Exploring models of D/deaf service user involvement in translating quality standards into local practice

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Abstract: *This article concerns the participation of service user groups in the translation of social work standards into social work practices. The context is a development and research project about quality standards in adult social services with Deaf and hard of hearing people. The project was set up both to support effective changes in local working practices, as well as to study the processes underlying those changes. Central to these processes had to be the engagement of local service user groups of Deaf or hard of hearing people. Specifically this article analyses three differing styles of engagement between providers and users involved in the project. We have termed these: a co-worker model; a rights-based model; and a politically aware model. It explores the consequences for developmental action of these styles and the extent to which what is achieved, not just how it is achieved can be attributed to the manner of engagement. The role of locally contingent conditions as adequate explanation for different kinds of service user/service provider involvement is also considered. The article contributes to the wider debate of how to turn user rights-in-theory into user rights-in-practice, through an analytical focus on the structuring of provider/user engagement when there is an overt agenda of service improvement in line with pre-established standards.*

Key words: *deaf; hard of hearing; BSL; best practice standards; service user involvement*

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Introduction

As Biehal (1993) has remarked: 'Rights in theory, embodied in policy statements, do not automatically lead to rights in practice' (p.445). Indeed if service user rights can be considered to exist at four levels: theory, policy, procedure and practice, a fundamental issue becomes, not the identification of those levels, but rather how to move between them meaningfully. How do we progress an agenda of service user participation so that theory does indeed become embodied into policy; policy takes on the form of organisational procedure, and all of these elements actually become translated into practice? This issue of translation into meaningful practice lies at the heart of the research and development project reported in this article, and its specific focus on user engagement within that process. The project overall was concerned with understanding how best to implement into practice a set of principles – in this case, the Best Practice Standards in Social Work with Deaf and Hard of Hearing People (ADSS, RNID, LGA, BDA, 1999). Within such implementation there was a non-negotiable imperative, than any activity had to de facto involve partnership working between local service users and providers in the three sites where the study took place. It was a crucial opportunity to study the potentially transformatory nature of service user participation within a principles-into-practice process.

In what follows, we will explore that process, but not through an analysis of service user roles and tasks (a functional approach to participation). Rather the analysis will occur at the level of styles of engagement between service users and providers engaged in the same local implementation projects. In particular we ask the extent to which the differing styles of engagement we identify account for differences in the actual activities undertaken, not just the manner in which they are undertaken. We consider the influence on those styles and activities of pre-existing conditions in both the culture of the provider teams and the history of local service user participation. Finally, we discuss whether the relationships we have identified between style, activity and local circumstance can be thought of on a continuum of optimum participation. Or are they more rightly thought of as differing expressions of the same set of factors - just calibrated for local conditions? We begin first, however, with some general background to the project overall.

Background

The activity presented in this article is taken from a three year development and research project ('The Edge of Change Project') designed to investigate the implementation of the *Best Practice Standards in Social Work with Deaf and Hard of Hearing People* (ADSS, RNID, LGA, BDA, 1999), hereafter referred to as the 'Standards' (Young, Hunt, McLaughlin, Mello-Baron, 2004a, 2004b). These standards, agreed on a national

basis, considered only adult services and covered nine topics: Information; Access; Communication; Assessment; Equipment; Accessibility; Planning; Procedures; and Joint Working. They resulted from the significant concerns raised by the then Social Services Inspectorate (DoH, 1997) who had concluded that social work services with Deaf and hard of hearing adults were generally of poor quality; highly inconsistent between local authorities in terms of eligibility and services offered; with many staff were regularly required to work beyond their linguistic competence (in sign language); and with minimal service user involvement in local service planning and development. The Standards had been broadly welcomed for the reference point they provided local authorities. Nonetheless concerns persisted that the definition of best practice did not of itself ensure implementation, and that specialist social services teams continued to struggle with implementation (DoH, 1999).

This struggle was in part to do with the huge variability in local contexts of service organisation in terms of, for example, resourcing relative to population served. There were also considerable differences in the extent to which the specialism was recognised and valued within differing service delivery arrangements (Young, Hunt, Loosemore-Reppen, McLaughlin and Mello-Baron, 2004). There was also a lack of any clear analysis of the challenges involved in turning the Standards into practice within the highly heterogeneous population of D/deaf people. This service user group is in fact many different populations (DoH, 1997), differentiated by such factors as language, culture, identity and disability (McLaughlin, Brown and Young, 2004). The strengths and needs, for example, of a British Sign Language (BSL) user who is Deaf from birth are not easily comparable with those of someone for whom progressive deafness is a disability of older age (Young, 2006).

Within this context, the Department of Health funded a three-year development and research project, in partnership with the Royal National Institute for Deaf People (RNID). Its aims were on two levels (Young, Hunt, McLaughlin, Mello-Baron, 2004a):

- Firstly, to work with three Local Authority social services departments to audit their current social work practice with Deaf and hard of hearing people, to identify specific service improvements in line with the Standards and to support teams in the process of implementing change. In other words, to promote self contained, locally relevant service development projects.
- Secondly, from a research perspective to study that process of change in order to understand better what hinders and what facilitates the translation of the Standards into service development (McLaughlin, Young and Hunt, 2005).

Although these two are conceptually distinct levels, in practice they overlap.

However, within this structure, the project also introduced an additional requirement. Namely, that any project work identified by participants must be carried out in partnership with service users. In this respect we acknowledged from

the start that the very notion of partnership is complex and contested (McLaughlin, 2004). In line with Balloch and Taylor (2001) we understood that there was no single definition of partnership and that partnerships could exist along a broad continuum of theory and practice. In approaching social services teams, therefore, we did not specify who a service user group or groups might be, how they would be constituted, how they might be involved, what their role(s) might be, how they would be engaged in the process, nor on whose terms. We also did not presume that effective partnerships with service users already existed in the localities in which the project worked - building those may indeed have constituted an element of the work to be undertaken. In this way, *how* the user involvement requirement was interpreted in terms of service development, how service user/ practitioner partnerships evolved, the differing styles of engagement evidenced in the projects, and the characteristics of the activities undertaken all became the object of research concern in their own right. It is such analysis that forms the substance of this article.

The interpretation of the user involvement requirement

County

The first participating social work team consisted of 24 whole time equivalent posts and served a large county with a population approaching 1 million people (hereafter referred to as 'County'). For them, the question of how the service user involvement requirement should be interpreted was one and the same as how their involvement with the research and development project should be interpreted. Namely, they saw their first task as one of definition of the whole project's aims and objectives in their own terms; terms that were fundamentally expressed as those of vision and values. Thus having decided that the project afforded an excellent opportunity to improve information and service signposting in the county in relation to deafness, their focus lay not in working out how near or far they were away from the aspirations expressed in the Standards, but rather what the relevant section of the Standards actually meant to them. This process resulted in the statement:

> Our vision is to provide a co-ordinated, comprehensive and flexible approach, which aims to support and enable people to find relevant and up to date solutions to their question about all aspects of deafness.

So formulated, it was a short step to realise that what counted as support and enablement and how co-ordination, comprehensiveness and flexibility might be achieved depended largely on interpretations and meanings that lay with those who would be seeking solutions to their questions about deafness, not with those who

would be providing them. For example, for older people beginning to experience hearing loss, social services might not be the first location they consider to access information about relevant services, but where would they go instead? Would information left in the post office, or the local supermarket be effective and what form should that information take?

By formulating a value-driven statement, constituent elements of which were not pre-defined, County not only acknowledged that they needed to access service user views and experiences to inform their action planning and development, but more fundamentally demonstrated that what counted as knowledge (e.g. what was a 'relevant' solution) was user-constructed too. This approach moves towards the position Beresford (2001) has characterised as

> Service user campaigners aren't just calling for social policy to ask for and include their views … service users are demanding that social policy goes beyond seeing them as a data source … service users and their organisations can and want to offer their own analyses, interpretation and plans for action. They want to develop their own practice, services and organisations instead of just being subject to other people's. (p. 508)

We might term County's interpretation of the service user requirement as the 'co-worker model'. 'Co-worker' as a descriptor is used not simply to imply service users and service providers working together, but rather service users and service providers as co-constructors of the knowledge on which the service development should be based and how in practice this should proceed.

Metropolitan

The second participating social work team consisted of 8.2 whole time equivalent posts working in a metropolitan area of nearly a quarter of a million people (hereafter referred to as 'Metropolitan'). This team also began from an explicitly value informed position and challenged the very notion that the development and research project had begun with them as a service provider team rather than with a user group. They adopted a strong 'nothing about us without us' (Charlton, 2000) interpretation of the service user requirement and some team members were suspicious of researchers who failed to begin with service users rather than with them. The team view was that until it was possible to ascertain a user-led evaluation of the strength and weaknesses of local social services in line with the Standards then it was not possible to set aims and objectives for the work to be undertaken within the development and research project as a whole. They directed the research team to a pre-existing service user group made up of BSL users as the place to start. The social work team agreed separately (and subsequently to the ascertained view of the user group), to consider what local development projects they were prepared to undertake.

In other words, they sought a user empowerment approach that placed user views and experience not just at the centre, but in a deliberately constructed lead role. This was clearly a participation rather than a consultation model of involvement (Morris, 1997). It was also heavily influenced by the factors specific to social work with Deaf people in this country. It sought overtly to challenge the long history of largely oppressive and dependency producing power relations between social workers and the Deaf Community (Parratt, 1995). This dynamic originally arose when social workers were amongst the few professionals who could sign and had contact with Deaf people (before the rise of an independent interpretation profession) and so they exerted considerable and largely inappropriate influence on all aspects of the normal life of Deaf people. It was not unusual that Deaf people had to become clients of social services solely because they needed access to communication services. Only in more recent times has the nature of the social work-Deaf community relations been actively challenged and new roles and service boundaries begun to be defined (Hawcroft, Peckford and Thomson, 1996; Harris and Bamford, 2001; UKCoD, 2001).

We might term Metropolitan's approach to be a 'rights-based model' where the support for the centrality of service users in playing a lead role (not just an involved role) derived essentially from an understanding of Deaf people as an historically disenfranchised and disempowered group. This project provided an opportunity to challenge such a position.

Unitary

The third participating social work team consisted of 8.5 whole time equivalent staff working in a Unitary authority with a population of nearly 140,000. They had little or no history of engagement with service users in any aspect of service planning, development or evaluation and were very keen to use the opportunity of the wider development and research project to establish some kind of user group from scratch. On a team level they felt they would learn a great deal from such an activity but they also felt strongly that they were not fulfilling their obligations to involve service user groups. This was an ethical matter for them as much as an operational issue in meeting the emphases of the modernisation agenda (DoH, 1998). The development of a local user group became in itself one of the local projects identified and undertaken (it was both outcome and process) and was seen by the social work team as crucial to the sustainability of any Standards-into-practice developments they may continue to undertake beyond the life of the actual development and research project.

We might term Unitary's approach the 'politically aware model'. In other words, they were quite clear what they should do and why they should do it (awareness and support was well established), but had as yet no experience of the implications of that in any kind of pro-active way.

Differences in model or only differences in context?

Looking across the three sites and comparing their interpretations of the requirement for service user involvement, two issues stand out:

- Firstly, how significant a self-conscious expression of values was in thinking through their various approaches. None took an instrumental approach. All, be it in slightly differing ways, sought to define from a values perspective what underpinned why and how they would want to establish service user involvement in the research and development project. Whether as constituent of a co-worker approach (County), as an expression of rights (Metropolitan) or as a raised political awareness (Unitary), values were a central consideration.
- Secondly, given this commonality of values first, we were left wondering whether the differences we had identified in conceptualising the co-worker, rights-based, and politically aware models, were in truth distinct, or only consequences of the differing characteristics of the contexts in which each service was seeking to operate. That is to say, they were not essential differences, but rather expressive differences that are consequent on context.

This latter point perhaps becomes clear if we consider further the user contexts in which all three were working. County had a long history of contact with service users (individually) and with user groups. Furthermore, most of these groups had been established for independent purposes and existed quite separately from any engagement with social services. In their area it was not unusual for deafened and hard of hearing people, including older people, to meet communally and regularly in a range of clubs and societies that existed for mutual support and social activities. The issue for County in embarking on the development and research project was not to establish contact with service user groups, but rather to face the challenge of purposeful contact. In other words to move from an ad hoc approach to service user involvement where it was not really that difficult to find service users to consult, to an approach that engaged the social work service and service users in joint activity for a common purpose. This would take service users from a position of objects of consultation, to one where they became active participants in setting the agenda for what it was that should be consulted about in the first place. However, without the pre-existing network of groups and clubs then this next stage of development we have characterised as 'ad hoc to purposeful' would not have been possible to consider.

Metropolitan, also had a pre-existing history of service user involvement that was already co-coordinated and integrated into social services activities. They had invested heavily in establishing a forum for Deaf sign language users through employing a Deaf development worker over a number of years to establish and facilitate the group. Previous research had clearly demonstrated that Deaf people faced additional challenges in becoming effective consultation groups able to respond to the requests

of statutory services (Hawcroft, Peckford and Thomson, 1996; UKCoD, 2001). Knowing that this group was well established, well supported and its members used to participatory activities with both health and social services, made it entirely realistic and totally appropriate to place them in the lead role in Metropolitan's response to the development and research project. The only real issue for Metropolitan and for the user group was the scale of the activity they were to undertake (auditing the local services against the 9 Best Practice Standards) and what additional support and resources would be required. We are not suggesting that the pre-existence of a well established user group with close connections with social services is what of itself enabled Metropolitan to take such an uncompromising rights-based approach. However, its existence clearly meant that in doing so, social services could be confident that the consequences would be practically significant and not merely attitudinally tokenistic. They could be confident that an assertion of rights would be synonymous with a guarantee of action.

Unitary found themselves in a very different position. Whilst there were many examples of positive contact between social workers and the local Deaf community there was no established history of service user involvement. On the one hand, the ordinary members of Deaf Community in that area were largely not conscious of concepts such as consultation and not particularly politically empowered. It is not uncommon for many Deaf people to be more used to dependency models of engagement with services (Hawcroft, Peckford and Thomson, 1996; DoH, 1997) and to experience relentlessly poor linguistic access to many social, educational and community services that the hearing population take for granted (Harris and Bamford, 2001). Sign Community (formerly the British Deaf Association) consistently campaign on these issues (www.signcommunity.org.uk). On the other hand, social work practitioners in the team whilst wanting to move forward to a position of greater engagement with service users on a routine basis and in a supported manner, were not confident they had the skills to do so. Furthermore they had not been resourced to do so and time for such development work was not considered a priority by management.

In describing, therefore, their approach as the politically aware model, we are not suggesting that it was somehow less motivated or less action orientated than those of co-worker or rights-based. Rather, it describes a situation where the context of low levels of previous development predominates to such an extent that even to formulate activity instead of awareness is a major definition of engagement.

It is clear, therefore, from this analysis, that what we have previously described as differing 'styles of engagement' between users and providers is not an adequate formulation. Whilst it is true to say that the co-worker, rights-based and politically aware approaches are conceptually distinct, they are not choices of approach that are independent of the influences of local circumstance. The pre-existing history of service user involvement strongly influences the character of those styles of engagement. This history might be about preparation and resources that, because already in place,

enable certain kinds of activity to occur (as in the case of Metropolitan). It might be influence arising from a history now perceived as not having gone far enough yet (as in County). Or it might be history that essentially has no history (as in the case of Unitary) where the issues of practice have remained largely theoretical.

In other words, we argue that it is impossible to uncouple provider/user styles of engagement from the circumstances in which they occur. A focus on joint activity forces a fit between the two. This raises interesting questions about how far it is possible to choose an approach to provider/use participation separate from an analysis of the historical context in which intended activity is to occur. How our teams approached their work was as strongly shaped by the history of their previous kinds of involvement as by their current values and goals in moving forward to new kinds of involvement.

Consequences for the activities undertaken

Hindsight is a wonderful thing and in presenting the kind of critical analysis we seek in this article, it can too easily seem that decision making and activity (including our own) followed neatly upon a full and a priori understanding of the similarities and differences between participating groups, as we have thus far presented. Of course in reality it did not. The processes were much more organic and reactive to circumstance, and only with the luxury of retrospective analysis does coherence become explicit and patterns proceed in a linear fashion from style of engagement, to influence of context, to character of action. Elsewhere we have focused on presentations of the fine details of what projects actually did, largely in their own words and own styles of presentation, and with a close attention to issues of process, development and challenge (e.g. the CDRom that accompanied the official project report and contained user group produced materials, resources and narratives of involvement). In this section of the article the focus is slightly different, in that we want to stand back from the fine detail of the action and continue our analysis of how what was actually required and executed in each site relates to the style of engagement we identified and the pre-existing characteristics of context.

As previously discussed, County began from a co-worker approach to engagement between service users and service providers in which service users were centred as co-constructors of the knowledge to be sought. Their main contextual challenge was to move from an ad hoc to a purposeful approach to contact,. In practice this translated into an interesting role reversal in which service users were trained as community researchers and social work personnel became their support workers.

The service user group and the social work team decided to focus on the issue of what kind of information people losing their hearing actually wanted, in what form and where (a project that colloquially became known as 'right stuff, right place, right

time'). To do so, they decided that they had first to carry out some kind of research with both the general public and also relevant professional groups. The service users opted to tackle the general public and with the assistance of the social workers and the research team, designed a short face to face interview. They received basic training in how to carry out such research (including issues of personal safety, ethics and interview skills) and set about collecting data. Their professional colleagues provided practical support, for example, writing official letters of authority to various locations (supermarkets, libraries etc) where one of the user-researchers might sit to recruit people to the interview; printing and collating all necessary materials; arranging facilities and transport for peer support meetings during the data collection processes. Behind the scenes the research team supported the professional service providers to think through the range of support that they might want to provide and facilitated joint meetings between all concerned.

Thus, the service user group became co-constructors of the knowledge in two distinct ways. Firstly, they were not simply asked what they thought should be in a general public interview, but rather worked on the team to design that interview, thus ensuring its content was, from their perspective, pertinent. Secondly, because as hard of hearing people they would be the ones to ask members of the general public to respond to questions, they simultaneously confronted those respondents with the relevance of the subject matter. Respondents were forced to interact with someone who was themselves hard of hearing. An abstract set of 'what if' questions about information access, format and content, thus became more real.

In Metropolitan's case, the character of activity undertaken with and by the service user group was predicated on the fact that a well developed group already existed. As previously discussed, the social work team had taken the view that it was impossible to identify a likely project for development and research until the user group had used the Standards to audit the current state of services. They would have the lead role in defining the focus of concern. This position, supported by the research team, in reality resulted in its own extended project. The idea that the Standards, produced only in English, could simply be picked up and used by the Deaf User Group as an audit tool, was unrealistic. It was not simply that they were linguistically inaccessible (the only BSL version is a short summary). Rather, they were conceptually inaccessible for many of the group. Generic concepts like 'standard', 'evaluation' and 'audit' themselves needed to be explored and understood, as did the purpose and status of the document in the first place. Also in terms of content, understanding standards such as 'accessible services within and outside the home' requires knowledge about the function, role and structures of social services. In other words, much work was required to equip the group with the understanding and knowledge they needed prior to any activities that would use the standards to audit, from their point of view ,the quality of services locally.

A research team member who was a BSL user worked with the Deaf facilitator of the group (the group ran in BSL with no interpreter) over a 12 month period to

equip the group as needed. In this time, many creative materials and approaches were developed that made the standards relevant in terms that were immediately recognisable within the life experiences of group members, and in linguistically accessible formats. These were written up as a separate project within the overall study and are reproduced on the CDRom that accompanied the main project report (Edge of Change, 2004). Thus equipped the group did indeed go on to audit local services and their conclusions (produced in BSL as well as English) were fed directly into local planning and joint planning development mechanisms.

For us, the experience with Metropolitan, confirmed the importance of ensuring that service user groups who work with service providers are equipped for task. In this case, the terms of the Standards were not their terms and only when they became 'translated' (not just linguistically) were they sufficiently meaningful even to allow consideration of whether and how the group might wish to use them. From a research and development point of view, the main issue was to enable understanding and ownership of the task that the service provider group has suggested should begin with users. Frankly, from our point if view, if thus equipped the Deaf User Group had felt that activities associated with using the Standards were rather pointless and not something they would have wanted to undertake, that also would have been a successful outcome.

In Unitary's case, the primary focus was on the achievement of that first step, of moving from awareness to activity. The development and research project did not create political awareness among the service providers nor the desire to engage service users more meaningfully. These were already there in abundance. It did create the space, support and legitimisation to do so. (Service managers suitably impressed by Unitary's involvement with a national project felt more able to support such developmental work). Similarly, the project per se did not create the wish amongst members of the local Deaf community to find out more about services and contribute to feedback about them. It did, however, create the vehicle, opportunity and organisation to do so (as well as some limited financial resources to start things off). From our perspective, this is a prime example of how incremental development does not necessarily lead from awareness to action in the engagement of service providers with service users. Rather a catalyst is needed to force the issue.

In terms of actual activities, one of the newly formed user group's main achievements was to create accessible information for their own community about the role and function of the local social services team. The group also engaged other services such as the police in information and discussion sessions in order to promote mutual understanding of needs and purpose. As the Edge of Change project was coming to an end, the social workers who had been the primary facilitators of the group were engaged in a process of handover to a local Deaf society to ensure further Deaf-led development of the activities whilst maintaining close links with social services.

Conclusion

One could argue that in this discussion of service user involvement in a research and development project, all we have done is demonstrate different varieties of participation that are theoretically well conceptualised already. In the co-worker model we see the reflection of a consumerist approach to participation (Beresford and Croft, 1993): agencies seek service improvement though an involvement process that enables them to be more responsive to the needs of service users through engaging with their insider perspectives, although the essential nature of the service remains in the control of the agency/professional. In the rights-based model we see the reflection of a more radical approach to participation (Mullender and Ward, 1991) that seeks through its processes actively to challenge the social positioning of those designated as service users and to redress the nature of the provider/user power relationship. In the politically aware model we see the reflection of a more consultative type approach (McLaughlin et al, 2004) where a policy driver instigates the creation of the participatory context but where the professional, rather than user mandate for activities remains strong (Braye, 2000). Yet to characterise what we have documented in this way is both too reductionist and a misrepresentation of the evidence.

County's consumerist underpinning nonetheless radically fronts the nature of user knowledge as the basis of service planning and provision, rather than seeing it merely as a responsive constituent element of that. Metropolitan for all of its radicalism still pursues processes of participation that are fundamentally predicated on a process of empowerment that to a large extent remains under professional control – in seeking to provide the structures and resources necessary for it to occur. Unitary for all its seeming agency-led consultative approach in getting service users involved for the first time, has as its core a longer term commitment to emancipatory processes that will render the involvement of professionals redundant.

We make these points not to highlight contradictions as if they are problems, but to reinforce the organic and situated nature of the service user/service provider involvement that we experienced. We found that in moving from rights-in-theory, to rights-in-practice through the direct involvement of service users then close attention has to be paid to pre-existing local characteristics; the historical investment and development of service user engagement; and the nature of the value based approaches that provider teams display towards such engagement. These elements are essentially inter-related. Furthermore, as we have shown, the styles of engagement of service providers with the research-driven condition of service user involvement were influential not only for the processes of the involvement we documented, but also for the products of those processes. To some extent, means and ends merge, and the locally contingent is both modifier and modified.

It might appear that in arguing in this way we are rejecting any absolute principles in considering service user/service provider joint working and focusing entirely

on the relative and contingent. This is certainly not the case and there are many fine examples of guidance on underpinning values and supporting processes for promoting empowering service user partnership working whether in the deafness domain (UKCoD, 2001) or elsewhere (e.g. Braye and Preston-Shoot, 1995; McIver, 1994; Morgan, 1992; Morris, 1997; Stevenson and Parsloe, 1993). What we are arguing is that if we are seeking to understand the very particular territory of service user involvement in translatory activity – in this case between standards in theory to standards in practice, then the dynamic nature of that translation is a product of both model (of participation) and context (of participatory activity). Furthermore, these two dimensions enjoy an interactive relationship.

Finally, we acknowledge that in this analysis the primary perspective we have adopted has been that of the service provider teams engaged in joint activity with service user groups that they largely initiated. The perspectives of service users involved in these processes were significantly represented at user-led presentations at a national dissemination conference of findings in June 2004 and in various 'practice resources and site reports' documents collated and published on CDRom as part of the Edge of Change dissemination process (Edge of Change, 2004). Many of these were written by or in collaboration with the participating service user groups and are direct records of activity undertaken.

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References

Association of Directors of Social Services, Local Government Authority, Royal National Institute for Deaf People and British Deaf Association (1999) *Best Practice Standards in Social Work with Deaf and Hard of Hearing People*. London: RNID

Balloch, S. and Taylor, M. (2001) Introduction. in S. Balloch and M. Taylor *Partnership Working: Policy and practice*. Bristol: The Policy Press

Beresford, P. (2001) Service users, social policy and the future of welfare. *Critical Social Policy* 21, 4, 494-512

Beresford, P. and Croft, S. (1993) *Citizen Involvement: A practical guide for change.* London: Macmillan

Biehal, N. (1993). Changing practice: participation, rights and community care. *British Journal of Social Work,* 23,5, 443-458

Braye, S. (2000) Participation and involvement in social care: An overview. in H. Kemshall, R. Littlechild (Eds.) *User Involvement and Participation in Social Care Research Informing Practice.* London: Jessica Kingsley (pp.9-28)

Braye, S. and Preston-Shoot, M (1995). *Empowering Practice in Social Care.* Buckingham: Open University Press

Charlton, J.I. (2000) *Nothing About US Without Us: Disability, oppression and empowerment.* Berkeley: University of California Press

Department of Health (1997) *A Service on the Edge. Inspection of services for deaf and hard of hearing people.* London: Department of Health

Department of Health (1998) *Modernising Social Services: Promoting independence, improving protection, raising standards.* London: The Stationery Office

Department of Health (1999) *Stepping Away from the Edge. Improving service for Deaf and hard of hearing people.* Available at doh/gov/uk/scg/steppingaway.htm

Edge of Change (2004) *Edge of Change Project Practice Resources and Site Reports.* (CDRom) London: RNID

Harris, J. and Bamford, C. (2001) The uphill struggle. Services for Deaf and hard of hearing people: Issues of equality, participation and access. *Disability and Society* 16, 7, 969-979

Hawcroft, L., Peckford, B. and Thomson A. (1996) *Visible Voices.* Carlisle: BDA

McIver, S. (1994) *Obtaining the View of Black Users of Health Services.* London: Kings Fund Centre

McLaughlin, H. (2004) Partnership: panacea of pretence? *Journal of Interprofessional Care,* 18 2, 103–113

McLaughlin, H., Brown, D. and Young, A.M. (2004) Consultation, community and empowerment: Lessons from the Deaf community. *The Journal of Social Work*, 4, 2, 153-165

McLaughlin, H., Young, A., and Hunt, R. (2005 under review) Edging the Change: Action research with social workers and Deaf and hard of hearing service users to achieve 'Best Practice Standards' *The Journal of Social Work*

Morgan, J. (1992) *Getting to the Core: A practical guide to understanding users' experience in the health services.* Shropshire: Shropshire Health Authority

Morris, J. (1997) *Community Care: Working in partnership with service users.* Birmingham: Venture Press

Mullender, A., Ward, D. (1991) *Self-Directed Groupwork: Users take action for empowerment.* London: Whiting and Birch

Parratt, D. (1995) Working with Deaf people. *Disability and Society* 10, 501-519

UKCoD (2001) *Setting Up a Deaf Users' Forum.* London: UKCoD

Stevenson, O. and Parsloe, P. (1993) *Community Care and Empowerment.* York: Joseph Rowntree Foundation

Young, A.M. (2006) The Experience of Deafness: Psycho-social effects. in V. Newton, (Ed.) *Deafness and Tropical Disease.* London: Whurr

Young, A.M., Hunt, R., McLaughlin, H. and Mello-Baron, S. (2004a) *Edge of Change (Final*

Report). London: RNID

Young, A.M., Hunt, R. and McLaughlin, H. (2004b) *Edge of Change Project Research Summary in British Sign Language*. London: RNID,

Young, A.M., Hunt, R., Loosemore-Reppen, G., McLaughlin, H. and Mello-Baron, S. (2004) A profile of 15 social work services with deaf and hard of hearing people in England. *Research, Policy and Planning*, 22, 1, 31–46