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## Active service user involvement in human services: lessons from practice

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How to cite:

Seden, Janet and Ross, Trish (2007). Active service user involvement in human services: lessons from practice. In: Aldgate, Jane; Healey, Lynne; Malcolm, Barris; Pine, Barbara; Rose, Wendy and Seden, Janet eds. *Enhancing Social Work Management: Theory and Best Practice from the UK and USA*. London: Jessica Kingsley, pp. 199–216.

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Version: Accepted Manuscript

Link(s) to article on publisher's website:

<http://www.jkp.com/catalogue/book/9781843105152>

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## Chapter 9

### Active service user involvement in human services – lessons from practice

Janet Seden and Trish Ross

#### Introduction

*What's the use of asking us if you don't take any notice? A service user*

This question, posed by a service user, invited to take a role in an advisory group committee, encapsulates the dilemmas of service user/patient consultation, involvement, participation and control of services. Beneath the philosophies and aspirations of handing over power and recognising people as experts about their own lives who can competently comment on services, lurk the dangers of tokenism. This may prevent them from being involved in both the design and management of services. Complex dilemmas exist when professionals try to create real partnership between people who are not equal because of social and role differences (Thoburn *et al.* 1995). This chapter starts by outlining the current policy mandates and drives for service user led and controlled services. Then we examine some of the contradictions, dilemmas and challenges this presents, not least from the people who are said to be 'empowered' by such approaches to health and social care provision.

The ideological basis for health and social care services in the UK was changed by significant policy shifts in the late 1990s and early 2000s. As John Harris outlined in Chapter 1, there has been a move from the paternalism that was inherent in the way welfare services were set up after the second war and conceptualised in the 1950 – 1980s. The three

governments under the premiership of Margaret Thatcher, between 1979 and 1997 introduced significant changes to the way services were provided, changing public sector provision to a 'mixed economy of welfare'. This was based on arrangements that set up internal markets within welfare services for 'purchasing' and 'providing' services a practice referred to as contracting in the USA.

Such changes brought with them parallel changes in the language and thinking about welfare (Page and Silburn 1998; Waine and Henderson 2003). When the first New Labour government under Tony Blair's premiership took office in 1997, the changes of the Thatcher years were already established in practice. The new government issued a range of papers aimed at modernising health and social services across the UK (see, for example, Department of Health 1998; 2000a; Scottish Office 1999) to regulate the market and move from notions of consumerism to an emphasis on social inclusion, participation, citizenship and partnerships between agencies, workers and users of services.

There has been a parallel move in the US to involve services users in planning, evaluating, and delivering the services they use. A good example is Project Head Start, an early childhood program begun in the 1960's as part of America's 'War on Poverty'. Head Start aimed at helping pre-school children from disadvantaged families get a 'head start' on elementary school through a range of health, nutrition and educational program components. Early on, the value of parent involvement was recognized and fostered. Today, Head Start parents are involved in the classroom and in policy making in local centers (Maluccio *et al.* 2002).

### **Service users ‘having a say’ in the provision of services**

There is now an awareness, both in the UK and the USA, that most people at some time in their lives will need some kind of service, and will expect, when that time comes, to have a ‘voice’ about what services they receive and how they receive them. Alongside this notion of participation in service delivery runs the concept that service users are actors in their own lives, whether or not social disadvantage or exclusion leads them to be people needing support to achieve their full potential. Services are viewed as a growing force for combating disadvantage and promoting citizenship and social inclusion (Department of Social Security 1998; Scottish Office 1999; Scottish Executive 2001). People are seen as citizens who have rights and entitlements. In Scotland, for example, a recent policy directive for children (*Getting it right for every child*, Scottish Executive 2005) includes a vision from the Scottish Cabinet that all Scotland’s children should be: ‘safe, healthy, active, nurtured, achieving, respected and responsible and included’ (Scottish Executive 2005, p.3). The devolved Scottish Parliament believes it has an obligation to provide a range of universal and targeted services to ensure these aims are achieved for every child. As Chapter 12 outlines, similar policy initiatives have been developed in England. In the USA too, there are several national advocacy organizations such as the Children’s Defense ‘Fund, the Child Welfare League of America, and the National Association of Social Workers that have similarly sought and gained, through public policy, increased rights for children.

Listening to what people say about services has become a key feature of public policy (Connelly and Seden 2003). Service user views are seen by government as a powerful component of shaping and evaluating what services should be in place (Scottish Executive 1999; Department of Health 2000b). *A Quality Strategy for Social Care* asserts:

We must focus on what people want from services. There is now a strong body of evidence pointing to the qualities people value in social services. (Department of Health 2000a, p.6)

There are many examples in health and social care of consultation and research into user views of services (see Henderson and Atkinson 2003). Key words which characterise the relationship of health and social care with its service users and patients are – information, consultation, involvement, partnership, participation, ownership and control. In the National Health Service (NHS) patient involvement in clinical governance has become a critical issue (Sang and O’Neill 2002).

The idea of the service user or patient as expert has taken hold, but it is not unproblematic. Research and literature have raised the dilemmas of practice and the complexity of making such policies work on the ground (Beresford and Croft 2003; Read 2003) Further, service users should not just be consulted about what they want and asked to evaluate what has happened, but can more actively manage the processes and means of delivering services. And, as Beresford and Croft (2003) point out, involving service users in service management means much more than seeing user involvement as an ‘add on’ to the conventional, management mix. It has implications for the whole ethos and philosophy of management, ‘a real shift to ‘user-led’ services demands a different,

much more participatory approach to management' (p.21). In Chapter 2, Barbara Pine and Lynne Healy discussed the participatory approach in detail and provided a case example of an agency using a team that included parents.

### **Taking an active approach to service user involvement in management**

As Sang and O'Neill (2002) suggest, when discussing patient involvement in clinical governance in the National Health Service (NHS), effective implementation means taking an active, mapping, communicating and networking approach to management activity. If the National Health Service is to be patient-centred or social services is to really be managed by service users in partnership with fund holders and workers, the approaches that can deliver this will need to be learned and implementation worked out carefully. In adult services, the lead has come from services created and controlled by service users, who have come to be known as 'survivors' of services (Read 2003) and also from personal assistance schemes where individuals directly pay care workers. Additionally such 'survivors', particularly in mental health services, have taken up paid employment in the social care field. This makes them pivotal in seeing the issues, but again there are dilemmas, as Beresford and Croft (2003) comment:

... involving service users in service management needs to be approached in a holistic and strategic way. This must be recognised if broad based and systemic involvement is to be achieved. Two components seem to be essential if people are to be able to get involved effectively and if all groups are to have equal opportunities for involvement. These prerequisites are *access* and *support*. Both are needed. (Beresford and Croft 2003, p.27)

### **A continuum of involvement**

Thus ideas about the role of service users and patients in care services move on a continuum (Association of Metropolitan Authorities 1991) which starts from ideas about better information giving, moves through consultation and participation to user-control of service provision. It is only when users control services or manage elements of service provision that they can be said to be managing the service. For example, former users of mental health services who are working in health and social care services are now seeking to set up a user-controlled national co-ordinating scheme to support their work (James 2002).

While mental health services provide some examples of this happening, for most organizations it can be argued that service users are taking on management functions and roles within organizations on a participatory model, but that truly user-controlled organizations and services remain rare. Nonetheless, the ‘survivors’ of adult services have set a lead and generated a discussion that has fed similar developments in child and family services.

It can be argued that unless the building, other resources, personnel management (e.g. staff selection) and a range of other management functions are handed over, service users are involved but not in control (This is an issue which is also addressed in relation to the use of space in residential care by Jill Reynolds and Sheila Peace in Chapter 8 of this book). It is also a feature of many social work services that elements of compulsion are often thinly disguised as partnership. Furthermore, people are ‘choosing’ to use the service because of ‘needs’ arising out of social disadvantage, or a level of vulnerability. Such situations add another layer of complexity to the issues of power sharing and to how service users

might really manage services. These hurdles alone are no reason to hesitate and once such imbalances are in the open and shared, the redistribution of some power becomes more likely. In the next chapter, Myron Weiner and Peter Petrella note the important uses of technology to facilitate communication with service users and involve them directly in the agency's work.

Users of services seldom hold the traditional management roles. Nor do they frequently have real roles in managing and supporting staff, appraisal, budgets, buildings, training objectives, or complaints procedures unless they become paid staff, although there are some exceptions in the area of family centre services (Tunstall *et al.* 2006). It can be argued that no one should have to carry these roles unpaid or without the necessary training and support for what are complex and onerous tasks. Once service users are in these roles, not only may they not be fully supported and protected by the organization for possible difficulties that may arise, but also there can be additional conflicts of interest, which come from their own requirements as users of the service.

For example, the allocation of scarce resources such as crèche places (child care or nursery care places in the USA) is difficult enough, but more difficult perhaps when it involves competition between your own, your relatives' and neighbours' children and those from further afield. Is it feasible to expect parents of young children who have at last gained access to some much needed and scarce services to want to try and target new people, thereby increasing competition for the scarce places? Will they want to reach all children, perhaps outside the immediate area, because the social services department has a wider brief and a more strategic view? It takes some confidence and skill to argue against the



paid managers and government backed large agencies. On the other hand, service users cannot be dismissed from employment, cannot be disciplined and may have little to lose. Such an absence of sanctions may cause much anxiety for paid managers and certainly add layers of complexity to their role.

### **Issues and dilemmas that arise from service users being involved in management**

Many questions arise about the involvement of service users. Are roles for service users in managing or on management committees sustainable or do they exemplify power imbalances, such as possessing or not possessing information, giving or withholding access to resources, education and prior work experience? If service users want services that are not in line with policy directives, how is this managed? Are service users set up to fail by systems that claim to devolve power but do not? Such dilemmas are far from academic. For example, if service users are running the service, it still has to be provided to the standards of the organization, but as the service users are effectively volunteers, the quality of the performance may not be monitored in the usual way, such as through agency supervision and appraisal systems.

Writing about paid managers supervising volunteers, Charlesworth (2003a) points to a range of issues around managing people in the role that, following Willis (1992), she calls an 'exchange relationship' (p.54). Paid managers working with service users who are giving their time freely are in a similar position. There may be legal anomalies, role tensions and, without formal agreements about roles and responsibilities misunderstandings and conflicts may occur. There are complexities and ambiguities in these relationships, which need to be considered.

Here, we argue that these dilemmas are as apparent in children's services as they are in adult services. We now explore some of the challenges for practice further through considering examples of service user involvement in managing activities. This is based on the authors' experiences as children's services managers, working in range of parent support settings. These include two family centres, both situated on outer city estates in the East Midlands, one run by a social services department and one by a voluntary childcare agency. Family centres blossomed under the Children Act 1989, as a designated family support provision. There are many types of centres, some run by local authorities and some by voluntary agencies. Some have an 'open door' policy and some only take referrals from statutory social work (see Tunstill *et al.* 2006). The authors also draw material from a Sure Start programme, established under the Government's initiative for preventive targeted early years projects.. This Sure Start programme we were involved with is in a town within a former coalmining area of the north Midlands. All the centres we looked at are situated in socially and economically disadvantaged areas, where residents often experience discrimination because of where they live, varying degrees of social exclusion and difficulties in accessing mainstream services.

### **Lessons from practice**

Within all the settings there has been a commitment from agencies and staff to working within and building on the strengths of the local communities. This means there has been an expectation that parents and carers will participate in the planning, delivery and management of the services. Therefore, the examples on which the chapter draws are real and come from practice experience of working with parents, carers and

community activists across the continuum of partnership, involvement and control over a period of 20 years, through the 1980s to the present day. They illustrate some of the contradictions and dilemmas discussed earlier in the chapter about decision making, accountability, responsibility, consent, power and priorities and, hopefully also highlight some solutions and useful working practices. The views of service users (with their knowledge and consent) have been included but some situations have been disguised to ensure anonymity where necessary. The discussion also draws from material included in user consultations undertaken for The Open University course, *Managing Care* (Henderson and Atkinson 2003; Henderson and Seden 2003b).

### **Service user membership on management boards**

Service user representation on management boards or committees is frequently seen as desirable to ensure that services are credible, effective and relevant and meet the needs of the service user group. However, as argued, there are important issues to consider in practice, both in the process of establishing the board (or in introducing users to an existing board) and in ensuring effective and genuine participation.

First, there is a need for clarity about the role and responsibilities of board members: Do service user representatives have the same powers as other board members to make decisions about service delivery, allocation of resources and funding? How far can they be held accountable for decisions made? Are there policy directives or funding requirements that must be adhered to? It is important to address these by agreeing terms of reference generally and/or before undertaking a specific piece of work.

Misunderstandings can lead to resentment and disenchantment, such as that expressed by the parent at the outset of the chapter. This disillusion with the kind of participation, which is experienced as ineffective by service users, is frequently reported. For example a service user at a consultation, reported on being asked to participate in selecting staff in an adult residential service. She said to the researchers, “They ask us but it’s the bosses that make the decisions in the end” (Henderson and Seden 2003b). Another person in the same consultation expressed frustration at frequently being invited as the ‘token Asian service user’. She was becoming frustrated with the lack of outcomes for her time and commitment.

### **Service user representation**

Recruiting users to an advisory or management committee who reflect the diversity of the user group is often a major difficulty. Kubicek (2003) identified this as an issue in setting up patient forums within Primary Care Trusts (the NHS units that provide primary health services for everyone in local areas in the UK) and states that outreach is essential in recruiting more people from ‘hard-to-reach’ groups. This has also been an experience within Sure Start in trying to ensure that representation on Boards includes all sections of the local community. It is usually articulate, socially active members of a community who will put themselves forward; more disadvantaged residents may be suspicious or sceptical, may lack confidence or have other priorities or commitments (Beresford and Croft 2003; Connelly and Seden 2003).

### **Practical considerations**

Practical considerations will need to be addressed, such as provision of transport, interpreters and childcare to enable participation, but the more

difficult task is to persuade service users of their own abilities, of the value of their contribution and of the genuine commitment of the programme or agency to the principle. Outreach work in developing networks, building on skills and confidence is vital. Reputation is a key factor: evidence that views of service users have been listened to and the experiences of others involved will influence more reluctant participants. Resources both in terms of time and effort need to be made available to ensure success. Given that in the context of social care, many service users will be from socially excluded groups or will be experiencing difficulties in their lives, there is little point in espousing the principles of user management unless the resources are made available.

### **Empowering service user participation**

It is important to ensure that, having established service users as members of a board, the role is more than tokenistic: that individuals feel able to participate fully and that their views and ideas are valued and acted upon. Practical considerations as mentioned above are vital, but issues of power group dynamics, interest groups and personal agendas, motivation and commitment are also significant. These become even more complex when a committee or board has a mix of service users and service providers, a diversity of skills and experience and often a variety of stereotyped views of other members. There may be some service providers who are cynical about the participation of service users. They may patronise, exclude or sideline them. Hidden agendas or conflicts between different professional or community groups may lead to misunderstandings

### **Training and support**

Training and support can be instrumental in creating an ethos where these issues can be addressed. It is widely accepted that service users may need

training to participate effectively in meetings (Connelly and Seden 2003). It may also be necessary for professionals, with vast experience of bureaucratic meetings within their own organizations, to learn to communicate without the use of jargon, to be open to different ideas and to be aware of their own behaviour and use of power.

An example of the impact of training comes from the experience of setting up a Sure Start programme. Two training days with an external trainer were organised prior to the establishment of a Sure Start Board to support a local programme. These days were attended by service users, representatives from different agencies, managers and a community development worker who was to provide ongoing support to the parents on the Board. The training gave everyone an opportunity to agree ground rules and terms of reference but also to express anxieties and get to know each other. The trainer attended the first two Board meetings to monitor the balance of contributions and concluded that parents were able to participate effectively.

Parents also continued to meet with the community development worker before the Board meetings to discuss the agenda and any concerns. However, two years later, difficulties emerged that demonstrated the need for regular review. New parents had joined existing parents on the Board and agency representatives had changed. Though new parents had undertaken training, no further joint training had taken place. Attendance at meetings by parents had declined: some had family difficulties, others had gone on to training or employment (a possible positive outcome of the experience of being a Board member). Others were dissatisfied with meetings - they sometimes felt patronised, meetings were boring, and action often deferred. There was some learning for parents in

understanding that issues could be complex and change inevitably slow but there were greater learning needs for the whole Board. The formal nature of the meetings was not always conducive to genuine discussion and partnership. However the challenge itself led to a less formal atmosphere, more humour and a breakdown of some of the professional barriers. It also led to a review of structures and procedures.

### **Service users appointing paid staff**

Agencies increasingly involve services users in the appointment of staff. Two large UK not-for-profit agencies, Barnardo's and, in Scotland, Children 1<sup>st</sup>, always include young people on their appointment boards. There are many others. Another example, from a Sure Start programme demonstrates how an effective partnership can be established:

The Management Board needed to appoint to a management post within the Sure Start programme. An underlying principle of the programme was that parents/carers should be involved in decision-making and the Board discussed how this should be carried out in the recruitment and selection process. Parent representatives on the Board were clear that they had expertise in some areas, whereas others on the Board had professional expertise, and a recruitment process was devised, drawing on the different skills and knowledge of Board members.

Candidates were asked to make a presentation to a group of parents, who assessed their skills in communicating, their ability to relate to members of the local community and in offering workable solutions to problems. Representatives from education, social services and the voluntary sector and the Programme Manager formally interviewed the candidates to assess their management skills and practice knowledge. The outcome was that responsibilities were clearly defined, all felt valued for their contribution and,

more importantly, the successful applicant came to the post with the support and confidence of the service users.

### **Organizational issues**

Organization theorists have found that organizations tend to become entrenched in their own bureaucratic procedures and that new members are expected to fit in with existing arrangements. We have found that social care meetings can become ends in themselves, with the main aim becoming how to get through the agenda as quickly as possible, rather than to foster open discussion and a problem solving approach to providing better services. True partnership requires the commitment of all members of the group and a culture of questioning the status quo on a regular basis. There are real constraints of time and resources, and there may be conflicts of interest and need (for example, service users may find weekend meetings more convenient, but agency representatives may have their own commitments at this time). These issues need to be recognised and worked with in order to achieve optimum participation.

Many examples of user involvement in the management and delivery of children's services have come from the voluntary sector. However, the aim of some to hand over control of a project to service users has usually been difficult to sustain over time without continuing funding from either charitable sources or grants; fundraising in disadvantaged areas is difficult and time-consuming. Over the last two decades there has been an increasing regulation of children's services to ensure high standards of childcare, safety and probity. Whilst this is obviously positive for children, it has meant many community initiatives have no longer been financially viable, particularly in poor neighbourhoods where parents are unable to afford the true cost of the resource.



Funding bodies will always require a degree of management control, oversight of standards will usually require professional input so that the delivery of services to children and their families will inevitably mean a partnership between funders, professionals and service users (including both parents/carers and children themselves). Though this can be an exciting and dynamic process with positive outcomes for children, it gives rise to the potential for conflict, notably in the allocation of scarce resources and in planning services, and to many dilemmas around aims and objectives, differences in power, experiences and skills.

### **Differing viewpoints**

Parents usually prefer universal services where there is no stigma attached to attending; there is also the advantage of prevention and in the early identification of difficulties. However, when resources are scarce, decisions need to be made about who receives services, and there is an inevitable move towards targeting certain groups or setting eligibility criteria. This can lead to conflict between paid workers and service users, or between different interest groups in an area. There are some examples of misguided practice, where, for example, targeting one group discriminated against another.

- In a community centre there was a great deal of anger among some white parents when a group for black children was set up, as they felt their children ‘were getting a worse deal’
- A staff team had been set a target to attract more families from a certain ‘rough’ area where there were children living in families experiencing major social issues. Staff had tried to enlist the help of

current parents to advertise the centre but had underestimated the threat newcomers would pose to parents. The response was opposition to any erosion of the status quo, “Why do we want any more people coming? We’re alright as we are and it would get crowded with any more.”

If service users are responsible for, or are involved in, deciding how resources are allocated, it is important that they are representative of the community or user group, and they may also need training. Parents on the Sure Start Board we observed quickly learned to look at the needs of all families: “We don’t just say what we want; we try to represent all the parents’ views”. Service users often have the advantage of not having years of providing services in a certain way and can come up with more innovative solutions.

Planning services can give rise to dilemmas, as service users often have very different ideas about what constitutes a good service. The experience of many Sure Start programmes is that parents want local services, delivered by friendly people in an informal setting. They need to be able to get there easily, at a convenient time and to have facilities for young children. Yet many agencies are streamlining resources by providing centralised services within set hours. Social work teams have moved from neighbourhoods to an area-wide service and this has sometimes been judged as effective because it has reduced referrals! Family Centres often cover a wide catchment area rather than being a community resource and referral systems can be a major barrier to accessing a service.

## **Quality assurance**

On a more local level, service users can often have more influence on the way services are delivered. An exercise in establishing a quality assurance system for a parent and toddler group was undertaken by a voluntary agency. The group was funded and supported by the agency but the parents attending were responsible for activities and fundraising for outings etc. so it was felt that they should participate in the exercise. Parents were asked, "What is important in deciding how good the group is?" They identified many indicators in common with staff, such as safety and good quality play, but also, based on their own experiences, highlighted the importance of the atmosphere in welcoming new people, and in making sure disabled children and their families were made to feel comfortable. As a result of this, parents wrote a 'welcome' handbook, some took on responsibility for befriending new families and undertook training in listening and helping skills. They also demanded that a member of staff was always available at sessions and that regular review meetings were held.

This example demonstrates that where resources are available and aims are common to providers and users, involvement of service users in the management of the service can be effective in ensuring it meets the needs of families. By contrast, where the provision of services involves bureaucratic organizations with specified targets and limited resources, it is perhaps more appropriate and honest to work towards user 'consultation' rather than 'management'. Issues around professional demarcation of roles, perceived threats to jobs if services are provided in a different way, the need to reduce stress for workers and safety considerations are all real concerns to workers. Such issues may be of no significance to service users living in poverty or who are trying to protect

their children from engaging in criminal activities. Such differences of perspective can create misunderstanding and conflict.

### **The tensions of involvement for service users and managers**

Whilst it is seen by professionals and academics as fundamental that services should meet the needs of the service user if they are to be effective, other considerations may take priority in planning. There is often little time to make service users aware of all the factors, decisions may be made pragmatically by paid workers under pressure to meet deadlines, with the result that service users do not feel consulted. It can sometimes seem that the main aim of professional workers is to fill in the forms and to ensure procedures are carried out. A young mother, referred to social services for the third time by a voluntary worker, who was concerned about her care of the children, put this acutely. She reported back after a visit from a social worker, “They’re going to do an assessment. I’ve had so many assessments - when are they going to *help* me?”

Child protection issues may also raise dilemmas where service users are involved in management. Parents are usually very aware of the need for confidentiality and if they are part of a management committee will usually be bound by an agreement. However, if an investigation is taking place into alleged abuse in a family, other service user may be concerned for the safety of their own children. Judgements and gossip may be widespread and the situation may become far more complex than the investigation into one family. In allocating resources, (for example in deciding a child has a priority need to attend a club where there is a waiting list) a family in need may be seen as receiving preferential treatment. Service users involved in decision-making can face

questioning or even abuse because of their part in it. It could be argued that it is morally unacceptable to expect service users to handle such situations, unless a great deal of support is available.

While it is important to ensure more disadvantaged groups of service users are represented on boards or advisory groups or in other decision-making processes, consideration needs to be given to the level of participation and responsibility. The needs of the individual and of his/her family are paramount. To set someone up for failure because she or he cannot meet the demands and constraints of a committee can have serious consequences. Power imbalances also need to be recognised by workers: a mother who has been helped to gain some control in her life and to increase her self-confidence, for example, may need further support and training to be ready to be part of an advisory or planning group. Gratitude for the help received, or fear of not being offered further support, may lead her to feel unable to refuse if invited to participate. If she subsequently feels unable to sustain her involvement, and this is not sensitively resolved, she may feel a sense of failure and her previous progress may be set back.

There are also areas of management that demand professional skills and experience, and it is vital to recognise the possible limitations of non-professional partnerships. Small voluntary organizations are often run by a management committee, comprising of service users, community representatives and interested others. There may not be anyone on the committee who can provide the supervision and professional support that the co-ordinator or manager needs to implement the changes the committee wants. Where there is no professional line management, it may be necessary to buy in external support.

Another area in children's services is that children and older young people are themselves users of services and it is essential to consider how they can participate in decisions and shaping services, according to their age, ability and need. Work on consulting children and ensuring they are actors in their own lives is increasingly happening in agencies and children's homes. Similar care needs to be taken to make sure that listening to children, ascertaining their wishes and making sure they participate in decision making moves to real empowerment (Department of Health 2001a; Aldgate and McIntosh 2006).

## **Conclusion**

In this chapter, we have explored the policy drive to make service users more active in how services are managed. We have raised some questions, dilemmas and challenges. And illustrated them through experiences from various family support settings where attempts were made to make information, consultation and participation and user-control of service provision a reality. From this we conclude that if service users are to be active in managing services:

- A consultative, participative, model of management, which is 'bottom-up' not just 'top-down', is essential, both within the particular setting and within other organizations to which it relates.
- Time is needed to consider roles and responsibilities carefully and to discuss and explore them
- Support and training will be needed
- Dilemmas and challenges are inevitable and need care, commitment and flexibility

- The desirability of service users being active in management is clear, but there are pitfalls caused by power imbalances that cannot be ignored or underestimated –rather they are to be acknowledged and ‘worked with’.
- The danger of rhetoric without reality and tokenism is ever present and has to be constantly under review
- Working models for service user activity needs to be robust, but subject to constant revision, there is no neat pro-forma approach.
- Communication that is open, honest and at levels where both parents and paid staff can make sense of it is the bedrock of practice. Working out a mutual sense of meaning and purpose, where understandings are frequently checked out is needed to make partnership work.

The authors would like to thank the following for supporting the work drawn upon in this chapter: Andrea Sharp; Richard Lea; Pauline Jones; Sure Start, Ravensdale, particularly members of the Management Board; National Children’s Home; Nottinghamshire Social Services; The Open University.