



Report on user involvement in personal social services

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with the assistance of the Group of Specialists
on User Involvement in Social Services (CS-US)

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(CDCS)

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EXECUTIVE SUMMARY

1. **Project task** The task of this project was “*to examine the rights of users and their involvement in the planning and performance of social services*”. A Group of Specialists worked for one year, culminating in the production of this detailed report.
2. **Intended recipients** The report is suitable for use in all member states and for service organisations in the different sectors i.e. governmental, not-for-profit and also commercial organisations. It is particularly relevant for policy makers; heads of services; staff in middle management positions; operational staff; service users themselves and their organisations.
3. **Key principles** While recognising important differences between countries the report identifies several key principles as a basis for user involvement policies, systems and practices in all countries. These include
 - User involvement as a *right*
 - The centrality of users’ views and experiences
 - The fundamental need to provide social services of sufficient quantity and quality for users to access
4. **Main topics of the report** These include
 - Specially commissioned papers: ‘*Current strands in debating user involvement in social services*’ (Adalbert Evers); and ‘*Obstacles to an increased user involvement in social services*’ (Matti Heikkila and Ilse Julkunen)
 - Democracy, participation and user involvement – part of the more theoretical and conceptual background to the report
 - The perspective of social services by users themselves
 - Barriers and obstacles to user involvement
 - European examples and comparisons of user involvement in personal social services, based mainly on questionnaire material
 - Guidelines for good practice – with specific examples
 - Methods for developing user involvement (Appendix 2)
5. **Guidelines for good practice** This key section of the report offers clear, concise and practical guidelines for programmed implementation. They include
 - A diagrammatical presentation of a suggested integrated, holistic, national system for user involvement, primarily:
 - ✓ Key principles
 - ✓ Policies and legislation

- ✓ User involvement at the local level
- ✓ Users as collectives
- ✓ Other guidelines

6. **Conclusion** This project and its resulting report is an important contribution to the Council of Europe's longer-term work on its Social Cohesion Strategy, with its strong emphasis on the rights of European citizens. There is a case for further work to develop a 'Charter of Rights for Social Services Users'.

1. INTRODUCTION

The background to this project is the substantial long-term work by the Council of Europe on citizens' rights. This includes the European Social Charter and revised Charter; and more specifically, the report on 'Access to Social Rights in Europe' (2002). This latter report examined social rights as they apply in the fields of employment, social protection, housing, health and education. 'Personal social services' (see below for definition) were not included but became the subject of this separate project, with user involvement seen as a means to improve access to social rights. Overall, this project is an integral part of the Council of Europe Social Cohesion Strategy.

1.1 Purpose and working methods

A Group of Specialists in the field of social services (see Appendix 1) was formed in 2003 to work with a consultant to prepare a report "to examine the rights of users and their involvement in the planning and evaluation of the performance of social services". Special attention should be given to policy measures and good practice in user involvement, culminating in guidelines applicable to all countries and organisations responsible for delivering personal social services (PSS).

The timescale for the project was one year, finishing in June 2004. The group met four times. The project methodology included: reference to published writings and research; a questionnaire; specially commissioned papers; and the collective knowledge and expertise of the project group. The group was aware that a considerable range and quantity of published work already existed in this particular field, so that the output of this project should complement and add to – rather than duplicate – other work. A particular value of this report is its emphasis on European comparisons, including examples from Central and Eastern Europe.

Moreover, the group was sensitive to the criticism that too often there has been a 'top-down' approach to users' rights and participation, with too little understanding and concern for what users themselves have to say about their experiences and preferences. Ideally the group would have had direct access to and contributions from service users but this was not possible. Users' views as reported both in the research and other literature, and to individuals in the project group, were incorporated in this work. However, it is accepted that reliance on 'second hand' reporting of users' views is important but not completely satisfactory.

1.2 Definitions and approaches

1.2.1 *Personal Social Services*

This is a difficult term to define satisfactorily in a European context and even more so when used internationally. Within Europe there are important differences between regions e.g. between Nordic and Mediterranean countries. In the former there remains a strong emphasis on public provision, while in the latter traditional family responsibility for care is still more evident. To varying degrees changes in the role of women has impacted significantly on the need for and supply of social care services.

At a relatively early stage in the development of the post-1945 welfare state, the PSS were referred to as 'the fifth social service' – the other four being social security/protection, health, education, and housing. The newer and less known PSS were associated with the work of the growing numbers of social workers and emerging personal services for vulnerable children, elderly and disabled people. These services have for good reason been referred to as 'the Cinderella' of the welfare state. This characteristic is even more pronounced in countries of Central and Eastern Europe where in most cases PSS were usually regarded as ideologically irrelevant and of the most basic form – if they existed at all under communism (NB. Some people consider it more accurate to use the term 'Soviet' or 'state socialism').

PSS are *personal* services normally provided for individuals related to their specific needs and circumstances, in contrast to standardized services provided to people as members of categories. People who are typically users of PSS include elderly people and their carers, children and families, and people with disabilities. However, people with a variety of other needs and problems will use PSS, with differences between countries in who can and should use such services. Newer services for special groups have emerged such as people with HIV/Aids. Services are provided in different locations such as individuals' homes, in day centres and residential establishments. They are staffed by personnel including social workers, social assistants (or variations on this term), care managers, home-helpers, therapists, and kindergarten teachers. Organisations providing PSS may be: state – particularly local authority or municipalities; not-for profit non-governmental agencies; or commercial businesses. Services provided by third sector civil society organisations have become increasingly prominent in recent years.

A recurring question concerns the extent to which PSS are distinct from or similar to services provided within health, education, employment and social protection services. This is reflected in changing organisational structures, ranging for example from separate local authority departments for PSS – the 'PSS are distinctive' model – to arrangements where PSS are seen as essentially services

provided as part of a portfolio of services provided by health, social, protection, employment etc. Evers' (2003) view in his commissioned paper is that:

‘Social services include all services that are (a) considered to be of special importance for society on the whole and where (b) personal interaction between providers and users has a key role. Using such a broad definition, health, education, occupational integration and cultural services become as well part of the picture beyond the usual three fields of child day care, care services for the elderly and various small areas of services for problem groups’.

There are differing views as to whether the distinctive or broad definition of PSS is the most appropriate. Note that in this report the shorter term ‘social services’ is sometimes used interchangeably with the term PSS.

1.2.2 *Users and their involvement in PSS*

The basic premise must be that users' (greater) involvement in PSS is ‘a good thing’ both in and of itself – the intrinsic and social right justification; and because it results in better service outcomes. This broad statement requires refinement in terms of how user involvement is to be changed to produce better outcomes. Heikkila and Julkunen (2003) in their commissioned paper refer to Dahlberg and Vedung's arguments for increasing user involvement:

- The responsive organisation provides better quality services
- Service efficiency is increased
- The imbalance between users and the administration is changed (empowerment argument)
- The service system gains greater legitimacy
- Users become more confident and self-reliant
- Involvement is education in democracy.

Of course, users of PSS are not a homogeneous, undifferentiated group of citizens. They vary according to many significant characteristics so that some forms of involvement in PSS may be possible and suitable for one group but not another. The project considered confining its work to certain well defined groups of users but decided against this approach.

Heikkila and Julkunen suggest that users fall into one of two major groups, based on the types of services they use. They distinguish between *mainstream* and *targeted* services. The former are PSS that respond to a dependency due to old age, disability or young age (children). The latter respond to an individual (social) problem or need. Mainstream services normally have clearly defined criteria for access to services while targeted services are discretionary, based on needs or means-testing by social workers and others e.g. care managers. There may be some differences

between countries in deciding exactly which users fit which category e.g. in Nordic countries day childcare services are a right and available to all children of a certain age but this is not so in some other countries. It should be noted that in some countries these day childcare services are part of education rather than PSS.

This distinction raises the important subject of users' **rights** to certain services which is considered later. Concerning user involvement in the two types of services, Heikkila and Julkunen suggest the following propositions:

The more there is one-sided professional discretion both in regulating the access to services and in its internal implementation, the weaker are the rights of users, and the vaguer is the base for a proper user involvement and participation. This can be a particular feature of care/case management where the service provider has special responsibility. The users of targeted services, involving much discretion, tend to be disadvantaged, poor people whose voice is weak and political weight small.

Many of the mainstream services are for people who can demonstrate their need and therefore can be seen as middle class services. Even if this is not true in all societies (where public services are provided only for the poor) the role of users can approach that of *consumers* who mobilise and act politically with a strong and effective involvement.

Consequently, in relation to user involvement, the need to define the formal position, rights and obligation of the users is especially urgent in services where the user's competence is weakest because of status or history, such as in institutional/residential care.

The term 'user involvement' is itself rather bland and needs to be examined within its context of democracy and the rationale for citizen participation in society. This will be considered in the next section.

2. DEMOCRACY, PARTICIPATION AND USER INVOLVEMENT

2.1 Democracy and participation

It is important to understand the subject of this report within its historical and political context. It can be argued that the roots of user involvement go back as far as the origins of democracy in Greek and Roman culture with their democratic practice of (some) citizens debating and deciding the important issues of the day on a mass debating and voting basis. This sounds attractive to many present-day alienated citizens in Western representative democracies but participation in Athenian democracies was confined to the more privileged groups.

Member states of the Council of Europe are more familiar with 'representative democracy', although some have a much shorter experience than others. In Western European countries two sharply contrasting trends have emerged in recent years. On the one hand, citizen participation in democracy as seen in willingness to vote in local, national and European elections has – with some exceptions – declined to an almost alarming extent. There is now talk of introducing compulsory voting (e.g. as in Australia). On the other hand, demands by citizens to have a great involvement in major public services such as health, education and social services have grown stronger. This contrast is probably and understandably not evident to anything like the same extent in the newer democracies in Central and Eastern Europe.

Since the end of World War II, there have been two distinct periods of 'grass roots' interest and activity to increase citizen participation and involvement as democratic rights. Internationally, the first period began in the late 1960s with fierce student protests in America, Paris and elsewhere against bureaucratic, non-participatory forms of higher education. This movement broadened into a lengthy period of community protest in the USA and in many parts of Europe, with local groups often using militant methods to achieve a greater degree of involvement and power in local political and services decision-making. Attempts by the authorities to offer limited forms of participation were usually rejected as tokenistic, as seen in the translated version of the Paris students' graffiti: "I participate, you participate, we participate – they profit".

This phase in the participation/involvement struggle achieved important but still limited gains, and declined with the near demise of left-wing politics in Western European countries during the economic crisis for capitalism in the late 1970s. The second more recent phase in this region started at a more indeterminate time in the 1980-90 period and is associated with the growth of 'third way' politics, the growing popularity of 'communitarianism' (Etzioni 1995) and a widespread critique of both the paternalism of the traditional professions and the bureaucratic institutions in which they mostly practised. The growing importance and influence of markets have also played a major part in these developments. This continuing period has seen the growth of user movements in, for example, health and social welfare with accommodating responses from both the professions and the service organisations.

Countries in Central and Eastern Europe have rather different histories with a voice for the user only emerging as legitimate post-1989. Previously 'the state knew best' with individuals' needs and any service response determined by the prevailing 'communist' ideology. User involvement in countries in this region remains relatively weak due to the continuation of a dependency culture and the sheer pressure of the material needs of typical users of social services.

Hambleton and Hoggett (1998) amongst others have analysed this phenomenon in Western Europe – tracing its development from the 1970s to the present day.

They plot the different ideological and more pragmatic responses to the root problem of unresponsive public service bureaucracies, with explanation of the significance of the terms client/consumer/user/customer/citizen. In his commissioned paper for the project Evers (2003) conducted a similar review, drawing out the implications for user involvement in the PSS. This is now considered in detail below.

Heikkila and Julkunen suggest it is important to distinguish between user participation, user involvement, and user empowerment. Participation is the weakest term as users are only partially involved and serve more as informants. User involvement always entails that the users' activity has an impact on the service process in some way. User empowerment may be seen as the most radical form of involvement as it may entail professionals giving up their power and control, with services being truly run and controlled by users. This rarely happens. A weaker but still important meaning of empowerment may refer, for example, to the power that follows users gaining more knowledge, information and skills.

2.2 Current strands in the debate concerning user involvement in social services

Evers identifies five main strands of thinking on welfare and social services.

The strands are:

- Welfarism
- Professionalism
- Consumerism
- Managerialism
- Participationism

Each is considered in turn together with their implications for different approaches to user involvement in social services.

Welfarism

This old style approach is associated with rather rigid, inflexible, mostly state controlled welfare bureaucracies that allowed little opportunity for service user involvement. The most extreme and negative examples were found in the former communist regimes where users had virtually no say at all. In Western Europe welfare states positively provided a range of social services as of right but user involvement was largely confined to 'arms length' representation through Trade Unions and intermediary NGOs with limited or no inclusion at all of actual users themselves. Disabled people particularly criticised this approach, demanding the right to speak for themselves rather than having others speak for them.

But as Evers comments 'One of the strong points of traditional service systems has been that routinized and uniform services can well be combined with a set of clear cut social rights', creating a platform for the development of a Charter of Rights for certain services. Nevertheless, the conclusion must be that the old style welfarism 'represents more barriers than potentials for individual and agency-related user involvement'.

Professionalism

Evers contrasts strong and mild forms of paternalism evident in the development of attitudes and practices of welfare professionals. The former – often associated with working in the old style welfare bureaucracies (above) – involved the social worker 'working **for** the clients rather than **with** them in partnership, calling for compliance rather than negotiating the services to be provided'. This 'daddy knows best' paternalism allowed little room for the clients' opinions and preferences.

The modern professional welfare practitioner is more bound by professional codes regulating ways she/he should act in favour of the client/user; has been trained in client-centred practice methods; and has been influenced by changing societal attitudes towards the professions and user involvement in a wide range of services. She/he is likely to show an up-to-date concept of professionalism that emphasizes openness, consultation and cooperation with users as co-producers of services, rather than passive recipients of services determined by paternalistic professionals.

Evers refers to the social service model of *case/care management* that raises some concerns about user involvement. It emphasises the importance of practitioner-user consultation and cooperation but the reality of limited service resources too easily turns case management into a rather mechanistic, managerial rationing style of service provision that prevents any real user participation.

'Summing up one can say that professionalism has two sides: one side may be the often-complained arrogance of power while the other side is the burden of responsibility taken. The latter side can be a good point of reference for those who strive for a better user involvement. To the degree that professionalism puts clients' interests first it can be a strong antidote against old and new ways of putting the interests of authorities, business and providers ahead of the concerns of users and citizens.'

Consumerism

As Hambleton and Hoggett illustrate, one approach to the problem of unresponsive public service bureaucracies has been to introduce markets or quasi-markets into public services to produce benefits to both producers and

consumers of these services. 'The basic premise of consumerism is that by giving users choice and exit options and by establishing competition among providers, this kind of consumer power will be more effective in making services user-centred than any other policy direction' (Evers). This approach was particularly evident in the public sector reforms of the right wing Thatcher governments in the UK in the 1980s.

The belief that users of social services should enjoy the same benefits in their transactions with service providers as do customers of supermarkets is attractive but also flawed. Certainly, real possibilities of choosing between competing services and exercising the power of exit from unsuitable/poor quality services would significantly empower the user of social services. But the reality is that the social services user rarely pays directly for a service – a crucial ingredient in the power of the supermarket consumer. The use of voucher systems goes only some way towards overcoming this obstacle. Another more successful innovation has been the introduction of 'direct payments systems' or client budgets to enable some groups of users to purchase services from alternative providers. This scheme is reviewed later in the report.

A further limitation on the application of the commercial consumerist model to social services transactions is that many users are significantly different from the free, discerning and well-resourced consumer. Some users are constrained to use certain services; others have no real possibilities of using the exit option (e.g. elderly people in long-term care); while the educational, economic and social disadvantages of many typical users put them in a weak position in transactions with service providers. But Evers argues that

'Many of the limits for making users act as consumers who make their own choices can be moved. Governments and NGOs can provide them with various kinds of possibilities to learn that role (consultancy, marketing the services etc.)... So there is little doubt that introducing consumerist elements can contribute towards upgrading the role of users.'

Managerialism

This strand in welfare has connections with *consumerism* in its aim to import commercial/business concepts and practices into public services, including social services. Previously, terms such as cost effectiveness, quality control and competitive tendering were unknown in the world of the PSS. Now, to varying degrees, they are common currency.

Hambleton and Hoggett's model sees 'new managerialism' as the least ideological response to unresponsive public service bureaucracies, a more pragmatic technical approach that refers to 'customers' rather than consumers. They see it as an approach that preserves existing power relations between service producers and their customers, while using intelligence gathering

methods such as market research, user satisfaction surveys and customer care programmes to bring the provider closer to its customers. As the writers observe 'This model has become extremely popular in local (UK) government – it is difficult now to find any local authority that does not claim to be trying to get closer to its customers'.

Evers argues that here the focus is not on the user but on the interest of the provider. Modern management methods are to be used in public services to improve their efficiency in a context of global competitiveness and constrained budgets for public services. Commercial style managers now become powerful players in public service systems, operating between user orientated professionals (e.g. doctors, social workers) and their newly termed 'customers'. This introduces yet another new term 'managed care' that merges socio-economic and traditional professional considerations, involving more top-down regulation with negative implications for former provider-user relationships in the PSS.

Evers concludes:

'These processes of bringing social services nearer to the ways other commercial products are managed (e.g. electronic media and communication systems) imply a corresponding transformation of the role of users – in the positive as well as the negative sense...tools of user involvement such as advice and consultancy increasingly become a matter of website information and service packages which substitute personalized dialogue'.

In this context, 'managerialism is making the role of organisations that represent the interests of users and facilitate their participation in complex service systems much more important'. But within limits, 'managed care may quite often offer more than traditional practices in making information accessible, offering courses etc'.

Participationism

Evers uses this innovative term to include 'all those strands of thinking and practices that call for cultivating or bettering various forms of direct and at-place participation of users, in addition to their indirect involvement by taking part in broad public debates and by collectively participating in decision-making processes via NGOs.' Hambleton and Hoggett use the term 'extend democracy' to refer to the same type of response to unresponsive public service bureaucracies, with 'voice' as the empowerment strategy and a focus on people as citizens.

As will be seen later, this is the heart of the matter for the thrust of the modern users' movements, epitomising their approach to user involvement in social

services and other public services. In a nutshell, 'The specific point of participationism is then the belief that people should also engage personally in the shaping of services' (Evers). Crucially in this strand, the emphasis moves from the individualising of the user in other strands to that of the user as part of a communitarian collective (e.g. parents in relation to childcare). 'Citizens engage in public debates about shared concerns which lead to collective political decisions, whereas customers engage in comparison shopping which leads to individual economic decisions' (Hambleton and Hoggett). Evers makes a similar point in commenting that participationism differs from the consumerist perspective because 'it values more the user's abilities to act as well as a citizen and to take co-responsibility together with others. This identity of users as collectives is particularly evident in the campaigns of both disability and mental health user groups and to some extent with older people. The growing significance of women's groups is yet another example.

Further, this approach to user involvement in social services emphasises users as co-producers of services, cooperating fully with professionals and their agencies in planning, providing and evaluating these services. This may happen to the extent that a society is a 'civil society' with a rich diversity of citizens-led grass roots organisations. But in this model citizen users are required to make a substantial commitment of their personal time and energy to civic action, which some are better placed than others to contribute.

Moreover, there is a danger that state organisations may be only too ready to hand over too much responsibility – with insufficient funding – to civil society, with negative results for disadvantaged users of social services. So Evers concludes 'Summing up, one can say that participationism offers a rich manual for a concept of user involvement that gives users the promise of gaining a lot of impact – but also requires them to give a lot in return'.

Summary

Evers' review – together with that of other commentators – of the different strands or traditions of thinking on welfare and social services provides a necessary conceptual and analytical framework for the subject of this report. It will contribute to subsequent discussions on user involvement in social services in different European countries.

It is not argued that in any one country welfare thinking is dominated by just one strand of thinking. In reality, there are mixtures of strands – or mixed governance of social services – with changes and varying emphases over time. This is evident, for example, in countries in Central and Eastern Europe with their post-1989 break from the domination of state welfare and the development of democracy, civil society and citizens' rights. In most European countries, governments – to varying degrees – have a social policy preference for mixed economies of welfare and social services that open up a greater range of

involvement possibilities for users. As identified in the review above, these include seeing users as

- *citizens* with rights and entitlements, central to real as opposed to token user involvement
- *consumers* to be empowered and protected, with choice and exit possibilities
- *customers* whose needs, views and preferences must be taken into account in well managed, modern public service organisations
- *co-producers* who take up their civic roles and concerns as members of communities in cooperating with service managers and professionals or by building their own services

It should be emphasised that civil society with its associations and non-state social service providers has assumed great significance, particularly in most Western European countries but now in many Central and Eastern European countries. Civil society enables users also to act as producers of care services – a third sector along with the state and markets.

A crucial perspective on all this is what users themselves have to say about their involvement and, not least, how their experiences and preferences relate to more distant theorising. The next section of the report turns to this important topic.

3. THE SOCIAL SERVICES USERS' PERSPECTIVE

3.1 Introduction

The experience and views of social services users themselves must be of first-rate importance in this project. There is a long history of complaints by users of public services that their opinions are, to varying degrees, under considered or even completely ignored by the authorities. But it is quite difficult to address adequately the question of the users' perspective on their involvement for two main reasons:

- firstly, social services users are not an undifferentiated homogeneous group. This means that it is unwise to make general statements about users' reported experiences and views. For example, there may be a significant difference in the involvement of well educated middle class users of day care services for children in Nordic countries, compared with the experience of socially excluded families in poverty in other European countries. The diversity of users makes it difficult to generalise from particular examples;

- secondly, the sheer size of Europe adds a particularly difficult dimension to this subject. A later section in this report indicates some of the differences between countries, ranging from those with longer experience of involving service users, to countries in Central and Eastern Europe particularly where user involvement is a relatively new phenomenon.

There is insufficient information and data about social services users' views on their involvement in enough European countries to enable useful comparisons to be made on this key perspective. Third party views on user involvement are important but no substitute for what users themselves report directly. Further research is required but has not been possible within the parameters of this project. Material in the remainder of this section of the report is drawn from reported experiences and views of users in one or two countries and so can only be suggestive concerning wider relevance and application. Nevertheless – and allowing for differences referred to above – much of what follows has a common sense quality which suggests wider relevance across Europe.

3.2 Limited progress and users' criticisms

There appears to be a general 'law' operating in this field that the more progress is made in user involvement the greater is the awareness of the limitations of progress. Accusations by users of a tokenistic approach to user involvement by the authorities are still evident, with the so-called rhetoric of *user-choice* subjected to heavy criticism. The rise of the consumerist strand in welfare referred to by Evers has increased the confidence of consumers/service users in the UK and elsewhere, enabling them to voice previously unexpressed criticisms of official services and professionals.

There is something of a paradox in that, on the one hand, there is probably greater-than-ever public commitment to increasing user involvement, ranging from pan-European organisations down to small local authorities. Consumers, clients, users are more confident than before and – thanks to the internet – possess far more knowledge and information on services than previously. In this sense they are now more empowered. But, on the other hand, unlike in the world of supermarket shopping, real choice for the service user is rarely available; while a combination of the imperatives of the 'new managerialism' with the severe resource constraints imposed on social service organisations significantly limits more radical approaches to user involvement. The result is considerable frustration for many social services users, individually and collectively.

Beresford (2003) argues that the relative neglect of the user's view stems from the traditional pre-eminence given to 'objective' scientific knowledge compared with the 'subjective' knowledge gained from what people say about their own personal experiences. The latter has been seen as unreliable and of rather suspect value. In his provocative essay Beresford challenges this tradition, putting forward the proposition that:

The greater the distance between direct experience and its interpretation, then the more likely resulting knowledge is to be inaccurate, unreliable and distorted.

This proposition cannot be examined in detail here but it sharply raises the fundamental question of just how much value is placed on what users themselves say about their involvement in social services when planning changes in countries' policies and practical arrangements.

As Heikkila and Julkunen indicate, Beresford and Croft have been two of the strongest critics of many official approaches to users' participation/involvement. They argue that

'...when we look at the substantive purposes that participatory arrangements may actually serve we discover that they are not consistent with people's effective involvement and increased say. Instead, other functions are identified, as, for instance, *incorporation*: people are drawn into participatory arrangements which limit and divert their effective action; secondly, *legitimation*: people's involvement is used to give appearance of their agreement and consent, and thus participation serves as public relations and a window-dressing exercise'.

Such criticisms of top-down approaches to citizen involvement are quite widespread and longstanding, going back as least as far as the Paris students' critique referred to earlier in this report. Arnstein's (1969) famous 'Ladder of Participation' develops this critique in detail, identifying a range of participation modes from suppressive to radical citizen control of services. Specific, detailed criticisms of current approaches to user involvement are found in numerous articles and reports, some of which are listed in the References for this report.

It is important to acknowledge that, despite the limited progress in this field, a view over time shows that significant advances have been made. A simple example concerns the right for users in many countries to have access to their social services records. At an earlier period this right would rarely have been recognised. Furthermore, the working style of social workers with users has changed considerably from the rather secretive traditional professional approach to a much more open and democratic relationship. A later section in this report provides examples of 'good practice' in some countries that may have application elsewhere.

There is a growing volume of research examining users' experiences of involvement in social services. There are many critical findings but also important points of guidance for improvements. These include

- Normally social services users wish to be directly involved and represent themselves, rather than being represented by well-meaning third parties. This has been a major issue in the struggles of the Disability and Mental Health user movements where users have developed a strong preference for user-led organisations which they control and best represent their views. Evers refers to how, in the 'welfarism' tradition, 'forms of indirect "corporate participation" of groups from society usually excluded the users themselves'
- Users want to be fully involved in service processes from an early stage, not consulted when plans are well underway
- There are major differences between *management centred* compared with *user-centred* involvement
- Users' preferences for involvement have necessary resource implications. There is a price to be paid by agencies and their funders for genuine involvement – it is certainly not cost-free
- There are also considerable demands and costs for users themselves. Effective involvement makes demands on users that are often not understood and allowed for
- User involvement planned and imposed from above rarely works
- Users value both good service outcomes *and* a service-providing process that treats them with respect

These and other findings from research will be incorporated in the Guidelines section of this report.

4. OBSTACLES TO USER INVOLVEMENT IN SOCIAL SERVICES

4.1 Common barriers to user involvement

Real sustained progress in user involvement requires awareness of the main obstacles to progress and how these may be overcome. Typical obstacles are usefully summarised in Heikkila and Julkunen's paper, with other examples provided by experts from the individual countries in the project. From these sources the following principal obstacles or barriers to user involvement are identified

- **Political/legal** There is either no legal provision for users' rights to be involved or legislation is inadequate. This is particularly evident not only in many Central and Eastern European countries but also in some Western

European ones. Generally, the legal foundation is strongest in Nordic countries and the Netherlands.

- **Administrative** Unclear goals in the administration and lack of knowledge of successful methods for user involvement can form potential barriers. The classic form of bureaucracy can be implicitly (subtly) – if not explicitly – opposed to more than token involvement by service users. Involvement can be seen as ‘messy’, inconvenient and time consuming and against the smooth operation of a hierarchical, routinised organisation. The continuing existence and strength of this barrier should not be underestimated.
- **Professional** The implications for user involvement of the traditional ‘we know best’ paternalism of much social work practice have been outlined in the earlier section on Evers’ five traditions in welfare practice. Despite changes to a more open, collaborative style of social work practice this professional barrier still exists. Two factors are particularly influential. Firstly, the continuing uncertainty in social work concerning its professional identity and status. Insecurity in social workers may well make them less inclined to be too open with users. Secondly, user involvement may be seen as an unwelcome additional demand on the time and energy of social services staff who are already hard pressed.
- **Language** There are two potential language barriers to effective user involvement. Increasingly the first language of the social worker and the service user may not be the same so that it is essential that an interpreter service is readily available. This is obvious but not always easy to implement, and there are cost implications. Moreover, some professional language may be over-technical and mystifying to many users, creating a serious barrier to good communication and joint working.
- **Personal** Heikkila and Julkunen refer to how personal barriers can be traced to different attitudes and different views on involvement. They cite Swedish research that concluded that users and professionals have different views on what empowerment entails. The most important aspect for users is concrete outcomes, greater financial security and decent living conditions. But the professionals put more emphasis on outcomes such as greater self-reliance of the users.
- **Resources** The point has been made earlier that genuine user involvement involves significant costs for both service providers and users. Either party may not wish or be able to afford these costs. For service providers costs are principally staff time and associated costs attached to different user involvement systems and methods. For users there may be (unrecognised) financial costs plus non-monetary time, energy and the giving up of alternative uses of time involved in participation.

4.2 Barriers reported from individual countries

- A lack of information and few formal, institutionalised mechanisms for influencing agency policies seem to be major obstacles to user participation in general (*Norway*)
- Limited awareness of newer, more innovative approaches to user involvement that are needed to enable particularly disadvantaged users to participate (*Iceland*)
- Non-participatory practices and traditions inherited from the communist regime; the economic situation of the country; changes in family functions and structure. Bureaucratic delays in service organisations, limited resources and large numbers of service users (*Romania*). The very difficult situation of many users (e.g. poverty, long-term unemployment, low levels of information) makes it hard for them to participate. Their passivity is understandable but is a barrier to their being more involved.
- A lack of mechanisms and tools structurally to assure full participation of users in designing new policies, monitoring and evaluating social services. An authoritarian tradition and culture preventing user participation from both sides – service provider and user (*Albania and Armenia*)
- Lack of policies and legislation on user involvement. Too much bureaucratic 'red tape' making systems inaccessible and inefficient for service users. A lack of cultural awareness by service providers about the concept and importance of user involvement. Negative attitudes towards users resulting in lack of information about their rights. Users themselves can lack assertiveness, energy and confidence to speak out and become involved. This can be due to their life situations and sometimes illiteracy (*Malta*)
- Attitudes, lack of necessary tools, and a lack of trust in authorities by users (*Finland*)

5. SOME EUROPEAN EXAMPLES AND COMPARISONS

5.1 Introduction

This inclusion of material illustrating various approaches and experiences of some European countries in user involvement is in line with a core value of the Council of Europe, namely assisting the development of good practice in social welfare through comparative work. Material for this central section of the report was obtained through replies to a questionnaire and from other published documents. The report of an Expert Meeting organised by the German

Association for Public and Private Welfare (1999) is particularly valuable in this respect.

Rather than adopting a country-by-country approach to presenting the European material, the following subject/theme structure is used:

- A 'culture' of user involvement
- National policies and legislation
- Users' organisations
- User involvement at the agencies level
- Rights to involvement

A comparison between countries inevitably leads to some assessment of their different stages of development. As stated earlier, countries have different histories, traditions and national cultures which help to shape their social services systems and their approach to user involvement, resulting in a rich diversity. For example, Nordic countries and the Netherlands have well developed legislation, policies and practical arrangements for user involvement reflecting a strong orientation towards citizens' rights in those countries. Countries do not start from a 'level playing field' in this subject with some perhaps having more to learn than others from European comparisons. This may apply particularly to countries in Central and Eastern Europe for reasons already stated.

5.2 A culture of user involvement

It is an obvious hypothesis that user involvement in social services is likely to be most advanced in countries where there is a national culture of citizen participation and involvement. 'Culture' is difficult to define precisely – and even more to quantify – but in this case it refers to a broadly based acceptance of participation/involvement as a core value in society, with its expression in rights-conferring legislation and in the policies and practices of state and non-state organisations. The existence of such a culture provides a supportive environment for the development of user involvement in social services.

In this study countries range from the Netherlands ('there is certainly a culture of client and user participation') to several in Central and Eastern Europe where understandably this is still lacking, with others at various stages of developing a national acceptance of involvement of users in many aspects of national life.

- In the *Netherlands* the trend has been ongoing for several decades, with important successes registered in a broad range of sectors and branches. How has this been achieved? 'The results achieved so far are largely the result of (political) influence exercised by relatively small but representative groups with the passive endorsement of broader grass roots support. For example, organisations representing the disabled and chronically sick have

argued for – and obtained – the right to participation in the running of care institutions’.

- In *Norway* ‘Buzz words like user involvement and user participation are increasingly seen in white papers, new or altered legislation and other policy documents providing a regulatory and administrative framework defining the role and the functioning of public sector services in Norway. This trend clearly reflects the desire to involve users at all levels of society and can be observed in health, education, as well as in social services’.
- In the case of *Finland*, the user perspective has been an important subject at the political level from the early 1970s when important principles were established. The position of users is also very visible in the national social welfare plan. Clients have a legal right to access all official public services records concerning him or her.
- In *Germany* the personal social services mirror the different cultures that exist with respect to user involvement and its meaning. To a large extent, public social service organisations take commercial providers as role models, e.g. with centres for complaint management and the like, taking up individual queries but keeping them from becoming a public issue. On the other hand, the publicly supported local consumer advice organisations increasingly make social services a part of their agenda. Popular journals like TEST do more and more tests and information on mainstream services such as hospitals and nursing homes. Active user involvement can rely on broader notions of participation and civic engagement, taking shape wherever cultural and social movements played a role – e.g. by groups of parents setting up childcare facilities and family centres and being increasingly engaged in schools. Finally, user participation has taken shape locally and on the national level wherever people that work with and for special problem groups form associations that take an advocacy role, influencing in various ways public opinion, patterns of professional behaviour, or even the policy process. A parliamentary commission prepared in 2003 a detailed report on civic engagement in Germany with large parts concerning engagement and active involvement in personal social services.
- Although not represented directly in this project, a similar situation is found in *Denmark* where the government has embarked upon a major programme of citizen involvement as central to its modernization of public services (see www.moderniseringsprogram.dk). To some degree this is also the case in the *UK*.
- *Iceland* and *Malta* may be typical of some other European countries where there has not been a culture of user participation in society but where a trend has become visible in recent years. However, *Iceland* has a long and

strong tradition of NGOs which may count as evidence of a healthy civil society and a culture of user participation.

- Project countries of Central and Eastern Europe such as *Albania*, *Armenia*, and *Romania* report a pre-1989 culture under totalitarianism of hostility towards citizen participation and involvement in their highly centralised societies. 'Daddy definitely knew best' leaving little or no room for user involvement in state run services. Citizens were socialised into dependency, attitudes towards the role of users that remain difficult to change. This is compounded by the effects of increased poverty and related social problems that make the change to 'active citizenship' much harder.
- But a gradual shift towards user involvement in social and other services is evident. In *Romania* 'the people have learned that, in a real democracy, the participation of all citizens in the social, economic and cultural life of the society is a basic condition of social development and welfare...different groups of the population are organised now in associations or other forms of NGOs, part of them being recognised and acting at the national level'. Likewise in *Latvia* NGOs are central to the development of a new culture of user participation in society. The all-important re-emergence of civil society in Central and Eastern Europe is discussed in Munday's study (2003). In the field of social services, international aid organisations such as the World Bank place a strong emphasis on user involvement in projects they fund in Central and Eastern Europe, e.g. in Albania.

5.3 National policies and legislation

This relates closely to the question of culture i.e. where a culture of user involvement exists a country can be expected to have explicit policies and legislation concerning rights for user involvement, and vice-versa. Evidence from the project suggests this is clearly so.

- In the *Netherlands*, the government has been working for some time to strengthen the position of the patient/consumer in public health. The last government memorandum on patient policy had two basic themes: strengthening the individual legal position of patients and clients, and increasing the influence of the organised patient/client by funding their movements and other initiatives. Three important Acts have now come into effect: the Client's Right of Complaint Act in the care sector; the Medical Treatments Contracts Act; and the Participation Act for Clients in Care Institutions. Also, regulation of the funding of patient and client organisations was improved, making them much stronger. This tripartite mixture of policies, legislation and funding is an outstanding feature of the Dutch approach to institutionalising user involvement in the social care and health fields.

- Similarly, in *Norway* several measures have been implemented to ensure significant user involvement in shaping the way social services are delivered. The principle of user participation is outlined in measures such as the Social Services Act, stating that 'social services have an obligation to consult with the client before taking a decision about what services or what type of help should be given'. The new Public Employment Services Act will require all users to have the right to have their needs evaluated and to participate at all stages of service delivery. Likewise, in *Iceland* there are legislative requirements to consult users before decisions are made. There is also legislation from 1997 giving patients in hospitals and nursing homes the right to see all papers concerning them.
- In *Germany* legislation that creates room for active user involvement can be found across various fields of service policies: the recent health reform of 2003 created a patient commissioner post at central level for widening all sorts of possibilities for participation of users; representatives from patients' organisations are now additional members of the federal commission for health, a central institution for policy and administration of the health sector; in the advisory boards of nursing homes since recently outside persons can as well be elected, which may help to get younger and stronger voices in. Other aspects concern the ways in which policies for innovation are designed, e.g. the ministry for family, eager to enlarge childcare facilities for which essentially municipalities and districts are responsible, has set up a central clearing and support office for giving help and advice to "local pacts" for the family, where organisations from the third sector, local policy and administration, as well as from the business sector are supposed to join in initiatives for strengthening childcare facilities.
- In *Finland* user involvement is included in the new (1999) Finnish Constitution. 'The public authorities shall promote the opportunities for the individual to...influence the decisions that concern him or her'. The legislation provides for social services user involvement (including parents or other representatives) in the planning and realisation of the services in question.
- The *Danish* public services modernization programme (see above) places great emphasis on increasing citizens' rights, freedom to choose between different service suppliers, and more readily available information – all in the direction of empowering the service user. In the *UK* a general government policy of encouraging greater public participation and user involvement is illustrated in the use of user involvement as a key performance indicator in regular inspections of local authority social services.
- Explicit policies and formal legislation emerge more slowly in other countries. *Malta* only recently introduced legislation such as the Data Protection Act 2001 (which came into force in 2003), and the Commissioner for Children Act 2003 has had an impact on service users' involvement in personal social

services. The Data Protection Act has given service users rights which are protected, such as: the right to be informed about the processing of data related to them, and the right of access to information held about them. Thus, the service users have a say about and greater control over how personal information about them is gathered, used and shared. There is a definite trend in *Iceland* towards user involvement, as seen in the 1991 Personal Social Services Act with various provisions on cooperation with users. 'Any collection of documents/evidence shall be with the cooperation of the user, and with consent of individuals or families. The Children's Act also stresses the obligation of the authorities to cooperate, to consider the rights of children to be heard, and to act towards both children and parents with respect and consideration'. But implementation is uneven across the municipalities, requiring more precise and directive legislation to achieve real participation nationwide.

- Policies and legislation in countries of Central and Eastern Europe are developing towards increasing user involvement. In *Latvia* the law on Social Services and Social Assistance states that one of the rights of clients is to participate in the decision-making process related to receiving a particular social service. The National Council on Disability Issues is involved in ensuring that users are involved in all processes concerned with decision-making.
- In *Albania* 'the field of social service is a new experience...is developing and passing through a structural process and has yet to find the ways and instruments of security and participation of users in building, implementing and monitoring the programme in individual services'. *Romania* has recent government ordinances concerning social services that require providers to involve users in service delivery, and sets standards for the involvement of civil society representatives in planning and providing services as part of an accreditation system. Another ordinance 'foresees that users are involved in the design of their individual plan for assistance and care. The associations and non-profit organisations must be consulted by the local authorities when the community decides to develop or initiate different types of social services'. *Armenia* does not yet have formal policies or legislation in this field.
- Service user involvement in *Italy* has received greater attention from the mid-1980s onwards. Concerning Personal Social Services, in 2000 a framework law for the development of integrated systems for interventions and social services included the active participation of citizens; the contribution of social protection associations; and a requirement that municipalities adopt methods for consulting citizens and civil social associations to evaluate the quality and effectiveness of services as a basis for service planning and development. This was followed in the 2001-03 National Plan which introduced the 'Social Services Charter' designed to strengthen the position of users in several important ways.

5.4 User involvement at the local agency level

National policies and legislation promoting user involvement in social services are very important, but translation into real involvement at the local level is the critical test. This includes the question of users' **formal rights** to participate and be properly involved. Without rights that are both **enforceable** (i.e. supported by legislation and/or formal regulations) and **accessible** (i.e. easy to use) the service user remains vulnerable to varying local arrangements, professional discretion and the all-too-familiar tokenism.

Users' rights to obtain certain social services are even more fundamental than rights to involvement. If services do not exist, or can only be obtained by satisfying the ever-changing eligibility criteria, then user involvement can be virtually meaningless. However, the question of users' rights to personal social services in European countries is a complex subject and outside the remit of this project. Here our concern is with the related question of the right to participate or be involved in different aspects of social services.

In the following examples of local practice in some countries it must be emphasised that they are mainly statements by service providers which may or may not coincide with the actual experience of service users. Some reference may be made to users' evaluations of being involved locally but the main material on users' views are found later in the report.

- In the Reykjavik municipality in *Iceland* the aim is to cooperate with interested organisations that work for user groups in developing and planning services. The stated aim is also to cooperate with the individual user in planning and providing services in an individual and flexible way. Users' opinions of services are surveyed and suggestions/criticisms obtained through 'suggestion boxes' in 30 service locations. Aims and arrangements for user involvement are written in the annual Working Plan. There are some clear and enforceable provisions on participation in both the Children's Act and Personal Social Services Act.
- The agency example in *Romania* is 'The Romanian Foundation for Children, Family and Community'. This NGO annually assesses the needs of service users through questionnaires and discussions. Committees of users meet regularly to express views on plans for the coming year. The views of users are included in annual evaluations of services. Individual contracts with users include agreement on both the rights and the obligations of individuals.
- In *Latvia* there are participation rights for family members in the different normative acts. Later reference will be made to the specific and valuable legal requirement for the setting up of a 'Social Care Council' for every long-term social care and social rehabilitation institution. The council comprises service users, relatives, staff of the establishment, and representatives of the

municipality. This is similar to arrangements in the Netherlands and appears to offer real opportunities for user involvement.

- In *Albania* existing social services legislation does not clarify users' rights to participate but work on new legislation includes the involvement of users through consultation, participation and co-operation in the different stages of social services planning and provision. Family members – especially in the case of disabled people and orphans – will have the right to participate in the process of designing individual rehabilitation and integration plans.
- *Malta* is an example of many countries where agency practice and the establishment of users' right to involvement have been developing in relatively recent years. The national social welfare agency 'APPOGG' (previously known as Social Welfare Development Programme) has only been in existence over the past ten years but is committed to the principle and practice of user involvement, e.g. in planning a Women's Shelter. Users' views and questions form the basis for the agency's website and information leaflets and users are fully involved in evaluations of the service, as well as in agency seminars. UK practice models are adopted concerning parent and carer involvement in child protection case conferences and reviews, as are children themselves, as appropriate.
- Practice is more advanced in the *Netherlands* where users have become known as the 'third party' at the agency level, along with financiers and practitioners. Clients have the right to access their personal medical and social services files and to receive full information about their situation and prognosis. Clients also have the legal right to complain. The important innovation of 'client budgets' is discussed later.
- In *Germany*, agencies that look for collective and individual ways of active user involvement can be found in childcare centres, schools and care services for the elderly as well as in agencies that deal with special settings or problem groups. In the health sector such movements are limited to self-help groups and centres that try to become acknowledged partners of the established health care institutions. For some years now, schools have developed towards lively forums that look for partnerships with parents, associations and local business, both because they are in need of additional resources and to give and open up to the community. The central government has initiated a social city programme where community building and additional centres for city management are busy to create the joint participation of investors and concerned citizens for the revitalization of decaying city quarters. Finally, childcare associations, started and managed by parents' initiatives, are part of childcare facilities in most cities and municipalities. There are more than 100 local volunteer sector-oriented centres that also act as developers for styles of service work, more in touch with users and the resources of the community at large.

- *Norway* likewise has an important system for user involvement at the local agency level. 'The overall approach in social services to involve users in the 434 municipalities is through the different stages of the service delivery process in each individual case'. Some municipalities use surveys as a tool for obtaining a more overall feedback from users. Others have written service declarations specifying what kind of services to be expected – and what formal rights users have. Audits by the County Governor include 'an evaluation of the agency's ability to treat their clients individually and to document that the perspectives of the users are taken into consideration before a decision is taken'.

But there are no participation rights for family members and other personal carers. Representatives of elderly people in home care and nursing homes, as well as families with disabled children are often active in achieving participation at the local level. User participation is also channelled through representatives of political parties in the municipalities.

- In *Finland* municipal agencies have a positive approach to user involvement but practical measures are still lacking. Concern has been mainly with consumers' rights: quality assurance, customer care and rights of redress and exit. Few approaches have been based on principles of democratisation and empowerment. However, users do have a greater role in the administration of some services and some projects focus on developing user involvement.

As far as participation rights of relatives and other carers are concerned, the requirement to hear all parties involved is regarded as 'good government' in all administrative decision-making and can easily lead to invalidation of a decision when this is not done. There are important exceptions to this requirement, one of them applying to a wide range of social welfare decisions.

- In *Italy* the highly decentralised social services system makes it difficult to identify uniform patterns of user involvement at the local level. Particular concern has been raised about access to services by the most underprivileged groups of citizens. This was the focus of a national seminar in May 2004 that emphasised the need for an integrated policy approach at the local level to include social, health, education and other related services, with a bottom-up approach to social policy planning. The full participation of third sector organisations was seen as highly important in the policy, planning and service provision system locally.

6. GUIDELINES FOR GOOD PRACTICE IN USER INVOLVEMENT

6.1 Introduction

These guidelines are designed to be of use to all member countries, while recognising that within Europe countries are at different stages in developing their social services systems. The guidelines are relevant to stakeholders at various levels within these systems, including: policy makers; heads of services: middle managers; operational staff; and – of course – service users themselves and their organisations.

The guidelines are relevant for social services provided by the government and local authorities, non-profit NGOs; and commercial providers. Users of social services are understood both as individuals and as collectives, noting the tendency for users to be seen too exclusively as the former.

It should be emphasised that these are *guidelines* and not formal *recommendations* as there are important differences in status between the two.

The 'Good Practice' section contains examples of particularly important innovations in user involvement in several European countries. They are selected for their potential for wider relevance and application in other countries.

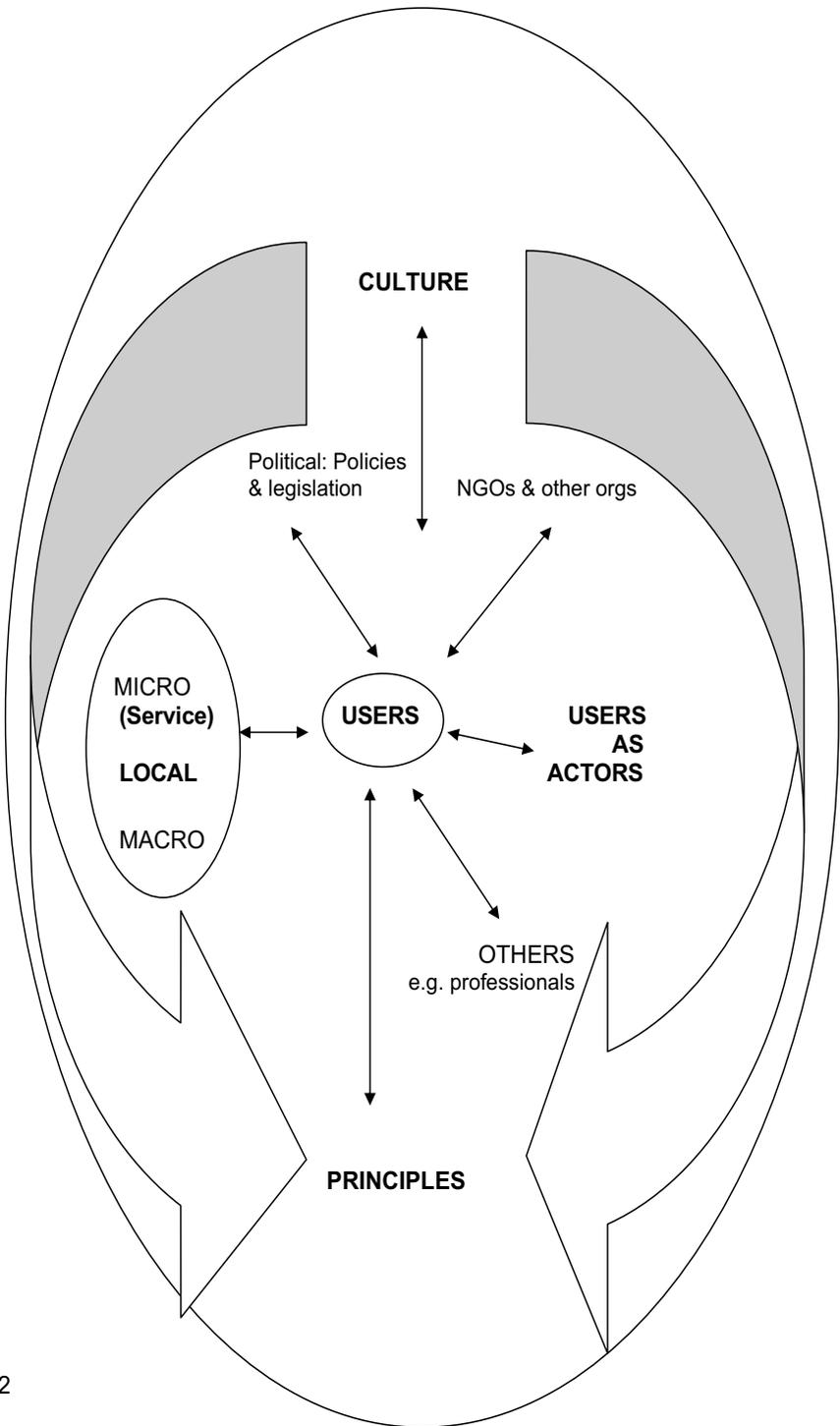
6.2 An integrated, holistic system for user involvement

It is helpful to locate individual guidelines within a holistic, integrated framework for user involvement – see diagram below. This approach underlines the need to design and implement a range of complementary inter-dependent principles and practices required for a modern national system of user involvement. Individual guidelines can be considered in their own right but also need to be seen as part of this whole system.

Using the diagrammatic framework the guidelines are now organised under the component parts of a holistic national system for user involvement in personal social services. Most guidelines are included under section 3. The sections are:

1. Key principles
2. Policies and legislation
3. User involvement at the local level
4. Users as collectives
5. Other guidelines
6. Examples of good practice

A HOLISTIC SYSTEM FOR USER INVOLVEMENT



6.3 Key principles

The following are fundamental or key principles, which inform and provide a value basis for an effective system of user involvement in personal social services. They might be considered appropriate for an eventual *charter* for user involvement in this field, but this has not been the remit for this particular project. The key principles are

- ✓ ***Involvement as a right and a responsibility*** In a democracy users should have a basic right for defined forms of involvement in services such as social services. This right should be enforceable and accessible. Services need user involvement to help ensure their relevance and effectiveness.
- ✓ ***Centrality of user involvement in agencies' orientation to their mission and task*** Organisations now have their 'mission statements' and other means for communicating their approach to undertaking their central tasks. Responsiveness to users should be central to this orientation.
- ✓ ***Access to social services*** User involvement is of little value if necessary social services are not available for users to access. The provision of services in sufficient quantity and quality is of fundamental importance to both actual and potential service users.
- ✓ ***Importance of evidence*** The development of user involvement should be based increasingly on evidence, while recognising that opinion, tradition and other sources of knowledge of 'best practice' still play a part. Research in this field remains relatively sparse and should be encouraged, including the necessary funding.
- ✓ ***Culture of user involvement*** Optimum user involvement in social services normally requires public policy to assist the growth of a national culture of user involvement, involving a consistent commitment from the different sectors of society. This cannot easily be created and is both cause and effect of the component parts in a holistic system – see diagram above.
- ✓ ***Users are recipients and actors*** Users are not solely passive recipients of services provided by others. They have the right – and responsibility – to play a full and active part in these services and in contributing to social care for other people. In their turn, organisations have a responsibility to support and enable users to contribute to social care.
- ✓ ***Taking account of users' networks*** User involvement should take into account the family members and other informal carers who may be important to the individual user. This has implications for service patterns e.g. recognising the supportive role of parents and family carers in childcare and education.

These core principles should apply to systems for user involvement in all countries

6.4 Policies, legislation and funding

- ✓ National systems of policies, legislation and funding are significant features of developed systems of user involvement. Countries can learn from one another's experience in implementing one or more of these three elements.
- ✓ Policies should be formulated at all levels of government with responsibility for social services – central, regional and local. This also applies, as appropriate, to non-state social services organisations.
- ✓ Systems of governance in the respective policy fields of social services should aim at a proper balance of central and local elements. The former establishes universal guarantees, standards and equality, while the latter allows for the special needs, circumstances and capabilities of particular groups of local users. Top-down decisions should be sensitive to bottom-up inputs of stakeholders and other important stakeholders.
- ✓ Mechanisms should be introduced to ensure that users and/or their organisations should be fully involved in the process of policy making and in any arrangements for policy review and change.
- ✓ The right of users to be involved in social services should be protected in specific legislation. The position of users is potentially weak when there is no enforceable legislation. Administrative regulations are required to ensure detailed and effective implementation of legislation.
- ✓ The establishment and operation of systems for user involvement should be costed and adequately funded. Policies and legislation will fail or prove to be inadequate – and expectations disappointed – if sufficient funding is not provided. There may be funding possibilities from sources other than the state e.g. the World Bank, European Union, national donors.

6.5 User involvement at the local level

The following guidelines cover many aspects of user involvement in and with social agencies, both state and non-state agencies. The guidelines are informed by the core principles.

Information for users

- ✓ Potential and actual users of social services should be provided with clear, accurate information about all major aspects of available services. It is

difficult to be involved if a user does not know what is available. Written information may need to be in more than one language, reflecting the ethnic composition of the local population, and in forms accessible to people with disabilities. Users will increasingly wish to access information from the internet. A priority is to provide information that users themselves have indicated that they need – not just what others think they may need.

- ✓ Agencies should inform users about the types, extent, and any limitations of the involvement available for them, including their involvement in decision-making compared with simply being consulted. Lack of clarity can result in disillusionment and an unwillingness to become involved.

Rights to specific forms of involvement

- ✓ In many countries a user has an enforceable right to access an agency's records relating to his/her contact. This should be extended to all countries, recognising that some users will need encouragement and practical assistance to exercise this right.
- ✓ Similarly, users now expect to be able to make a formal complaint to an agency if some aspect of a service has been unacceptable. Agencies should have a clear **complaints procedure** which is easy for users to access, with information about method and timescale for responding to complaints. There should also be provision for users to formally express their appreciation of any aspect of an agency's service.
- ✓ Family members and carers of users should have certain rights of involvement in defined circumstances e.g. when an elderly person is in long-term residential care; a child is taken into public care; and especially when a user is unable to exercise his/her right to involvement. The need for such rights is often not recognised and implemented.

Involvement in service planning and delivery

- ✓ It is good practice and the stated preference of users that they should be involved from an early stage in the process of planning services. They should be integral to rather than marginalised in the policy and planning process. Users are rightly critical when involvement is limited to being consulted about already planned services that they have had no opportunity to influence.
- ✓ The 'when', 'who' and 'how' of user representation in service policy and planning is a major question. Generally users prefer to represent themselves directly rather than be represented by third parties e.g. NGOs, which has often been the traditional approach.

- ✓ Direct user representation in relation to specific services is highly recommended, especially with services for the most vulnerable users (see 'Social Care Councils' below)
- ✓ It should be policy and practice to progressively include users as members of decision-making bodies at all levels within a social services organisation. The lone user representative can feel isolated and even intimidated, so there should be provision for sufficient user representatives for them to feel confident and valued.
- ✓ The 'mixed economies of social services' involves a plurality of organisations, public and private. It is particularly important that organisations that speak up for and represent users (e.g. consumer groups, advocacy organisations) should be fully involved in service planning and delivery.
- ✓ Users should be fully involved in an agency's evaluation of service outcomes, including selection of criteria for the evaluation. Insufficient attention has been given to user involvement in social services research.

6.6 Users as collectives

- ✓ Organisations should recognize that social services users have identities and interests both as individuals and frequently as collectives. Users will often organise themselves independently of agencies and adopt their own preferred approach(s) to services that are important to them. Agencies should respect the right of users to adopt approaches that may not always coincide with those preferred by agencies themselves.
- ✓ Agencies can assist user collectives through community development approaches, which practically support the formation and growth of self-help and other community groups e.g. by providing some funding and other resources.

6.7 Other guidelines

- ✓ There should be robust systems for checking the implementation of policies and procedures for users' involvement. Examples are Norway's Audit by the County Governor that includes 'an evaluation of the agency's ability to treat their clients individually and to document that the perspectives of users are taken into consideration before a decision is taken'. In the UK user involvement is one of the performance indicators used in national evaluations of local authorities' social services. Other countries should also use performance indicators.

- ✓ The growth of commercial providers of social services requires similar safeguards for users to those increasingly provided for customers in the retail field e.g. close control of quality, rights for consumer organisations.
- ✓ Staff training should be provided to ensure the success of user involvement in social services. Training in modern user involvement principles and practice should be included both in initial professional training and in later in-service courses. Inadequately trained staff may otherwise seriously impede the implementation of an agency's user involvement programme.

Three particular innovations in good practice in user involvement are commended for wider implementation. They are 1) *Personal budgets for users*; 2) *Social care councils*; and 3) *Ombudsmen*. Details of these innovations are found below. The first example empowers users by providing greater choice and control over services they need. The second example strengthens arrangements for protecting and increasing users' rights for involvement.

6.8 Examples of good practice in users' involvement

The term 'good practice' is regularly used but often left undefined in writings and discussions about social welfare/social services in Europe. A priority of the European Commission, for example, is to promote the dissemination of good practice in social policy for the benefit of the widest possible constituency in Europe; but sometimes the impression is given that its meaning is self-evident, i.e. we will recognise good practice when we see it.

What criteria are to be used in selecting examples of good practice in user involvement in social services in Europe? This is a difficult question. This section in the report relates closely to and overlaps with the earlier one on users' views and with the 'Guidelines' section above. An obvious criterion for identifying good practice in this field must be what users themselves say is good practice, based on their experiences and preferences.

Two complications with this view are that users do not always agree amongst themselves; and there are different kinds or groups of users, as referred to earlier in this report. Nevertheless, important points of agreement can be identified from what is known about social services users views as seen in the relevant section of the report.

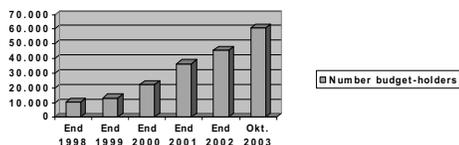
As the Guidelines indicate, 'good practice' is neither context nor cost free. Some forms of good practice suitable and achievable in many Western European countries may not yet be appropriate or possible in parts of Central and Eastern Europe. There are core common principles underpinning good practice in user involvement in all member states of the Council of Europe but their manifestation in practice will be substantially determined by national contexts.

6.8.1 Personal budgets for users

Possibly the most significant tangible innovation in user involvement in social services in recent years has been the introduction of some form of 'personal budgets for users'. Such schemes entail a fundamental shift in aspects of the funding (and power) of social services by placing some cash into the hands of users rather than concentrating funding completely in the services themselves. This is an illustration of Evers' 'consumerist' strand in welfare and has been positively welcomed by service users.

Three examples of users' budgets are outlined here. Personal budgets were first introduced in the *Netherlands* in 1996, the basic idea being 'to change the focus from supply to demand, to give the service user the lead in organising his/her own care'. Following initial assessment the amount of the personal budget is agreed for the individual who requires long-term care. He/she can then purchase care services they choose. The user always has the initial choice of care as concrete services or as a personal budget. The latter is not suitable for all users because of the administration and book-keeping required. There have been improvements to the system since 1996. Previously users could not pay their service providers directly but payments had to be made by the Dutch Social Insurance Bank. Now users can opt for that system or act as normal employers and make the payments themselves.

The Dutch personal care budget has proved to be very popular. 10,419 clients used it in 1998, compared with more than 60,000 in October 2003. Translated in Euros this means that in 2003, €750 million will be spent on personal care budgets in the Netherlands.



A similar user-led scheme operates in *Norway*, known as 'user-managed personal assistance to people with severe disabilities', introduced in 2002. This approach aims to enable the user to administer and coordinate an assigned personal assistant according to his/her personal needs. Funding is provided partly by municipalities and partly by the state, with 668 people using the service in 2003. The *Norwegian* scheme is based on similar principles to the Dutch one but appears not to go quite as far in empowering the service user because the user does not control a fund from which he/she decides exactly which services to purchase.

The long-term care insurance programme for elderly care in *Germany* also offers a significant degree of control and choice for the user through access to an insurance based fund that he/she can use to purchase care services. From September 2004 there will be arrangements in seven model regions for eligible elderly people to receive a personal budget which they decide how to use, including advice from a case manager if required. This advice can help users avoid the perils of any possible 'black market' in care services.

Similar initiatives in user involvement are found in other countries. They are positively assessed by users themselves and meet key demands of users concerning choice and empowerment. It is a form of user involvement that will progressively become more firmly embedded throughout Europe.

6.8.2 *Social care councils*

It can be argued that as part of good practice there should be a formally constituted group set up to work closely with most residential institutions in social services, with full involvement of service users themselves. 'Elderly councils' representing the needs and issues concerning elderly users are already in place in some countries. Users in residential care – particularly long-term care – are especially vulnerable in terms of loss of rights, lack of choice etc. In a few countries this arrangement exists as a legal requirement but generally it does not.

Latvia is an example of a country where this type of good practice exists. Its social care councils are set up 'to promote the observation of the rights of persons living in long-term social care and social rehabilitation institutions, as well as to promote the quality of the services provided.' Council members are 'persons living in the institutions, their relatives, employees or the head of an institution, and representatives of the municipality.'

Iceland has also developed 'user group councils', for example in services for vulnerable people such as poor parents, drug or alcohol abusers, and frail elderly people in residential and sheltered care. Interestingly, in the latter instance the head of the home makes imaginative use of a special TV channel to communicate important matters to residents, including the meetings of the user council.

The main responsibilities of councils include

- Coordinating the internal rules of procedure of the institution
- Submitting proposals for improvement of the performance of the institution
- Reviewing the conflicts between clients and the administration of the institution
- Participating in the quality assessment of the services provided by the institution

It would be helpful to know just how well the councils work from the perspective of the users involved before deciding on the merits of such arrangements. Sometimes groups such as these can be dominated by staff and local representatives, with users and relatives playing very minor roles. But in principle Latvia's social care councils – and similar arrangements elsewhere – are an important advance in user involvement for some of the most traditionally vulnerable service users.

6.8.3 Ombudsmen systems

In some countries there are ombudsmen (the gender neutral term seems not to be used) systems which citizens can appeal to when they consider that they have been wrongly dealt with by a particular service. These systems are normally generic and not specific to a particular service. They are a valuable addition to other safeguards for the rights and interests of service users. It is important to note that ombudsmen generally deal with matters other than citizens' complaints, e.g. they may investigate matters concerning the civil service.

In a few countries the system has been developed to include service specific ombudsmen. In *Norway* there is an ombudsman for health issues, for children, for gender issues – but not yet for social services. An exception is the municipality of Oslo where there is an ombudsman for social and health services. In *Iceland*, the Althing's ombudsman (Ombudsman of the Parliament of Iceland) is in charge of monitoring the State administration's and local authorities' acts and of safeguarding the rights of the citizens in their relations with the authorities. The Ombudsman's role is to ensure that the principle of equality is respected and that State administration behaves in conformity with the law and rules of good administrative practice. There is also an Office of the Ombudsman for children, which is under the authority of the Prime Minister, and a similar office for health issues.

Malta too has a generic ombudsman system at the national level whose office deals with complaints from citizens about services. There is also a Commissioner for Children appointed under legislation of 2003. This gives the right for anyone to lodge a complaint about an alleged breach of a child's rights. The Commissioner is responsible for promoting the rights and interests of children, ensuring that they are able to express their views and have them considered, and protecting the rights of children to have their interests considered by public and private bodies when policies and decisions affect them.

Finland has a local ombudsman system at the municipality level, with some municipalities operating a system for social services dealing with individual cases. One complication is that the ombudsman is employed by the system that provides social services. The neutrality of ombudsmen has also been questioned in the *UK* where the system is also facing problems of overload.

The conclusion is that ombudsmen can significantly strengthen the position of social services users, acting as a necessary check on the implementation of rights of some of the most vulnerable members of society.

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Appendix 1

Composition of the Group of Specialists

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Appendix 2

Some methods for involving social services users

Ilse Julkunen

Introduction

As this report has indicated, there are various important components in effective systems for involving users in personal social services. This appendix concentrates on the very practical subject of the kinds of *methods* that can be used to help ensure that users are involved in different ways. Certain methods such as surveys and public meetings are well known and have been used with very varying degrees of success. For example, the model for service user questionnaires seems to be substantially based on models from market research in the private sector (Lehto 1994). Other methods such as 'focus groups' have been introduced more recently and are less well-known.

The methods outlined here are examples rather than a complete list of known methods. Some are referred to in more detail than others, including information on other sources of information. The guiding principles in selecting a method(s) for a particular form of user involvement should be

- a) Methods chosen in genuine partnership with users themselves, rather than a top-down 'we know best' approach
- b) Attention to evidence of which methods work best for different groups of users, different services – and any other relevant factors

Denmark has produced a handbook of different methods on the internet (www.moderniseringsprogram.dk). It lists the different methods, both traditional and new ones, and provides information on their advantages and disadvantages. To date, we still lack sufficient knowledge of effective user models where the objective is to develop the public sector through communicating ideas and problems that would not otherwise be heard, or only assigned secondary importance.

Future search conferences

'Future search' is a planning meeting for large groups of people to share information and agree on action for change. In the context of community engagement it can bring local people and agencies together to determine and agree on action. Future search is about mutual learning as a catalyst for action. The method has been used worldwide and can be applied to a variety of contexts including education, housing, health and business development. Future search is a structured way of agreeing on how a project should be developed.

Future search events can accommodate up to approximately eighty people, working in small groups and individually. The event usually takes place over four half days. Participants work in small groups, using discussions, mind-mapping and drawing timelines on:

- a) the history of the topic;
- b) the factors affecting the topic at the time of the event;
- c) the contributors' role and contribution to the topic.

On this basis participants focus on an ideal future and agree on common themes and actions to achieve this.

The Future Search Network offers information and advice on planning and organising an event. Guidance recommends that a group of people plan the event. The main costs will be the venue and associated costs and a facilitator. Further information <http://www.futuresearch.net/>

Polyphonic evaluation (Emergent evaluation)

Polyphonic evaluation is a qualitative evaluation approach in multi-actor settings, especially useful in network contexts. The background to polyphonic evaluation lies in the development and research of our network team (e.g., T. Arnkil & Eriksson & R. Arnkil 1999, 2001; Karjalainen & Lahti 2002). It has been developed in social welfare, health care and employment services, specifically in the context of services for childcare and rehabilitation.

The evaluation dialogues have their origin in the development of anticipation dialogues by Arnkil and Eriksson. Some colleagues (R. Arnkil & Spangar 2003) also talk about emergent evaluation with the same meaning in mind.

It belongs to the tradition of stakeholder-based and responsive evaluation approaches. It is said that a dialogic approach is one way of revitalising praxis and the moral-political life in society (Schwandt 2001).

For further information see: Karjalainen (2004): *Polyphonic evaluation – how to use dialogues in organisational and network development*. In Julkunen (ed) *Perspectives, models and methods in evaluating the welfare sector – a Nordic approach*. FinSoc Working Papers 4/2004

User focus groups

The UPQA model is an abbreviation of **User Participation in Quality Assessment**. The Nordic term is 'BIKVA-modellen for Brugerinddragelse i Kvalitetsvurdering'. The model was originally developed in Denmark and published for the first time in 1996/1997 (Krogstrup 1996; 1997a and b). The model has subsequently been

used for many different efforts in and outside the Scandinavian countries. In Norway the UPQA model has been used for evaluating child welfare in a Sami municipality (Saus 2001), and in Scotland in connection with evaluating activation of mentally disabled persons (NSF 1998). In a Danish context the model has, for example, been used for evaluating day-care centres, achievements within the housing-social field, evaluation of social-psychic services, in connection with the planning of services for disabled citizens (Hansen et al. 1999), and in a series of other municipalities. Furthermore, the model is referred to, for example, in Swedish (Dahlberg & Vedung 2001), German (Kromrey 2001) and Italian (Bibliografia 1997) literature.

The UPQA model has been developed in response to growing demands for involving users in evaluations in the mid-1990s. The model available at that time was primarily user satisfaction surveys that were criticised for not actually evaluating user satisfaction. In most cases, these surveys assess satisfaction on the basis of questions/criteria defined by others than the users and are not capable of capturing the essence of what is important for the users. Also, user satisfaction surveys are seldom appropriate for challenging existing social work and for producing new ideas for developing the services. However, it would be a mistake to see the UPQA model as the replacement of more traditional user satisfaction surveys. The two approaches have different uses and should perhaps rather be viewed as supplemental.

The UPQA model includes users in evaluations to secure correlation between the users' perception of problems and those of the public services, and, further, between the users' perception of problems and the social work at different levels in the organisation (Krogstrup 1996 and 1997a). The idea is that users possess important knowledge that can contribute to the greater effectiveness of public sector services.

The evaluation process is bottom-up, oriented toward learning, and is expected to contribute to methodological development. The evaluation starts with focus groups of users where the problems that they find relevant are discussed. Front-line staff (employees in direct contact with the users), managers, and politicians are also included (Krogstrup 1996, 1997a and b).

This method ensures that users are assigned a key role as triggers for learning, enabling public organisations better to know future demands. This is also an important method for marginalised groups to gain access to communicate ideas and problems and contribute to change.

Critical Incident Analysis

The CIA is an open-ended retrospective method of finding out what users feel are the critical features of the practice being evaluated. It is more flexible than a questionnaire or survey and is recommended in situations where the only

alternative is to develop a questionnaire or survey from the start. The CIA is a method for obtaining a subjective report while minimising interference from stereotypical reactions or received opinions. The user is asked to focus on one or more critical incidents that they have experienced personally in the field of activity being analysed. A critical incident is defined as one which had an important effect on the final outcome. Critical incidents can only be recognised retrospectively.

Methodologically, Jan Fook (2002) uses critical incident analysis in reflective workshops, where the social worker discusses one case that is particularly difficult. This method has also been used where users have been asked to talk about situations which have affected them in either a positive or negative way during their care (Björklund and Fridlund 1999). The service and practice can both be developed by using information gathered through this method.

Client narratives

In Finland, Anna Metteri (2003) has used clients' writings in analysing pitfalls and developing practice strategies. Clients build their own stories based on inequitable situations. Useful changes in practice have been made possible through analysing these situations and involving the social worker.

Citizens' panels

These are ongoing panels which function as a 'sounding board' for the local authority. Panels focus on particular service or policy issues, or on wider strategy. It is especially important that a panel comprises a statistically representative sample of citizens in the area. Their views are normally requested several times each year.

Citizens juries

These are a variation on the panels. A jury is a group of citizens chosen to be a fair representation of the local population and brought together to consider a major issue facing the local authority. The jury receives evidence and opinion from the main parties involved in the issue. The process can last up to four days, culminating in a report to inform the local authority's eventual decision.

Service, issue and interest forums

These are ongoing groups that meet regularly to discuss and contribute to decision-making on specific social services e.g. an older people's day centre; particular issues e.g. contracting services to outside organisations; needs and interests of a particular group e.g. a minority ethnic group. Such groups may have the power to make recommendations to council committees and contribute to decision-making.

User management of services

As indicated elsewhere in the report, the most complete or radical form of user involvement is where citizens achieve direct control over the management of local services and resources. Examples include community-run day nurseries, youth clubs and community centres. Such initiatives usually operate through committees elected by the wider group of users, but others prefer a less formal management structure.

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