to exercises in which they had taken a leading role, or when they had been the initiators. One survey respondent highlighted the reason for the success of such self-initiated UI:

Then there is an expectation that [members'] views will be acted upon as the organisation is accountable to its users/members.

Observations like these, drawn from practical experience in the current 'UI industry', are contributing to the formulation of 'rules of engagement'. It is to be expected that these principles will solidify and sharpen disabled people's involvement, particularly if they are disseminated to new or less experienced groups.

### ***Facilitation and inclusion***

As Walmsey (1997) stresses, facilitating the inclusion of people with learning difficulties in service reviews and research projects can be more complex than that of meeting the general access needs of other disabled people. If people who are labeled as having learning difficulties are to be enabled to understand complex ideas and to articulate their views, they will require facilitation which is, to a considerable extent, reliant on human intermediaries in the form of skilled supporters and advisors.

Furthermore, as identified in other studies (for example Barnes, Mercer and Morgan, 2000; Vernon, 2002) and

echoed in my own, more effort is needed to include disabled people from minority ethnic communities and the wider community of unpoliticised disabled people. As a survey respondent commented:

What usually tends to happen is that a small core group of disabled people become involved in a range of different initiatives and the real voice and experiences of disabled people then become muted.

However, when attempts are made to be more representative and the access and support needs are met in an appropriate manner, the benefits of UI to both service users and providers have regularly been shown to be significant (Lindow and Morris 1995, 2001; Morris 1995). Satisfaction with facilitation and participants' ability to influence the conduct of projects was rated as average or above for 34 of the 44 projects surveyed in my study. Exceptions occurred where facilitation was organised exclusively by professionals or by inexperienced non-disabled people from the voluntary sector. Some disabled service users themselves frankly acknowledged their own initial lack of understanding of the needs of others. They also emphasised that effective involvement requires commitment, not only of resources, but also of time.

### ***Building alliances and funding***

For the past decade disability theorists have criticised the material relations of research production, and the power relationships inherent within (Oliver 1992). Similarly, the validity of a large number of UI projects must be questionable when the subject of the consultation is also the funding body, which often controls the purse strings of the organisations participating (Pagel 1988; Barnes, Harrison, Mort and Shardlow 1999; Barnes, Morgan and Mercer 2001). Those who contributed to this study were keenly aware of these tensions.

Looking back, we can see that campaigning for changes to the way society is structured and for equal rights was the mobilising force behind the emergence of the disability movement: recent studies (Barnes, Morgan and Mercer 2001) demonstrate that, although there may be differing views on the shape of such activities, this remains a key function for the majority of organisations of disabled people. However, as a consequence of the uncertainties surrounding the resourcing of organisations and therefore UI, it is perhaps inevitable that disabled people have tackled issues in a 'piecemeal' way, most often at local levels. This may be a factor contributing to the difficulty of assessing the impact that disabled people's involvement has had on influencing policies and services. Until alternative forms of funding are made available to promote citizenship participation, there will always remain an imbalance of power and a limit as to how far disabled people can effect changes through UI alone. Furthermore, it is important to remember that user involvement is a means to an end and not an end in itself (Campbell and Oliver 1996). This end is the emancipation of disabled people through full human and civil rights, and the right to participate in society on equal terms with others.

### ***The future for disabled people's involvement***

If UI is to be viewed as a valuable resource and worthwhile activity, as seen from the researchers own small study, it will require a commitment from all concerned, an investment in time and resources and it must be relevant to the lives and needs of all disabled people. Furthermore, the future for UI has to be one of equal partnerships between disabled people and the agencies and other professionals involved. Having employed the principles of the social model and emancipatory research in order to develop a critique of recent examples of UI in research and wider activities, how then did my own research practices measure up?

## **Reflections on the project**

This research was undertaken as part of an academic project, and as such, it was subject to limitations in terms of accountability, time, resources and the extent to which the researcher was able to fulfill her intention to work within the emancipatory research paradigm. Although the researcher was a disabled person, and was committed to the social theory of disability, which provided a framework in which to contextualise disabled people's experiences and position, it would be inappropriate to claim that disabled people had initiated the topic or that the fieldwork undertaken for this study was user-led. However, every effort was made to ensure that participants did not find the research process oppressive and, wherever possible, the methods employed respected individual preferences and opinions. It was also hoped that the subject of disabled people's involvement would be one of wider interest and practical use, to those who took part and a summary report of the key findings were made available to those who requested a copy.

The projects and groups under study were, of necessity, selected by the researcher and the participants (both in the focus group and individual interviewees) were self-selected, introducing the possibility of sample bias. Nevertheless, this was principally an explorative study, from a disability perspective, which sought to highlight emerging issues and themes, as well as providing some pointers towards possible further research in this area.

In order to maximise participants' control over the collection of data both through the interviews and focus group discussion and also, although to a lesser degree, with regard to the surveys, informed consent was sought. To this effect, information sheets, draft interview schedules in accessible formats and covering letters were provided which clearly set out the aims and objectives of the study. Participants were given the opportunity to

decline or withdraw from interviews at any time. Furthermore, participants were able to amend or change their answers as individual's contributions were read back to them before being written up. However, due to the timescale and nature of the study it was not possible for participants to comment on the researcher's commentary or final analysis, although one disability activist and researcher advised on the survey design and gave some useful insights into the results of the initial findings. In future research projects, attempts will be made to undertake more in-depth analysis and so help validate the findings more fully.

### ***Empowerment and accountability***

Within emancipatory disability research there is a focus on empowerment of the research subjects through ownership of projects and their outcomes as well as by the process of data collection. To some extent this was achieved within my research, if initial feedback to me from participants can be counted as suitably objective! However, as Oliver (1997: 20) has pointed out, empowerment is a process that requires people to do something for themselves: empowerment cannot be given.

Additionally, in the debate over changing the relationships of disability research, Shakespeare (1997) argues that there is a difference between loyalty to a cause or movement and accountability to research subjects. He also raises the question of the extent to which 'independent' researchers can, or should, commit themselves to causes like the disability movement, if this will inhibit constructive analysis or debates, which may at times appear to undermine their positions.

Regarding accountability to the research 'subjects' within my study, I feel that I went some way towards enabling participants to have a degree of control over the process, that they decided on the level and method of

their involvement and that I reflected accurately their experiences, in the final analysis. Despite being mindful of the barriers that disadvantage disabled people, having a commitment to the 'movement' and striving to work in an anti-oppressive manner that would not alienate people from the research process, I could not claim to have 'equalised' the research relationship to any great extent. As others have recognised (Barton 1992), regardless of how much effort you make to remedy power imbalances, or are committed to a cause, it is ultimately the researcher's view of the world which is produced and which carries the intellectual weight, whatever value that may have. Furthermore, when undertaking research of concern to oppressed groups the researcher cannot be 'independent' in researching oppression, but is either on the side of the oppressor or the oppressed (Barnes 1996).

In conclusion, within any study there will be aspects of the research process which could be improved upon or done differently, especially with the benefit of hindsight, and mine was no exception. Was it emancipatory or participatory research? I think that my project was a hybrid of both: I believe a number of the fundamental principles within the emancipatory paradigm were upheld and that the outcomes will be of practical use to those concerned. However, it was undoubtedly 'my' project in which disabled people were participants: I did not put my skills at their disposal to use as they wished; they were not the initiators; and the end results were mine.

## **Conclusion**

I have used my study on disabled people's participation in research and policy reviews to illustrate a number of the key principles and issues surrounding the social model and carrying out emancipatory research, from what might be termed both 'inside' and 'outside' perspectives. As experienced by other researchers the path of disability

research is never a simple formulaic process and nor should it be: it requires a variety of skills, access to resources and a commitment to challenge the oppression experienced by disabled people.

In common with other civil rights movements, the disability movement has developed to encompass diverging strands of opinion on how best to effect political and social change. While it appears that there have been a number of advances towards emancipation as a result of disabled people's participation in research and in other areas of policy formation, the emerging themes arising from my small scale study and the wider experience of the last few decades indicates that the emancipation of disabled people will not come about by research and reformist methods alone, but through a combination of methods, some of them revolutionary. I suggest that the way forward will require a degree of pragmatism in the choice of tactics to be employed, but that these are very likely to include direct action in the form of civil disobedience; campaigning and lobbying at different levels; underpinned by rigorous academic research, evidence and argument. Ultimately, as for all civil rights struggles, success will lie in the strength and solidarity of a disability movement that is inclusive and remains relevant to all.

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