Involving disabled people in planning future strategies

"…equality is not about treating everyone in the same way. It is about responding to different needs in the different ways which best suit them" (Bert Massie)

"Disability equality is the business of all public authorities."
(Disability Rights Commission)

A report for Leeds City Council
March 2006.

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Abbreviations used

BME:	Black and Minority Ethnic
CIL:	Centre for Integrated (or Independent) Living
DDA (plus year):	Disability Discrimination Act
DRC:	Disability Rights Commission
GLAD:	Greater London Association of Disabled People
JRF:	Joseph Rowntree Foundation
NHS:	National Health Service
PMSU:	Prime Minister's Strategy Unit
SSI:	Social Services Inspectorate

A note on sources

Informative local Leeds sources are the 'Framework' document from 1998 relating specifically to disabled people with physical impairment and 'Having Our Say', which focuses on people with sensory impairment. These result from the work of the Leeds Disability Modernisation Team, a collaborative effort that includes service users, disabled people and representatives of local voluntary sector organisations alongside professionals from the council and local NHS units. Equally valuable are minutes from the Access Advisory Group and the Reference Group, and documents originating from the Leeds Improvement Group, its various components and supported groups. Some of these are in the public domain, but others may not be so.

The author wishes to express his thanks to the council for the help extended to him in the preparation of this report.

This report is also available in large print, community languages, Braille, on cassette tape, and on computer disc.

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Contents

Executive Summary

Leeds City Council's Chief Executive's and Social Services Departments and Leeds Centre for Integrated Living commissioned the report. The methodology consists of a review of relevant documents and literature with the aim of informing the council's Equality and Diversity Strategy.

Section 2: The Introduction

'Disability' is a broad area, which has attracted increasing attention from policy makers during the second half of the twentieth century. There is a strong statistical connection between disability and poverty or social exclusion, and the report of the Prime Minister's Strategy Unit (PMSU) is cited as authority for the claim that some 21% of the UK population is disabled.

Section 3: The Legislative and Policy Context

This section provides a summary of the major legislative and policy directives relating to the treatment and involvement of disabled people. I point out that the council is required by law to consider the effects of all and any of its actions upon disabled people.

Section 4: Individual and Medical Approaches to Disability

I give a brief overview of two models, the medical/individual and the social, which have been developed by disabled people in order to understand disability. I introduce the idea of social barriers to the inclusion of disabled people.

Section 5: Disabled People's Priorities

I identify the particular social barriers in the context of the recorded views and opinions expressed by a range of disabled people, both local to Leeds and from other areas of the UK.

A special concern of both government and disabled people is that service provision should be aimed at promoting their independence. Disabled people themselves have defined 'independence' in terms of the right to make decisions about their lives in the same way as 'non-disabled' people do. This means being able to exercise choice. In order to have a meaningful degree of choice, disabled people have said that they require clear, accurate and accessible information.

Disabled people have identified specific social barriers that stand between them and their social inclusion, these include:

- prejudice and stereotypes;
- inflexible organisational procedures and practices;
- inaccessible information;
- inaccessible buildings and;
- inaccessible transport

Section 6: The council's approach to involving people

In this section, I describe the different types of knowledge and experience that disabled people can bring to involvement and consultation – personal, shared and technical. I suggest that the best methods of involvement will attempt to match the knowledge of participants with the requirements of the particular consultation or involvement task. I briefly explain the added knowledge and experience that ethnicity and youth can bring to consultation and involvement.

Section 7: Consultation or Involvement

In this section I describe some different ways of thinking about' consultation' and 'involvement', that can provide a simple framework to guide the council in its interactions with disabled people.

Section 8: Key Points

I finish by listing the key points from my report, which include the following:

- When preparing to consult with disabled people remember their priorities as presented in this report, and do not re-invent the wheel.
- Before beginning a new consultation or involvement project, or when looking at the results of previous projects, systematically map the knowledge, skills and experience that disabled people bring.

Introduction

The council wishes to:

- make best use of disabled peoples' knowledge, skills and experience
- avoid consultation fatigue amongst disabled people
- avoid duplication of consultation
- make best use of resources and existing information
- reflect diversity amongst disabled people in Leeds

Existing and proposed legislation and public policy have the effect of fundamentally altering the relationship between disabled people and the council. The Disability Discrimination Act (DDA) 1995 introduced the concept of a right of disabled people to receive equal treatment, and the DDA 2005 imposes new duties on the council both to enhance public awareness of disability issues and to encourage disabled people to become more active in public life. There are also policy pressures to involve people, disabled or not, more fully in the democratic process.

The prime policy statement here is that of the Equality Standard for Local Government, which provides an agenda for a process of change in the relationships between the council and its local population. As the title implies, the aim is to combat inequality and abolish discrimination. The Equality Standard in particular, and recent policy initiatives in general, place increasing emphasis on the desirability of greater involvement of local people in the design and implementation of council services.

'Disability' is a word that includes and may sometimes mask a complex set of social issues. For example, the Prime Minister's Strategy Unit (PMSU) reports that disabled people:

- are more likely to live in poverty than the 'general' population
- have fewer educational qualifications
- have a significantly higher rate of un- and under- employment
- experience prejudice and abuse
- receive generally lower standards of service than other people [1]
- added to this list is a comment that BME groups are less likely to report disability, but tend to suffer its effects more acutely than do members of the majority population.

The PMSU suggests that some 21% of the UK population is disabled. This figure indicates that the number of disabled people within the Leeds area exceeds 150,000. The effects of under-reporting of disability amongst BME groups noted above would suggest that the actual number of disabled people in Leeds may be higher than this estimate.

Leeds is also a major centre within West Yorkshire and beyond for further and higher education, employment, shopping and leisure (including tourism). As such, the council has responsibilities that go beyond its resident population, for its functions extend to catering for the needs of visitors.

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[1] PMSU 2005

Legislative and Policy Context

Introduction

When working with disabled people, the council is required to operate within a number of parameters. Some of these are set by law; others are a matter of national policy and yet more are the result of local policy decisions. The purpose of this section is to clarify the situation as it is now: both law and policy may change in the future.

In particular, this section looks at:

- effects of European and UK law;
- policy guidelines introduced by the PMSU;
- policy guidelines introduced by the Equality Standard for Local Government

The law

The UK legal framework is affected by the primacy of certain European Union legislation, especially Human Rights law. Amongst the sixteen rights specified by law are:

- the right to life;
- the right to respect for private and family life;
- the right to education;
- the right to freedom of expression;
- the prohibition of discrimination

These rights are very relevant:

> The DRC has also been ... supporting judicial review cases in which the Human Rights Act has been invoked.[2]

In UK law, the DDA 1995 established the idea of a set of rights to which disabled people are entitled. The principle is that disabled people should not be expected to accept inferior provisions or conditions to those offered to 'mainstream' society. This applies equally to employment and to the provision of goods or services: as both a major local employer and as a provider of services, the council is doubly affected.

The DDA 2005 is specific that 'it is unlawful for a public authority to discriminate against a disabled person in carrying out its functions'. The effect is that the council must, whenever it is acting in its capacity as a public authority, fully consider any implications for disabled people. The whole range of council activity is included here, for the simple reason that it is impossible to imagine any function of the council that is not relevant to disabled people.

The Disability Discrimination Acts 1995/2005 are clear that it is lawful to offer preferential treatment to disabled people in order to allow them to benefit fully from council provisions. The 2005 Act also states that the council shall 'have due regard to' a need 'to encourage participation by disabled persons in public life'. 'Public life' is not defined, but the context of the Act suggests that it should be construed widely.

Policy

Nationally the PMSU provides a clear statement of policy. Disabled people do not share fully in the benefits and opportunities of contemporary UK socio-economic life, and this fact is to be addressed. By 2025:

> ...disabled people ... should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society.[3]

Breakthrough UK urges speeding this up where possible.[4] The PMSU is clear that this is an inter-agency task, but insists that 'disabled people should be at the heart of these initiatives'. The PMSU explicitly adopts a social model / social barriers approach to disability.

The Disability Discrimination Acts 1995 and 2005 make it lawful to provide preferential treatment for disabled people. The PMSU takes this point further, and combines it with the DDA 2005 duty on the council to 'promote' equality for disabled people. It is now national policy for the council:

> ...to become an exemplary employer; responsive to the needs of disabled people through its service delivery; and a driver for wider change through its relationships with contractors and its regulation of the private sector.[5]

Meanwhile, the Equality Standard for Local Government provides a route map and introduces three vehicles for the journey: **quality**, **leadership** and **community involvement**. There is a clear understanding within the Equality Standard that a 'more of the same' attitude is ineffective:

> current assumptions and practices can set up barriers that prevent access and discriminate against people.[6]

Existing UK law already requires consultation in a number of areas. Whilst the nature of this consultation varies according to specific legislation, the Audit Commission has said that making consultation inclusive is important because:

- consultation exercises are needed in order to find out the views of an accurate cross section of the population;
- sections of the community such as disabled people may have views that differ from those of the majority: if they are not consulted effectively these may remain invisible [7]

Summary

- The DDA 2005 requires the council to consider all potential effects upon disabled people of any of its actions. Over and above this, the council is also required to promote the equality of disabled people and encourage them to play a full role in public life.
- Disabled people may be given preferential treatment in order that they can experience the same or a better standard of goods/services enjoyed by the general public.
- The Equality Standard stresses “Quality; Leadership; Community Involvement”.

- A Human Rights principle is that disabled people should not be expected to accept inferior provisions or conditions to those offered to 'mainstream' society.

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[2] Crowther 2006

[3] PMSU 2005

[4] Breakthrough UK 2005

[5] PMSU 2005

[6] Equality Standard for Local Government executive summary

[7] Sheffield City Council undated

Two Approaches to Disability

Introduction

This section is a brief résumé of two contrasting ways of thinking about 'disability'. Neither is inherently 'right' nor 'wrong', nor in practice are they necessarily mutually exclusive. The council is beginning to apply a ‘social model', often promoted by organisations of disabled people and more recently adopted by national government.[8]

Topics covered in this section are:

- medical/individual model of disability;
- social model of disability;
- self-perceptions of disabled people

Organisations of disabled people have sought ways to raise awareness of their position in society. Two 'models' have been developed as conceptual aids to illustrate how different world-views may lead us to think of disabled people in very different terms. These are the medical (or individual) and social models of disability.

Individual approach

In this model, the structure of society is taken as being inflexible. This may be, for example, the built environment, transport, workplace or policy practices or social attitudes. Because the situation is assumed to 'be as it is', the focus is on the individual and her/his body. This firmly locates 'disability' within the individual. In a medical/individual model, bodily, intellectual or sensory impairment is thought to lead directly to 'disability'. Such a way of thinking may lead to healthcare practitioners seeking to 'cure' the body or mind, policy makers looking to 'compensate' people for some 'disadvantage' arising because of their 'condition', and the introduction of 'special' services for disabled people.[9]

The cumulative effect of this way of thinking about disability is to label disabled people as being 'not normal', and thus to set them apart from 'normal' or 'mainstream' society.[10] An example of a medical model approach is to speak, as did the then government Minister Margaret Hodge, of:

> ...people who face substantial barriers to employment as a result of their disability.[11]

The assumption behind this quote is that a person is disabled because they do not fit some idea of what a 'normal' person can do. There is no suggestion here that the workplace could be at fault in not being accessible to all, and developing that train of thought leads to an idea that the responsibility lies with each individual to fit into the environment, social or built, as it exists.

By emphasising the supposed 'difference' of disabled people, any existing prejudices are potentially strengthened. Not only does the reaffirmation of social attitudes regarding 'normality' deflect attention away from efforts to incorporate disabled

people within the 'mainstream', it also affects the way in which many disabled people think of themselves. Because disabled people are constantly exposed to such social attitudes, they often internalise them and may develop a strongly negative self-image. This is sometimes referred to as 'internalised oppression', and may appear as a passive acceptance of social inferiority. A large proportion of disabled people, on the other hand, adopt a social model approach.

Social approach

Here, people with some form or other of impairment are disabled not by their personal attributes, but by the reaction (or inaction) of society towards them. The onus is shifted onto society to take action to facilitate the social inclusion of all sectors of the population. Thus, it is that:

> ...the social model is all about ... the way in which society disables people who have impairments by failing to accommodate their differences.[12]

In a social model approach the key definitions are:

> Impairment: an injury, illness, or congenital condition that causes or is likely to cause a long term effect on physical appearance and/or limitation of function within an individual that differs from the commonplace; and
>
> Disability: the loss or limitation of opportunities to take part in society on an equal level with others because of social or environmental barriers.[13]

It is this 'loss or limitation of opportunity' that is the important point. The restriction of opportunity is a result of people's attitudes or organisations' policies (social environment), the way in which physical spaces or vehicles are arranged (built environment), or more frequently a combination of these. This means that 'disability' is not an inherent property of the individual, but something assigned them by society:

People do not "have" disabilities like attachments compelling them to live different lives; society disables some people by creating or approving barriers.[14]

It is useful to consider the social barriers that disabled people routinely face in their everyday lives. This will be done in detail in the next section, but these include:

- attitudinal ...
- policy ... design and delivery which do not take disabled people into account
- physical ...
- those linked to empowerment ... disabled people are not listened to, consulted or involved [15]

The whole point about such barriers is that they are in no way 'natural' - they are made and imposed by society and, as such, they may be removed by society. It follows that if disabled people are to join in 'mainstream' society, the way society is organised must be changed. Removing barriers which exclude (i.e. disable) people with impairments can help bring this about.

Self-perceptions of disabled people

Whilst government and the council, alongside very many disabled people, have adopted a social model perspective, this does not mean that all disabled people think in these terms. There is no 'right' or 'wrong' view here, and it is inconsistent with a 'social barriers' approach to attempt to enforce some form of orthodoxy. That of itself could lead to inflexibility, which in turn may create further social barriers.

Individual disabled people may consider themselves to be disabled directly by their impairment(s), by society or by a combination of both. This will partly arise from their own understanding of their situation, influenced by dominant social attitudes which they have been exposed to. For example, one person may say 'I am prevented from attending the meeting because the flight of steps means that the venue is not accessible to me', whilst another may say 'because my legs don't work, I can't get up the steps to come to the meeting'. The first is a social model approach, the second an individual/medical model one. Both report the same exclusionary barrier (to physical access in this case).

Neither person in the above example is 'right' or 'wrong' in their interpretation, and both provide valuable information about a social barrier. In order for the reports or comments of disabled people to be of full value to the council, it may sometimes be necessary to translate them into the social model view preferred by the council. This is simply to assist the council in its function: it is not a value judgment of the view adopted by the reporter.

Self-perception of the mechanisms of 'disability' may also relate to an individual's personal experiences of impairment:

> Many of us remain frustrated and disheartened by pain, fatigue, depression and chronic illness...[16]

Summary

- The medical/individual model concentrates on the person's body which can be useful in the context of treatment and medical care – but when applied outside this context can make disabled people appear to be 'not normal' and set them apart from society.
- A social model perspective looks at society, and leads to recognition of social barriers - 'disability' is not an inevitable result of impairment, but is caused by the way society is organised. Because of this, a social approach to disability will be a more useful model to apply when thinking about services and employment.
- Different disabled people will have their own ways of understanding their position in society.

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[8] DDA 2005; PMSU 2005

[9] SSI 2003

[10] Manchester City Council

[11] DfEE 2000 introduction

[12] Zarb 1995

[13] SSI 2003

[14] Derbyshire CIL 2000

[15] PMSU 2005

[16] Crow L 1996

A Review of Disabled People's Priorities

Introduction

This section will consider what disabled people themselves have identified, either as problem areas or as their priorities for the council to act upon. It is important to remember that there is no single voice of disabled people, either in Leeds or nationally. In consequence, what follows here can only be a partial discussion. This is a review of the recorded views of those disabled people who have been consulted, or who have volunteered opinions.

There is a major theme running through much of the available material, both from disabled people themselves, whether locally or nationally, and increasingly from government, whether local or national. This is that service provisions for disabled people should be geared towards promoting independence, whilst reducing any tendency towards causing dependence. What is meant by 'independence' here is really 'autonomy'. The point is that:

> independence is not about doing everything for yourself … but simply about being in control.[17]

Specific social barriers that stand between disabled people and their social inclusion have been identified. These are:

- prejudice and stereotypes;
- inflexible organisational procedures and practices;
- inaccessible information;
- inaccessible buildings and;
- inaccessible transport [18]

These provide useful headings to consider the priorities of disabled people on the one hand, and the ways in which the council may address them on the other. This does not mean that it is appropriate to consider each barrier in isolation. Social barriers often overlap and compound one another. The sections on the priorities of disabled people from Black and Minority Ethnic communities and young disabled people highlight the diversity of priority, perception and understanding of disabled barriers that is present in the population.

Prejudice and stereotypes

> When people dismiss you and exclude you and treat you like you are from another planet, that's when the veneer cracks and tears flood inside.[19]
>
> As I am unable to read due to my dyslexia, I am often humiliated in front of colleagues, friends and clients. I've been called: 'dim', 'lazy' and attention seeking.[20]
>
> I feel too afraid to admit I've a mental health problem. The stigma and rejection are too hard to face.[21]

We all carry unconscious and often prejudicial stereotypes within ourselves, however, and these generally reflect the social attitudes to which we have been

exposed. It is important to recognise and counter such stereotyping, especially as a Government survey has found that:

> there is no fine distinction between exclusion, prejudice and discrimination.[22]

The survey report then defines what it calls 'exclusionary attitudes' to disabled people:

- Labelling, referring to, or treating disabled people as different to *'normal people'* or outside of *'mainstream society'.*
- Attributing general characteristics or behaviours to disabled people simply because they are perceived to be disabled, for example assuming someone who has a *'visible'* disability is mentally impaired.
- Expressing fear, dislike or mistrust of disabled people ...
- Making assumptions that a [disabled] person's quality of life, or that their ability to live life fully, is diminished ...[23]

A recent study of young disabled people approaching adulthood clearly shows some of the prejudicial effects of stereotyping. Complaints from people in this group were that:

- they were not offered the same opportunities as other young people;
- staff were prejudiced about their potential to gain full-time employment;
- staff attempted to coerce them into dead end jobs or benefits [24]

Locally, the 'Framework' document tells us that disabled people have expressed concerns about 'attitudes' towards them, and this refers to both prejudice and stereotyping. In 'Having Our Say', although almost three-quarters of respondents found that professionals were 'supportive', similarly over a quarter were critical here. At least one respondent to Leeds Deaf Forum's 'Deaf View' reports that staff 'could come over patronising, and they talk down to you...', and elsewhere in that report mention is made of 'the patronising team'.

Outside Leeds, similar concerns have been raised. A recent report found that 'some people felt patronised' by professionals,[25] whilst the national BBC radio programme 'Does He Take Sugar?' has been largely devoted to attacking often unconscious patronising attitudes towards disabled people. 'Having Our Say' comments on similar matters and a report from London contain complaints from a Deaf person about:

> Ignorance of Deaf issues, what it means to be deaf, communication issues, patronising attitudes.[26]

In the 'final words' summary section of 'Deaf View' is the comment that:

> ...over half of the respondents thought that the attitudes of professionals are often negative and discriminatory.

The 'professionals' referred to here are not necessarily council staff. When considered alongside commentary from 'Framework' and 'Having Our Say', this again points to a continuing problem related to 'prejudice and stereotypes'. The evidence is clear that Leeds is by no means unique in this:

> My experience now is much more of being patronised and not taken seriously by people whose intentions are often not at all malicious. I have a PhD...[27]

A group that faces particularly prejudicial attitudes is that of people labelled as having 'mental illness'. People so labelled face very real barriers to their social inclusion:

> The level of discrimination ... shows the extent to which stigmas and taboos surrounding mental ill-health affect every area of life including employment, housing, parenting...[28]

Apart from unconscious or unintended prejudicial stereotyping is found a degree of deliberate antagonism towards disabled people. The Leeds Involvement Project newsletter of September 2005 explicitly links such incidents directed against disabled people to Hate Crimes.

Inflexible organisational procedures and practices

> Disabled people have been expected to fit into services, rather than services being personalised to respond to individual need.[29]

The answer given by the PMSU is to 'tailor' services to empower disabled people to live independently.

The 'Framework' document includes, in its 'Principles to guide service planning and delivery' section, a call for flexibility in service provision. 'Having Our Say' reports that, of its respondents, less than 46% agreed that 'the services on offer are the ones that I want to receive'. This marks a high proportion (54%) of service users who are, in effect, complaining of inflexibility.

Similarly, 'Deaf View' reports a high level of dissatisfaction amongst its respondents on questions relating to service provision. Over 50% found Equipment Services to be either 'fair' or 'poor', and 59% of respondents found services to be 'slow'. Other relevant comments from service users reported in 'Deaf View' are 'I can't choose what I like', 'lack of choice...' and 'limited choices...'

This is by no means a situation restricted to Leeds, nor is it anything new. As long ago as 1966, complaints were raised about inflexible regimes and lack of autonomy in residential accommodation for people with physical impairments.[30] More recently, it has been noted in respect of other areas of the UK that:

> significant numbers of disabled people ... remain dependent upon the decisions made by community care assessors,[31]

and that:

> the aim of independent living is held back by an ideology ... which does not recognise the civil rights of disabled people.[32]

This last point has also been identified by an organisation of disabled people, who note that:

> If you have to be at work by 9.00am, it's no good waiting all morning for a "carer" to arrive to help you get up.[33]

Organisational inflexibility has been highlighted nationally by disabled people for forty years. Such inflexibility creates feelings of powerlessness and dependence, amongst disabled people.

Leeds disabled people have offered their opinions on how to negotiate this social barrier:

> Disabled people expect workers to listen to what they are saying and act accordingly. People feel that it is vital that workers place them, the user, at the centre of the assessment and care planning process.[34]

Meanwhile, 'Having Our Say' notes that, of those disabled people surveyed, 70% wanted 'more say over the services provided'. Effectively, these people are calling for the 'tailoring' of service provision to suit the needs and aspirations of the individual. This ties-in with both the PMSU report and the Equality Standard provisions on policy. The disabled people of Leeds who have registered a view appear to be broadly representative of the national scene.

There is another important point here. Whilst people with a particular form of impairment may require appropriate specialist services, overall disabled people would prefer that 'mainstream' services were broadened to include their needs. There is an informative insight in a comment from Leeds disabled people:

> if all mainstream services were truly accessible then there would be less need for specialist services ... if public transport were accessible to all there would be less need to provide “special” transport ... if leisure and educational opportunities were more accessible to all there would be less need to provide specific services in specialist settings.[35]

This is in line with the statement by the Chair of the Disability Rights Commission, Bert Massie, that:

> Just as the institutions of the past speak of disabled people’s exclusion, so the institutions we build for the future should speak of their full inclusion at the heart of our society.[36]

Inaccessible information

> In order to make decisions about what happens to you, you need **information** about choices. You may need help making those decisions from someone who has been in the same position themselves, hence **peer counselling**.[37]

The minutes of the Access Advisory Group and the Reference Group provide strong and repeated evidence of the desire amongst local Leeds disabled people for information. 'Having Our Say' is particularly clear on this point:

> As many as 45% of respondents experienced difficulties getting information that would help them to lead an independent life ... it was very difficult and time consuming to track down the person/organisation who could supply and/or communicate the required information ... almost half of respondents agreed that they generally received information in the format they required ... The suggestions for improvements ... highlighted accessible formats for specific impairment groups ... A further theme was that information should be available in

languages other than English including BSL and generally more sensitive to minority ethnic group users.[38]

It should be noted from the above that more than half of the respondents **did not** agree that their information needs were 'generally' met. A disabled person who is a member of a Housing Consultative panel reports:

> the format of information is not always acceptable to me as I am dyslexic and need it in a clear, easy to read format.[39]

It is impossible to over-emphasise the value to disabled people of information that is accurate, appropriate and accessible. Without this, any attempt to live life on the same terms as other members of society becomes very difficult:

> Disabled people cannot have choice until they know what is available.[40]

Just as important as accessible information is access to information. This is said clearly in 'Having Our Say' - respondents complained of having to seek out the relevant person before they could ask for information. There was a call for more 'one stop shop' provisions, where disabled people could collect information both face to face and in portable (and appropriate) formats. 'Deaf View' contains several critical comments about the difficulties of accessing information.

There is also an issue of consumer confidence in the existence of accessible formats:

> If people require written information in another format such as Braille, tape or large print, they are much more comfortable asking if they know it is readily available.[41]

Inaccessible buildings

> **Access** to the built environment is essential not just to people in wheelchairs, but also those with sensory impairments, learning difficulties, babies and small children, tall people, small people in fact everyone.[42]
>
> There should be equitable access to buildings, for example, disabled people should not have to use the back entrance or the service lift.[43]

This latter point is important. Not only should a disabled person be able to gain entry, they should also be able to do so with dignity.

'Accessibility' is about more than the means of entry. It also relates to the facilities provided for public use inside:

> There is no point in being able to get into a building if you can’t move around when inside.[44]

The council issued, in June 2004, a policy statement on 'Access to Buildings' which promises to act within the 'context of reasonable adjustment' and using 'consultation' as part of the process. The DRC routinely adds 'and open spaces' to its discussion on access to buildings.[45] The minutes of the Access Advisory Group show repeated concerns about both the accessibility of parks and, equally important, the provision of fully accessible toilet facilities.

The scope of 'reasonable adjustment' is flexible and open to interpretation, and each case must be considered on its merits. As the 'Framework' report says:

> disabled people feel that there should be more consultation with them when new, or refurbished, building is being proposed.

Housing is of great importance to disabled people alongside the possibly less obvious surrounding environment. 'Framework' states that:

> [disabled] people see housing as the key (or barrier) to independent living. ... The feeling is that there is not enough housing designed to meet the needs of disabled people.

This sentiment is echoed by Derbyshire CIL:

> you need **housing**, which you can get into, move about in, live in, and which is in the right place.[46]

There is more to this point than simply where disabled people live. It also matters where others live:

> I can't visit friends or neighbours because many homes do not have wheelchair access – leads to social exclusion, if I don't try extra hard.[47]

It is also seen from the minutes of the Access Advisory Group that particular concerns have been raised in Leeds about new developments that have proved problematical for disabled people in terms of the layouts of roads, footpaths and verges.

The Access Advisory Group has drawn attention to issues around pavements being congested by various items, and inconsiderate car parking, which is reported as a particular problem in the City centre. Leeds is by no means alone in this: 'obstructions on pavements are still a major problem' in Bradford,[48] whilst in London:

> dropped kerbs, lack of parking, cars parking over dropped kerbs, inappropriate street furniture and lack of facilities for Deaf people were top of the list of barriers.[49]

Inaccessible transport

> In order to work or participate generally in society you have to be able to get out of the house and get around which means **transport**.[50]
>
> It would be nice to use public transport and not specialist transport: we are not freaks; we just need reasonable adjustments to get about our daily lives and be independent.[51]
>
> There is no point in having an accessible building if disabled people can't get to it.[52]

To be of use to disabled people, transport must be accessible. This point has been made elsewhere:

- people who do not have equal access to mobility systems, whether personal, private or public, are mobility disabled, they are socially dead; and

- the existence of systems which prevent equality of access to social mobility are systems with a deficit, and systems with a deficit are disabled systems, in time they, too, become socially dead.[53]

This is about more than just being able to board a vehicle. Concerns have been raised by local disabled people about the provision of dedicated parking areas for 'Blue Badge' holders, and the imposition of time limits:

> Wheelchair users take longer to park, exit, return and then leave in general.[54]

Wheelchair users, and other disabled people, do not simply travel from A to B. As with anyone, on arrival they then have business to conclude, be that work-related, shopping or leisure. Here again, mobility or other impairments come into play. What may be a two-hour task for a non-disabled person might take considerably longer for a 'disabled' one.

The Blue Badge scheme is of no use whatsoever to those without the option to use personal transport. 'Having our Say' found that:

> As many as 60.6% of respondents did not have access to a private car ... while a third used specialised transport, such as the Access Bus ... Opinions on the Access Bus were overwhelmingly critical.

In this, Leeds is not alone. A recent report by a neighbouring authority, based on surveyed comments by disabled people, also found that:

> The Access Bus is unreliable, inflexible and under resourced.[55]

These comments may also be considered as representing the barrier of 'inflexible procedures'.

Public transport is a problematic area for disabled people:

> My biggest problems are seeing timetables (the print is usually far too small, in difficult and light font styles), seeing the right bus stop or platform number, and knowing the right stop to get off.[56]

Similarly, 'Having Our say' reveals criticisms by disabled people which:

> demonstrated high levels of concern about ... the lack of, or inaccessible information on, bus routes and timetables and recognition of when to get on and off buses ... among guide and hearing dog users there was ... agreement ... about the prejudice they encountered, most typically from taxi drivers.

Leeds taxi drivers are not alone in attracting criticism from disabled people. In neighbouring Bradford, comments by disabled people include:

> Some taxi drivers also require customer care training.[57]

Black and minority ethnic disabled people

Disabled people from the BME population face a proliferation of social barriers over and above those directly associated with disability.[58] Furthermore, equality monitoring categories will not in themselves tell us in any detail about disabled

peoples priorities. For example, A woman of dual heritage (African-Caribbean / white British) put it this way:

> [I] don't see myself as black or white. ... It's more about who you are, I think, rather than where you've come from.[59]

There is widespread recognition within the literature that disabled people from within the BME population have been particularly disadvantaged in the provision of both services and information.[60] A report produced by disabled people from this sector makes several points that the PMSU confirms remain valid:

- black disabled people feel that they are a minority within a minority and that they occupy an inferior status to that of their white disabled counterparts
- multiple discrimination has such a profoundly negative impact that, as a group, they are the most socially, economically and educationally deprived members of society
- cultural differences are a crucial factor in assessing the nature of the service provided
- social services departments are perceived by many people from BME communities to be white organisations catering for white people
- service providers tend towards a Eurocentric model of care and have not confronted the diversity of need in a pluralistic society.[61]

Younger disabled people

> Accessible leisure opportunities ... are crucially important in enabling disabled young people to make and spend time with friends and can contribute to a more inclusive society by making disabled people enjoying positive experiences visible outside of ‘special’ settings.[62]

The point here is that, wherever possible, younger disabled people should be incorporated into 'mainstream' activity appropriate to their age group. There are several reasons for this, not least the potential to demonstrate to 'non-disabled' younger people that so-called ‘disability’ need not be a bar to social inclusion. Also, this relates directly to the call in the 'Framework' document for 'special' services to be incorporated into general provisions (discussed in the previous section: see footnote [20]).

By effectively segregating younger disabled people, there is a recognised danger of teaching them to expect to be 'naturally' set apart from 'mainstream' society in adult life:

> Encountering barriers to doing the same things that other young people do defines many disabled young people’s experience of social exclusion.[63]

Summary

When preparing to consult with disabled people, it would be helpful to remember the following priorities and not re-invent the wheel.

Local and national research and consultation has identified disabled peoples priorities as:

- To have the same choice and control as non-disabled people in every day matters.
- Those responsible for planning consultation must beware of referring to, or treating disabled people as different to *'normal people'* or outside of *'mainstream society'*
- Overall, disabled people would prefer that 'mainstream' services were broadened to include their needs
- In order to have informed opinions, you need information you can understand about the choices open to you
- For local government and other service providers to make information routinely accessible in alternative formats
- To be able to use the built environment with the same freedom (and restriction) as non-disabled people
- To be able to use the same public and private transport as non-disabled people and not just specialist transport *for the disabled*
- For local authorities to recognise that disabled people from the BME communities can face a particularly complex set of barriers
- For educationalists to be aware of the dangers of inadvertently teaching younger disabled people to expect a lifetime of exclusion

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[17] Derbyshire CIL 2000

[18] SSI 2003

[19] Greater London Authority 2003

[20] Greater London Authority 2003

[21] Social Exclusion Unit 2004

[22] DWP 2002

[23] DWP 2002

[24] Davis & Hogan 2004

[25] Priestley 1998

[26] Greater London Authority 2003

[27] Greater London Authority 2003

[28] Read J & Baker S 1996

[29] PMSU 2005 chapter 4

[30] Hunt P (1966)

[31] Priestley 1998

[32] Morris 1993

[33] Derbyshire CIL 2000

[34] Section 3.2.1 of 'Framework'

[35] appendix 5 of 'Framework'

[36] Massie 2006

[37] Derbyshire CIL 2000

[38] 'Having Our Say' p11

[39] Greater London Authority 2003

[40] Sheffield City Council undated

[41] Bradford City Council 2005

[42] Derbyshire CIL 2000

[43] Bradford City Council 2005

[44] Bradford City Council 2005

[45] DRC 2006

[46] Derbyshire CIL 2000

[47] Greater London Authority 2003

[48] Bradford City Council 2005

[49] Greater London Authority 2003

[50] Derbyshire CIL 2000

[51] Greater London Authority 2003

[52] Bradford City Council 2005

[53] Finkelstein 1994

[54] Access Advisory Group minutes September 2005

[55] Bradford City Council 2005

[56] Greater London Authority 2003

[57] Bradford City Council 2005

[58] GLAD 1991; PMSU 2005

[59] Martin 2006

[60] see, e.g., GLAD 1991

[61] GLAD 1991

[62] O'Connell 2005

[63] Morris 2001

Knowledge and Experience

Introduction

The purpose of this section is to explore the ways in which disabled people may help bring different perspectives to inform the policies and services of the council.

Before beginning a new consultation or involvement project or when looking at the results of previous projects, it might be helpful to have some way of systematically thinking about the knowledge, skills and experience that disabled people bring. This section offers some broad categories or ways of describing knowledge that can help you to match the objectives of your involvement exercise with the knowledge and experience your prospective sample might bring.

The particular sections include:

- ways to make use of the knowledge and experience held by disabled people
- ways of describing the different types of knowledge and experience disabled people can contribute
- suggestions on how to avoid overburdening disabled people with repeated enquiries

Making best use of disabled people's knowledge, skills and experience

There are good reasons for promoting involvement. As the Joseph Rowntree Foundation (JRF) puts it, involvement:

- helps to deliver programmes which more accurately target local needs;
- [ensures] resulting projects are more acceptable to the local community;
- helps to build local organisational skills;
- helps to revitalise democracy.[64]

There is also a clear warning given by the JRF:

> without monitoring, token ... involvement could take the place of real participation.[65]

We have seen in Section 4 that there are two broad approaches to understanding disability – the individual and the social approaches. The medical /individual approach concentrates on the person's body which can be useful in the context of treatment and medical care – but when applied outside this context can make disabled people appear to be 'not normal, to set them apart from society, and consequently hinder the planning of mainstream services.

The social model perspective looks at the organisation of society, and leads to recognition of social barriers - 'disability' is not an inevitable result of impairment, but is caused by the way society is organised. Because of this, a social approach to disability will be better suited to planning services and employment.

However, in addition to the medical and social approaches to disability, there are different ways of thinking about disabled people's insights, expectations and aspirations within these two approaches. A useful way of describing this 'knowledge' is in terms of 'Personal Knowledge', 'Shared Knowledge' (in a wide sense), and 'Technical Knowledge'.

It is important to think about the knowledge and experience that disabled people will bring to a particular project. Whilst all disabled people have direct experience of impairment, not all of them will share the same perspective – some will see their social exclusion as a consequence of disabling barriers, whilst others will see their exclusion as a direct result of their impairment.

Dialogue has more chance of happening if those planning a consultation project are aware of the terrain in which they are operating. When accessing the knowledge and experience held by disabled people, the council may be called upon to exercise judgement and leadership where conflicting ideas are presented. The joint task will then be identifying the barriers facing disabled people and agreeing a way to eliminate or navigate them. It is for the council to take the lead (as promoted by the Equality Standard for Local Government), and in particular to ensure that those disabled people involved /consulted have access to knowledge appropriate to the task in hand.

Mapping knowledge

The task of mapping the knowledge to be analysed during an involvement project can range from simply sketching out broad categories (like those listed below) to identifying very specific categories (such as those described in Appendix One). The level of detail required will depend on the objectives of the involvement or consultation project in hand.

Personal Knowledge and Experience

'Personal' knowledge is that gained by simply living with both the bodily and social effects of some form of impairment. Perhaps the most relevant aspect of personal knowledge here is that of disabling barriers. Some barriers, such as a flight of stairs, are obvious. Many, such as the detailed way in which a service is delivered, are not. It is only by 'living the life' that someone is able to experience the existence and effects of these. The experience of living life as a disabled person can bring with it a high degree of insight into the effects of social barriers that can rarely if ever be fully appreciated by a 'non-disabled', or perhaps even a 'differently impaired', person.

Personal knowledge does not include any detailed insight into the complexities of service provision. This means that aspirations or expectations may sometimes be unrealistic in practice. Should this be the case, explanation may be appropriate.

Personal knowledge is subjective, and in a sense passive. Mostly, it consists of reporting on, but not evaluating, a situation.

Shared Knowledge and Experience

Shared knowledge refers to the extent to which an individual is aware of the social circumstances of others with similar or different impairments. Again, shared

knowledge from a social perspective does not depend on personal experience. Shared knowledge might arise from reading about the relative poverty or social exclusion experienced by disabled people; whereas shared experience may come from listening to many disabled people talk about the barriers they face and campaigning for better services, access and so on.

Community groups and organisations of disabled people can be good sources of shared information.

Technical Knowledge and Experience

Technical knowledge and experience relate to the structures and operation of organisation in its broadest sense. This knowledge can lead to the identification and removal of disabling barriers.

Technical knowledge identifies the way in which people with impairments generally are disabled by different forms of social organisation. Technical knowledge from a social perspective often requires detailed knowledge of service delivery and employment policies, procedures and practices.

Community Groups and organisations of disabled people can be a good source of technical knowledge from a social perspective, as these organisations often apply their knowledge and experience to their own organisational procedures in order to practically involve disabled people in the functioning of their organisation. Disabled officers from within the organisation can also bring both a technical knowledge of the barriers and personal experience of combating those barriers.

The table below summarises the types of knowledge that may be identified during particular involvement or consultation projects.

Form of involvement / consultation	Knowledge
• Collation and analysis of assessment data • On-going service and contract management reviews • Satisfaction surveys	Personal knowledge and experience
• Meetings with community groups to help solve a specific service problem • Consultation with staff groups about employment problems	Shared knowledge and experience
• Information Technology, and Occupational Health assessments • Commissioned / specified consultancy with organisations of disabled people about significant policy change	Technical knowledge and experience

Disabling barriers to consultation and involvement

It is necessary to remember the barriers to consultation and involvement faced by disabled people. In particular, many of them have been denied access to 'mainstream' education and, in general, have not always been encouraged to make their own decisions. This state of affairs is referred to by the PMSU, and the possible results noted by another Yorkshire local authority:

- People who have never had a choice need an opportunity to learn how to be able to make real choices
- Some people need support to take risks – try things out. ... Disabled people should be allowed to fail as non-disabled people are allowed to fail.
- Disabled people and the statutory agencies need to explore new ways of supporting each other ...[66]

Payment for consultation

The expertise of council employees is recognised by their being paid. This is not usually the case with disabled service users, and indeed the minutes of the Access Advisory Group for September 2005 reveal worries about the reimbursement of travel costs on at least one occasion. Because they are more likely to experience poverty, costs are a very real barrier for disabled people. Elsewhere, it has been noted that:

> Disabled peoples' expertise needs to be recognised and rewarded; this could mean being paid for their contribution, time, and effort.[67]

The situation should be considered alongside that of a 'standard' consultation exercise. The type of knowledge being sought will be the key. If personal or political knowledge is being collected, often this will be volunteered. When more specialised, 'technical', knowledge is sought, and disabled people are specifically involved as experts, then the question as to whether or not payment is appropriate arises.

Avoiding consultation fatigue

One way of working towards this aim is by fully using existing information gathered from previous involvement and consultation projects. There are potentially savings in costs, time and effort, which the council may make here, thus increasing its efficiency. It is also useful to broaden ideas of what consultation and involvement is. For example, it might be useful to think about tasks such as the collation and analysis of assessment and service review as involvement or consultation.

There is another aspect to the topic of 'consultation fatigue', and this is the matter of feedback or, more precisely, its seeming lack. If people feel that their views are not being considered, then they will come to resent being consulted.[68.]

The issue of using consultation effectively has been considered in Sheffield. It was acknowledged that previous approaches to gathering views were piecemeal, and therefore, were not efficient. Together with disabled people, Sheffield council found that any new arrangements for consultation:

- must overcome, or have the potential to overcome, those disabling barriers that the existing consultation structures fail to address

- should co-ordinate consultation with disabled people across the City Council
- should allow disability policy issues to be considered before decisions are taken, rather than scrutinising decisions once they have been made.
- should be governed by basic terms of reference for both the content and the method of consultation; and these should be applied corporately, thus saving disabled peoples' and officers' time
- must be supported by appropriate training, administration and information technology.[69]

Summary

- Before beginning a new consultation or involvement project or when looking at the results of previous projects, it might be helpful to have some way of systematically thinking about the knowledge, skills and experience that disabled people bring.

- In addition to the medical and social approaches to disability, there are different ways of thinking about disabled people's insights, expectations and aspirations within these two approaches. A useful way of describing this 'knowledge' is in terms of 'Personal Knowledge', 'Shared Knowledge' (in a wide sense) and 'Technical Knowledge'.

- Dialogue has more chance of happening if those planning the consultation or involvement systematically consider the knowledge terrain in which they are operating. Different combinations of perspectives and knowledge will lead to different outcomes.

- Accessible and timely feedback is important.

- Duplication of consultation is annoying to disabled people and inefficient for the council.

- The council already holds a large amount of information, but this is often compartmentalised. Sharing such information is effective and efficient.

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[64] JRF, March 1999 - Ref 169 Developing effective Community Involvement Strategies

[65] JRF, March 1999 - Ref 169 Developing effective Community Involvement Strategies

[66] Sheffield City Council undated

[67] Sheffield City Council undated

[68] Sheffield City Council undated

[69] Sheffield City Council undated s. 3.1.4.1

Consultation or Involvement?

Introduction

> Participation also brings interaction between disabled and non-disabled people, which helps build the capacity of communities to extend membership to groups previously left out.[70]

This section aims to guide the council in its efforts to promote the involvement of disabled people. To be efficient and effective, the council needs to plan and prepare carefully. In particular, there is a need to consider the types of knowledge (as discussed in the previous section) and where these fit into the council's immediate aims. There is also an identified need to be fully committed, presented by a disabled person:

> Consultation is not an event, it is a process - a process which needs thought, money and other human and material resources; a process which needs commitment from everybody from the chief executive downwards. Consultation is a meaningless and wasteful exercise, unless there is commitment to treat us as equals - equals with a valid and knowledgeable viewpoint; equals with the same commitment to best value and high standards of service.[71]

Specific areas addressed here are:

- degrees of consultation/involvement
- application of this understanding to involving disabled people

What is consultation and involvement?

There is significant potential difference between 'consulting' and 'involving'. 'Involvement' suggests an investment of energy and effort in a joint venture: it is proactive on all sides. In contrast, the process of consultation may in practice be one-sided, with the council seeming to 'harvest' information from a relatively passive group of disabled people. It is important to clarify terminology in this area, for there are shades of meaning involved.

At the top of the ladder, so to speak, is 'direct involvement': the sharing of ownership or control of a service provision. Here, within an enabling framework provided by statutory agency, disabled people are full partners in decision-making. A good example of this is Leeds CIL, and more generally the CIL movement nationally. Leeds Deaf Forum's report 'Deaf View' is also specific on this point: of those who responded to its survey, 69% wanted the Equipment Service to be managed by deaf people. This represents the use by disabled people of all three types of knowledge, personal, political and technical, identified above. It may be necessary or advisable to provide some level of support and training to disabled people, especially at the beginning of a project

On the next rung down is 'formal consultancy', where identified disabled people or organisations are recognised as having 'expert' knowledge in a particular area. In just the same way as a management consultant, for example, would be paid for her/his specialist services (and in return accept responsibility for the quality of advice offered), so might the council expect to purchase this degree of involvement in

certain circumstances. Here the case is that both political and personal knowledge will be combined, and there will also be a degree of technical knowledge added.

Descending the ladder further, we come to what may be thought of as 'informal consultancy'. At this level, disabled people are recognised as having a particular interest in, and direct experience of, a given aspect of the council's functions: perhaps a specific service provision or a review of options as to the means by which disabled people's needs and aspirations may be met. As currently constituted, the Access Advisory Group and Reference Group perhaps best fit into this area. This is the use of both personal and political knowledge held by disabled people, and may also provide an opportunity for them to gain technical knowledge.

Near the foot of the ladder is 'surveying'. This is, more simply, the gathering of information by canvassing the views of disabled people, either on specific points or in a more general sense. There is little 'involvement', but there is recognition of the value of the life experiences of disabled people. Largely, this represents the collection of personal knowledge from disabled people. It may be appropriate to involve disabled people in the design of tools such as questionnaires and publicity material associated with a proposed survey.

At the base of the ladder is what may be thought of as 'engaging' with disabled people. This is more important than it might at first seem - if a ladder is not grounded properly, it may topple. This is represented by the provision of clear, accurate and accessible information that is relevant to disabled people. This should include all and any information disseminated by the council, not simply that on 'specialist disability' issues, if disabled people are to become or remain 'involved' in 'mainstream' life.

More particularly, engaging with disabled people includes feedback on data generated or services provided/reviewed/initiated/discussed at any of the other 'rungs'. Ideally, involvement and/or consultation should be two-way processes that enable disabled people to gain further knowledge, experience and confidence.

Involving disabled people

When involving disabled people, it is important to match the person to the task. If, for example, the council wishes to examine the efficiency of a new design of tactile surface, then people with visual impairment are likely to have relevant expertise. Similarly, if an induction loop system is being installed, then Deaf and hard of hearing people have the required knowledge. On the other hand, if considering a new road layout it may well be appropriate to involve a number of people with experience of living with a range of impairments.

Of equal importance is to decide which type and what degree of knowledge is sought: in other words, where on the ladder a particular project is located. Having found the appropriate level, it is then necessary to identify the sources of the required knowledge, be these individuals, organisations or the general population of disabled people. Some disabled people, and particularly activists, will be expert on the wider view of disabling barriers. Some will concentrate on the narrower area of their own concerns and problems.

All disabled people are expert in living their lives, and the ways in which impairment may lead to their exclusion from societal activities. Because of these various degrees of expertise held by disabled people on the one hand, and the wide range of activities undertaken by the council on the other, it is necessary to have a clear idea of the outcome sought by a particular project. In this way, it is possible to match the people or organisations to the task in hand.

It is also important to recognise the difference between life experience and technical or political knowledge. The council, in general, adopts a 'social barriers' approach to re-enabling disabled people. It may be that an individual disabled person thinks in completely different terms about the effects of impairment on their life. This does not mean that the two views are incompatible, just that a degree of interpretation is required. Simply because someone does not recognise a social barrier as such does not make it any less real.

Since situations can change, and projects move in unexpected directions, it is advisable to review processes periodically. This provides the opportunity to ensure that the best use of disabled people's knowledge, time and effort continues to be made. It also protects the council against accusations of 'tokenism' in its involvement of disabled people.

Employment policy is entirely a matter for the council, but it is the case that technical knowledge is most often gained by direct employment and associated training. On the other hand, disabled people employed by the council bring with them both personal and political knowledge which is potentially of great value to the council.

Summary

- Decide on the appropriate level of 'involvement' or 'consultation' for the task in hand. In particular, consider which type(s) of knowledge the council wishes to draw upon.
- Remember the ladder - find the most suitable rung for the task. Match the person(s) or organisation(s), and the type of knowledge held, to the task.
- Provide a firm base with accessible information and feedback - this is a two-way process whatever the level.
- Disabled people reflect different views on 'disability', but all have valid and valuable knowledge, opinions and experiences.
- Be prepared to monitor and review the process.

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[70] Massie 2006

[71] Elder-Woodward 2001

Key Points

- The DDA 2005 requires the council to consider **all** potential effects upon disabled people of **any** of its actions. Over and above this, the council is also required to promote the equality of disabled people and encourage them to play a full role in public life.
- The medical/individual approach to disability concentrates on the person's body which can be useful in the context of treatment and medical care – but when applied outside this context can make disabled people appear to be 'not normal' and set them apart from society.
- A social approach to disability looks at society, and leads to recognition of social barriers - 'disability' is not an inevitable result of impairment, but is caused by the way society is organised. Because of this, a social approach to disability will be a better model to apply when thinking about services and employment.
- When preparing to consult with disabled people, it would be helpful to remember the priorities presented in this report and not re-invent the wheel.
- Before beginning a new consultation or involvement project or when looking at the results of previous projects, it might be helpful to have some way of systematically thinking about the knowledge, skills and experience that disabled people bring
- In addition to the medical and social approaches to disability, there are different ways of thinking about disabled peoples insights, expectations and aspirations within these two approaches. A useful way of describing this 'knowledge' is in terms of ‘Personal Knowledge’, ‘Shared Knowledge’ (in a wide sense) and ‘Technical Knowledge’.
- Dialogue has more chance of happening if those planning the consultation or involvement systematically consider the knowledge terrain in which they are operating. Different combinations of perspectives and knowledge will lead to different outcomes.
- Decide on the appropriate level of 'involvement' or 'consultation' for the task in hand. In particular, consider which type(s) of knowledge the council wishes to draw upon.

Appendix One: Examples of Knowledge and Experience

The following descriptions of knowledge have been taken from the Sheffield City Council's Best Value Review of consultation with disabled people.

Personal Knowledge and Experience from an Individual Perspective

Personal knowledge and experience refers to what a person thinks and feels about their condition – what they think and feel about their impairments and their abilities. For example, personal experience and knowledge of diabetes might be derived from the having the impairment (experience) and listening to doctors' instructions on how to manage it (knowledge).

Personal Knowledge and Experience from a Social Perspective

Personal social knowledge and experience refers to what one person thinks and feels about their social situation of living with diabetes – what they think and feel about their living and working with the condition. For example, personal social experience and knowledge might be derived from being unfairly rejected for jobs because of their medical record (experience) and learning how to apply the DDA to (knowledge) to get compensation or adjustments from an employer.

Shared Knowledge and Experience from an Individual Perspective

Shared knowledge refers to the extent to which an individual is aware of the individual circumstances of others – either other people with similar or different impairments. Shared knowledge does not necessarily depend on personal experience; however, it does depend upon some knowledge of other peoples' situation. Shared knowledge could come from reading about improving the health of populations, whereas shared experience can be derived from participation in group therapy or self-help sessions.

Shared Knowledge and Experience from a Social Perspective

Shared knowledge refers to the extent to which an individual is aware of the social circumstances of others with similar or different impairments. Again, shared knowledge from a social perspective does not depend on personal experience. Shared knowledge might arise from reading about the relative poverty or social exclusion experienced by disabled people; whereas shared experience may come from listening to many disabled people talk about the barriers they face and campaigning for better services, access and so on.

Community groups and organisations of disabled people can be good sources of shared information from either the individual or social perspective.

Technical Knowledge and Experience from an Individual Perspective

Technical knowledge and experience relate to the structures and operation of organisations in the broadest sense. This perspective can lead to the identification and removal of disabling barriers.

Technical knowledge from an individual perspective would focus on how existing organisational rules can be used to the best advantage of individual disabled people – whether this relates to making adjustments for individual disabled employees or helping individual service users get the best out of services as they are. However, this perspective will not lead to any fundamental organisational development.

Technical Knowledge and Experience from a Social Perspective

A social perspective will encourage people to look at the way in which people with impairments generally are disabled by different forms of social organisation. Technical knowledge from a social perspective requires an intimate knowledge of service delivery and employment policies, procedures and practices.

Community Groups and organisations of disabled people can be a good source of technical knowledge from a social perspective, as these organisations often apply their knowledge and experience to their own organisational procedures in order to practically involve disabled people in the functioning of their organisation.

It is worth bearing in mind that none of these categories are mutually exclusive, which means it is possible that a particular person could have both individual and / or social perspectives on Personal, Shared and Technical knowledge and / or experience of a specific issue.

Applying Knowledge Maps

A person's contribution to a consultation or involvement exercise can be categorised in terms of the approach to disability and the type of knowledge / experience.

For example, a disabled person contributing to a discussion of welfare benefits might have a social perspective (which holds that benefit payments should be made to compensate disabled people for the social exclusion caused by disabling employment practices); they may have personal experience of the benefits system, be aware of how the system impacts on other disabled people in the city, and know something about the legislation, organisation and administration of the benefits system. Alternatively, a contributor might have personal experience of relying on benefits, but know nothing about other disabled peoples' experiences or the benefits system itself.

Different combinations of perspectives and knowledge will lead to different outcomes.

For example, if a consultation meeting is made up of disabled people who have personal experience and knowledge from an individual perspective; and officers with the group and technical knowledge from an individual perspective, there is an opportunity for dialogue, even though the disabled people do not have the technical knowledge, for the officers can easily take what the disabled people are saying and fit it into their conceptual framework – a round peg into a round hole. The disabled people however, are not in a position to challenge the officers' technical knowledge, for they have none of their own. This mixture of perspectives might lead to existing services being improved; however, it will not result in any significant change of policy direction.

For example, if a meeting is made up of officers with group and technical knowledge from an individual perspective, but the disabled people present have a social perspective on their individual and group experiences but no technical knowledge, then there would be the potential for communication to break down amid accusations of activism and political campaigning. A similar breakdown in communications could occur if the officers were equipped with a social perspective, but no direct experience of impairments and the disabled people used an individual perspective – with the officers being accused of being idealistic not knowing what is like to live with a ‘disability’. Of course, the situation would be different if the officers did have direct experience of impairments and disability.

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