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ACHIEVING USER PARTICIPATION

Planning Services For People With Severe Physical and Sensory Disabilities

LIVING
OPTIONS
IN PRACTICE

Living Options In Practice
Project Paper No. 3

THE PRINCE OF WALES'
ADVISORY GROUP
ON DISABILITY

COMMUNITY LIVING
DEVELOPMENT TEAM
KING'S FUND CENTRE

ACHIEVING USER PARTICIPATION

Planning Services For People With Severe Physical and Sensory Disabilities

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Living Options In Practice
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Chapter 1. Achieving User Participation

Summary

Effective disability services will only be achieved when disabled people[1] actively participate as partners in service planning and development.

Since January 1990 Living Options In Practice has been working with eight multi-agency Practice Teams throughout England (see map, p. 43) to create comprehensive disability service systems. The development of effective strategies for involving disabled people in this process has been central to the Living Options work.

Based on the experience gained from two and a half years' practical work in the Practice Localities, *Achieving User Participation*:

- Defines user participation and describes some essential elements of 'good practice' participation in service development
- Analyses key steps in the process of developing effective user participation
- Shares lessons from the eight Practice Teams as they worked towards the full participation of disabled people.

Achieving User Participation discusses these elements in the context of the project's commitment to a multi-agency 'service development team'[2] approach, and its focus on people with severe physical and sensory disabilities. The principles and guidance set out in this document, however, will also be of use to localities which are developing services in different ways and for different client groups. *Achieving User Participation* is intended for all planners, purchasers, providers and users who want to minimise disabled people's dependency and to target services more efficiently to meet disabled people's needs.

The Living Options Foundations

All of the Living Options work is underpinned by the principles first set out in *Living Options Guidelines*[3] (1985). These principles — which place the individual disabled person at the centre of service planning — are:

- **Choice** as to where to live and how to maintain independence without over-protection, or the risk of unnecessary hazards, including help in learning how to choose
- **Consultation** with disabled people and their families on services as they are planned
- **Information** clearly presented and readily available to the most severely disabled consumers, and in minority languages
- **Participation** in the life of local and national communities in respect of both responsibilities and benefits
- **Recognition** that long-term disability is not synonymous with illness and that the medical model of care is inappropriate in the majority of cases
- **Autonomy**: that is, freedom to make decisions regarding the way of life best suited to an individual disabled person's circumstances.

A Framework For Action[4] (1990) presented the Living Options vision of a comprehensive service system. Building on the experience of the Practice Teams, the Framework outlined the basic components that are shared by any effective service system for people with severe physical disabilities:

- A response point to users' needs
- A place to live
- Personal support services
- Access to the community
- Specialist services
- Opportunities for personal development;

and suggested an action strategy (including user involvement) for achieving such a service system.

Tracking Success[5] (1991) proposed a systematic approach to testing whether effective services are being developed, offering practical ways to measure progress against three key standards for user satisfaction, user participation, and partnership working:

- Services should meet user and potential user needs, expectations and preferences
- Disabled people should have real power over the way services and policies are planned and implemented
- Service development teams should work effectively together to produce results.

Defining User Participation

There is now widespread consensus that 'participation' of users is desirable, and the 1991 Community Care legislation and guidance call for consultation with service users about their needs. However, what is meant by consultation and participation, and how these are to be achieved, is less clear.

Living Options In Practice believes that disabled people must have the opportunity to participate on an equal basis in planning, designing, delivering and monitoring services at both the individual and service levels. Localities will be addressing individual assessment of need and individual service planning to meet the requirements of community care legislation. This document focuses on participation in service planning.

A continuum of user participation in service planning was outlined in *Tracking Success,* encompassing:

- **Information** — Sharing ideas and plans about services, ensuring relevant information reaches disabled people
- **Consultation** — Asking people's views and advice on plans, policies and services, including access to ordinary public consultation exercises
- **Partnership** — Working on an equal basis in setting goals, making plans and deciding funding priorities, including representation on public committees and planning groups
- **Delegated control** — Giving authority and money to disabled people to plan and implement services. A growing

number of purchasers and users of services are seeking to devolve responsibility for service provision directly to user-run groups.

'Ideal' user participation would enable disabled people to be involved at each stage of the participation continuum. (Some disabled people, of course, may choose not to become involved, or may wish to join a users' organisation whose main agenda is not about changing services.) *Achieving User Participation* is concerned with moving current practice further along the continuum towards effective partnership working.

Achieving User Participation

Having agreed the importance of working with and learning from disabled people, those responsible for services face the challenge of making user participation a reality. Among the Living Options Practice Teams the process of involving users has grown in different ways, but has been based on the following common elements (see diagram, opposite).

- **Reaching consensus** — Sharing aims, expectations and intentions for involving disabled people in service planning.
- **Getting started** — Securing the human and financial resources to achieve aims.
- **Making contact** — Reaching a wide range of local disabled people to share plans and enlist their involvement.
- **Establishing user groups** — Enabling the start-up of a group of disabled people who will represent the views of a broad spectrum of disabled people and work with the service development team.
- **Working together** — Developing partnership between professionals and users on the service development team.
- **Tracking results** — Reviewing user participation strategies against goals and standards.

Achieving User Participation takes these six elements as the basis for developing effective user participation. Subsequent chapters assume the existence of a Living Options-style service development team, bringing together — often for the first time — professionals from relevant agencies and disciplines with responsibility for the same client group; facilitating collaborative (e.g. community care) planning; and providing a single forum through which users can influence service development. Reality is less tidy than models, of course, and localities must begin with the existing 'status quo'.

This document also assumes the existence of only minimal or erratic user participation mechanisms. Where authorities are starting from scratch in developing user participation the strategy outlined in this document is a simple and comprehensive way to start. This approach may also be useful to localities that wish to review or confirm the effectiveness of their participation procedures, or extend existing pockets of good practice to a wider constituency.

Notes and References

1. The terms 'disabled people' and 'users' refer to physically disabled users or potential users of services. The Living Options work targets severely disabled people aged 16–64 — those whose physical or sensory impairment makes them dependent on others on a long-term basis for normal daily living activities. Living Options believes that improving services for this group will have a positive impact for people of all ages and all levels of disability. Living Options recognises that family carers are also users of services, and that their needs may be different from disabled people's needs, but believes that getting services right for disabled people will also benefit carers.
2. A service development team, based on the model of a Living Options Practice Team, refers to a multi-agency group (including representatives from health, social services, housing and other statutory agencies, voluntary and consumer groups, and users) with a mandate from senior management to develop principles and plan strategies for building effective, comprehensive services for disabled people.
3. *Living Options Guidelines for those Planning Services for People with Severe Physical Disabilities.* The Prince of Wales' Advisory Group on Disability, London, 1985.
4. *A Framework For Action: Developing Services For People With Severe Physical and Sensory Disabilities,* Fiedler B, Twitchin D. Living Options In Practice, London, 1990.
5. *Tracking Success: Testing Services For People With Severe Physical and Sensory Disabilities,* Fiedler B. Living Options In Practice, 1991.

Chapter 2. Reaching Consensus

Before inviting the involvement of disabled people, the service development team needs to be very clear that all members share an understanding about their plan and purpose, aims and expectations. The first task of such a team should be to set out their intentions clearly with regard to consultation and participation and to consider the implications of this at a local level. Teams which already include disabled people will have a head start in considering local issues and attitudes. If disabled people are not represented on the team when discussions about participation begin, then plans need to be reviewed as the process evolves. This chapter considers key steps to help service development teams assess the benefits of user participation, and begin to think positively about how to work with local disabled service users.

Aims and Expectations

In many instances this will be the first time professionals have looked at *how* disabled people in their locality are involved in the planning process, and — more importantly — *why* disabled people should be fully involved. Service development teams should brainstorm the following questions — but recognise also that one talking session will not be enough!

What's in it for Professionals ?

Team members and other professionals need to be persuaded that working with disabled people will be 'worth it'. Box 1 (overleaf) shows the results of one Practice Team's 'brainstorm' on this question.

Service development team members also need to explore fully their concerns — based on past frustrations — about involving disabled people in service planning, and discuss what can be done to overcome barriers and antagonisms. Box 2 (overleaf) lists some of the concerns raised in another Team's exercise.

Box 1. Why should planners / providers involve users ?

- Finding out about disabled people's needs, including Black and minority ethnic disabled people
- Providing quality (equitable, appropriate) services
- Valuing disabled people as individuals
- Increasing cost effectiveness
- Discovering unknown disabled people, and those who 'slip through the net'
- Sharing information about service plans (and limitations) with disabled people
- Fulfilling responsibility to consult users
- Learning what disabled people do *not* know about services
- Raising professionals' expectations for disabled people
- Acknowledging disabled people as 'experts'

Box 2. Common concerns of professionals about user involvement

- If you talk to disabled people you may raise expectations which you cannot meet — why bother ?
- You will only get the active users, who know what they want; what about those who cannot express what they want ?
- We talk to disabled people through local voluntary networks
- We only get 'moaning sessions' at open meetings
- We know services are not perfect; it does not help to be slammed publicly by angry disabled people
- We do not know how or where to make contact with local disabled people
- Talking with disabled people just slows down the process
- You get different views from different people; they don't know what they want

Team members need to feel safe in order to be honest and to share uncomfortable individual experiences about working with users: e.g. being personally blamed for service inadequacies; feeling sympathetic but unsupported by their own organisation; having the local MP intercede. It is important that all team members are present for these discussions so the team move forward together with a shared understanding of the issues.

Other issues that have arisen for disabled professional team members include:

- Conflict between role as professional / service provider and as consumer of services
- Concern about being seen by other disabled people to be colluding with professionals
- Discomfort about being the only disabled team member, and constraint about challenging able-bodied colleagues.

What's in it for Disabled People ?

Disabled people also need a stake in user participation. Box 3 lists some reasons why disabled people might get involved, based on an exercise carried out in one Practice Team.

Box 3. What's in it for users ?

— Fundamental change to make services more responsive to users, as well as improvement within existing services
— An opportunity to take responsibility for and make decisions about one's own life
— A voice: a chance to give rather than take, to be involved
— An opportunity to learn how the system works and how to influence it
— Self-esteem: recognition of disabled people's worth
— Partnership between users and providers
— An opportunity to develop a forum for consultation and a structure for representing other disabled people

Disabled people also have legitimate concerns (see Box 4) about involvement with professionals in service planning, based on a long history of powerlessness. Professionals must understand the source and strength of such views if joint working is to succeed.

Box 4. Common concerns about user involvement

- Frustration about earlier unsuccessful attempts to influence service planning
- Anger about sub-standard services
- Fear that professionals who control services may use new knowledge against disabled people
- Wish to share feelings and experiences with other disabled people before sharing with professionals
- Anxiety that participation may mean 'tokenism' and isolation

Options

Service development teams need to take into account existing local user groups and consultation / participation systems. It is vital to confront potential difficulties at the start. Teams may feel tempted to ignore disability groups that are seen to be ineffectual or 'challenging', or to see disagreement among local groups as an excuse to discount their views. The role of voluntary / charitable organisations managed by able-bodied people working on behalf of disabled people will also need to be considered, but should not be confused with groups *of* disabled people. The contribution of disabled people serving as individuals, without a 'constituency', on planning groups also needs consideration. An effective user participation strategy will take on board views of *all* individuals and groups. Those who feel bypassed or undervalued will not want to 'co-operate' later.

Although definitive structures cannot be set before disabled people have been involved, the team will want to have an outline plan of how they expect user participation systems to develop. The following questions should be discussed.

What will the relationship be with other existing user / voluntary / disability groups ?

The Living Options Team approaches included:

- **Building on an existing user group** — Even if not currently broadly based, an existing group can be helped to widen its membership and take on a new role.
- **Developing a new group** — A user advisory group can complement an existing group that has a different function (e.g. campaigning, peer support), but links within and support from the existing group are important.
- **Forming a consortium (umbrella)** of disability groups with different objectives. The user advisory group involved in service planning will be one group within the consortium.

What will be the role of users on the team ?

The team will want to think in advance about their intentions. Are they seeking representatives (how many) to join their team? Will the team merge with a user group to form a single group? Will users have equal status — a 'vote' — or act as advisers? Will they (and other team members) join as individuals, or will they have a 'constituency'? Where does the team's plan fit on the user participation continuum? Remember that disabled people may have different views: is the team's plan flexible, or a non-negotiable offer?

How will the team ensure that agencies and individuals will be committed to work with users ?

Based on previous experiences, many disabled people will be sceptical of the team's intentions (see Box 4, opposite). The team will need to be sure that things will be different this time.

Localities will be tempted to construct 'perfect' plans for user participation before making a start. However it is important to begin at once, from whatever baseline exists, while making clear that teams, user input and structures will change as interim arrangements move towards the ideal.

Living Options Checklist for Reaching Consensus

REACHING CONSENSUS

✓ Clarify aims & expectations, considering:
  - benefits for professionals
  - benefits for users

✓ Consider strengths, constraints & ways forward:
  - relationship with existing disability groups
  - users' role on the service development team
  - commitment from authorities to user participation

Chapter 3. Getting Started

A shared agenda for involving disabled people is essential, but service development teams must be confident that they will be able to carry through intentions and secure results. Little progress towards aims is likely to be achieved without the resources — human and financial — to put plans into action. This chapter examines the development task, and the funding required for genuine user participation to become a reality.

The Development Task

Chapters 4 and 5 set out in detail the things that need to happen in order that disabled people become effectively involved in service planning. Even with the will to accomplish this task, however, members of service development teams, or other officers, are unlikely to have sufficient time or skills. While empowerment of disabled people can be built into many key posts, overall responsibility for enabling user participation needs to be someone's main job. Two key factors enabling the development of user participation in the Practice Teams have been the appointment of a development worker, and the availability of disability consultants (Living Options Associates) to take on particular tasks.

Development Workers

The Living Options experience shows the value of appointing a worker at the earliest stage possible, with joint responsibility across authorities, to work with and on behalf of disabled people, developing user groups and the user voice in service planning.

Development work tasks might include:

- Identify and make personal contact with local disabled people
- Set up public meetings / consumer events
- Ensure information flow to disabled people through appropriate networks and systems

- Establish and support user group
- Establish need for and arrange training
- Ensure effective joint working between team and user group
- Help secure future funding for user group.

These tasks might be carried out by one worker, or by different or successive consultants / workers. The roles of setting up a user group, and of supporting an established group, require different skills.

The Living Options experience highlights the following lessons:

- Service development teams should make every effort to appoint a disabled person as development worker, both to establish credibility and intention and because personal experience of disability will be an asset in the job. Employing a disabled development worker gives positive signals to the local community about the involvement of disabled people. It also focuses the attention of statutory authorities on practical matters such as accessible venues, and full integration and interaction with professionals. Equal opportunities laws allow posts to be advertised for disabled applicants only.

- A development worker should have joint responsibility across agencies (a service development team makes this possible) and should ultimately 'belong' to the user group. Initially the worker will need to be appointed by a statutory or voluntary agency, but when the user group becomes formally established the development worker should be appointed and managed by that group.

- The development worker should not be expected to supplant or service the service development team. (Ideally, teams will have a joint funded co-ordinator and / or secretary; realistically, teams will be looking for administrative back-up from individual members' agencies.) As well as supporting and guiding the development worker, the team will have an increased responsibility to deliver results as disabled people begin to get involved. Development workers may need to be firm in insisting on continuing commitment from team members, and in resisting pressure to take on other roles.

- Structures will be needed to support the development worker, whose position can be demanding and isolating. In addition to direct employment supervision, a 'support group' of two or three team members meeting regularly with the development worker can serve as a sounding-board for ideas and frustrations, and allow for speedy decision-making.

- The success of the development worker — and of user participation development — can also cause problems. The empowerment of disabled people may be perceived as threatening some traditional professional roles. Professionals may need support in appreciating the benefits of new ways of working.

- An investment of several years will be required for a user group to become self-sustaining, and for user participation to be effective. A one-year post will not be enough.

Disability Consultants

Another key component of the Living Options work of developing user participation has been the availability of a pool of experts, most of whom are disabled people, to undertake a range of training and consultancy tasks to assist the Teams. Among the roles carried out by these disability consultants (Living Options Associates) have been:

- **Beginning the process** — A disability consultant was contracted to identify disabled people, hold a series of user forums, set up a user group, and oversee the appointment of a development worker.
- **Personal development and equality training** — Two disability consultants ran courses for local disabled people and for professionals on the service development team, to enable them to join forces more effectively on the team.
- **Support and advice** — An experienced disability consultant worked alongside a new development worker to explore solutions to problems and set up training programmes.

Funding

Lack of money is often cited by statutory and voluntary agencies and by users as the reason for not being able to provide better services, make changes, or enable user participation. Without doubt statutory and voluntary agencies are under intense pressure to do more with less; most authorities have suffered severe cutbacks associated with re-structuring, including elimination of physical disability posts, during the past few years.

It is essential that service development teams make plans from the outset to secure sufficient funds to ensure both a good start and long-term viability for user participation activities. One team member, or a sub-group, should take responsibility to ensure action on fund-raising. Disabled people will understand that money is difficult to find — but not that no effort is being made to find it.

Costs

Service development teams must be realistic about the costs of enabling disabled people to participate in service planning. Few Practice Teams anticipated the actual costs, especially of practical items. Planners must not make promises or raise expectations that cannot be met.

Sample costs for appointing a development worker for a year, based on one Practice Team, are given in Box 5 (opposite).

Once the user advisory group is established it will require its own budget to enable independence and productivity (see Chapter 5). Funding can be transferred directly to the user group as it takes on the development worker's functions. Costs will not be duplicated, although the balance of expenditure may change.

Box 5. Sample budget for development worker and user group

	£
Development Worker salary (F / T), travel and expenses	20,000
Secretarial support (P / T)	5,000
Office equipment	1,000
Stationery, supplies, newsletter, etc.	1,500
Transport / travel expenses for disabled people	1,500
Training, conferences for disabled people	2,000
Facilitation, interpreters, signers	1,000
	32,000 †

† Assumes office and overhead costs met by 'in-kind' grant from statutory authorities. Costs will vary from locality to locality, depending on plans and needs of group, geography, cost of living and 'in-kind' help received.

There are also costs associated with the effective performance of a service development team. Activities with resource implications include:

- Advertising for and appointing development worker, disability consultants
- Fees and expenses for consultants and training (e.g. awareness / equality; team building) for service development team and for joint work with user group
- Convening public meetings: room hire, refreshments, transport, facilitators / interpreters, publicity materials
- Secretarial / administrative help, including note-taking, photocopying, circulating papers
- Stationery (headed paper for joint service development team image), newsletter, publicity leaflets, postage.

Sources

Possible sources of funding for user involvement include mainstream agency budgets, Joint Finance, private finance, and grant-making bodies.

Mainstream agency budgets

Statutory authorities may choose to delegate a particular consultation or development programme and associated budget to the service development team, development worker or user group. Teams may also be able to 'borrow' secretarial time, office space, or small sums of money from their department budgets. Agency training resources can also be tapped. While such ad hoc arrangements may work well, they should be formally recognised so that all parties are clear about responsibilities and 'ownership'.

Joint Finance

Joint Finance continues to be the greatest source of funds for cross-agency and consumer-led work. Some localities will already have a jointly-financed co-ordinator / administrator for physical disability work. Joint funding (or other funding) needs to be in place as Joint Finance tapers off.

Private finance

Local businesses are a growing source of funds for consumer-led projects. The national organisation Business in the Community (Telephone: 071 253 3716) can offer advice about formulating messages to attract private funding.

Grant-making bodies

While disabled people may be offended by 'charity', charitable bodies remain an important source of money for developing and supporting user-led activities.

Without under-estimating the impact of cut-backs and scarce resources on agencies with a responsibility for disability services, with creativity and determination resources can be found. There is scope for considerable re-distribution of resources from inappropriate, inefficient ways of working to more effective practices. By co-operating across agencies / departments — including sharing budgets — much more can be accomplished with less duplication of effort. And when success is demonstrated and shared — when it is seen that involving disabled people leads to cost effective, appropriate service planning and delivery — it becomes easier to attract new resources.

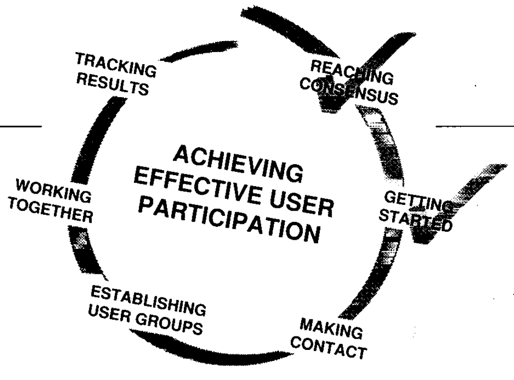
Historically, physical disability has had a low priority for funding in all agencies, making it difficult to secure financial support. Grants were made available through Living Options In Practice to each of the eight Practice Teams, matched by resources secured locally, to further the development work task and facilitate user participation. The Living Options experience shows that by joining forces, and with the help of a strong user voice, service development teams can raise the profile of physical disability, show the benefits of investment in user participation, and make convincing bids for funding for the work of the team and the local user group.

Living Options Checklist for Getting Started

GETTING STARTED

✓ Define the development work task, including:
  - role of development worker
  - role of disability consultants

✓ Explore funding issues, including:
  - costs of development work, user group, service development team
  - sources of funds



Chapter 4. Making Contact

In order to move from intentions to the reality of user participation, the service development team will need to make contact with as many disabled people as possible, to share the team's plans and aims, learn disabled people's views, and enlist their active involvement in service planning.

Links with any existing groups of disabled people will of course be a starting point. Unless a widely representative user group or active user network already exists, however, a public meeting (an open-invitation consumer event) is a useful way to begin an exchange of views with disabled people. Seven of the eight Practice Teams chose to begin the process of involving users with public meetings.

This chapter outlines some routes to 'getting in' to reach disabled people, and some of the practicalities of organising a successful consumer event.

Routes to Disabled People

Disabled people in receipt of an existing service will be most easily reached. However, there will be many more 'hidden' disabled people whose views need to be sought: those living in the community, alone or with family carers, without statutory services; disenchanted former or non-users of services; those sent to out-of-county homes or schools. In making contact with disabled people, service development teams will also gain valuable information about local issues and local tensions. The team will need to ensure they are reaching disabled people who are less confident or less articulate, and those from Black communities and other cultures. (Current services are particularly poorly publicised to Black disabled people.)

The service development team will want to try to reach disabled people by a variety of the following routes:

- **Consumer and voluntary groups** — Councils of Disabled People, Centres for Independent Living, access groups, Black groups, disability organisations (e.g. MS Society, Spastics Society); carers' groups, service groups (Crossroads, Family Support Service, Dial A Ride); sheltered employment workshops, neighbourhood / community groups

- **Team members and their professional networks** — Other agency contacts and colleagues, community nurses / therapists, GPs, Black community workers
- **Service settings** — Residential homes, day-care centres, YDUs or hospitals, rehabilitation settings, wheelchair clinics, sheltered employment workshops, special schools
- **Community 'marketing'** — Libraries, shops, community and leisure centres, local newspapers, radio, cultural / religious centres
- **Individual disabled people** — Disabled people on team, disabled people active in area individually and in groups, disabled people employed in agencies
- **Surveys, registers, existing records** — Confidentiality must be respected, but holders of registers, etc. may be able to circulate a letter or invitation to disabled people known to them.

Disabled people use disability networks and services in very different ways. Some isolated individuals may only hear of an initiative through, for example, a local radio programme. Information may not be passed on: news may get no further than the desk of a given professional or organisation; voluntary organisations can act as 'gatekeepers', assuming information is not relevant to their members / clients.

The following tactics may bring results:

- Make direct individual contact to explain plans and enlist support: word will spread via disabled people's own networks
- Visit and talk directly to groups of disabled people (in statutory and community settings) and organisations (including religious bodies) that assist disabled people
- Ask for help in distributing written handouts, posters, etc.
- Use advocacy schemes to facilitate involvement of disabled people with intellectual / communication difficulties
- Produce material in minority languages, on tape and in braille

- Seek out friendly local journalists / broadcasters for free publicity
- Explain why and how information sought will be used (people may not respond if they feel that requests for personal details such as type or cause of disability are unreasonable)
- Before making contact, be clear about the reasons for doing so.

Public Meetings

The following key steps in holding a successful consumer event are based on the experiences of the Practice Localities, whose public meetings took a variety of forms: a locality-wide forum, a series of neighbourhood-based meetings, a travelling 'roadshow'. Preparation is required for an event of any type.

While intended to help service development teams encourage disabled people's involvement in user advisory groups and service planning, these steps are equally pertinent to user involvement in other contexts — in community care planning, on joint planning teams, or in particular issue groups such as planning a disability information federation or a resource centre.

Purpose

Review shared goals for user participation, including concerns about talking to users (see Box 3, p. 9). Establish a clear purpose for this particular event: for example, to share the team's plans and priorities; learn about local disabled people's needs; identify individuals interested in forming a user group. Seek the advice of known disabled people in planning the event.

Participants

Taking into account maximum numbers, purpose and style of event, decide who will be invited to the meeting: define the 'target' audience (all disabilities, all age groups?), and decide which local agencies should be represented. Consider the balance between numbers of 'professionals' and of users, so that disabled people will not feel constrained in voicing their views.

Action plan

Prepare a programme for the meeting and a written plan and realistic timetable for making it happen. Identify each task to be undertaken before, during and after the meeting, the team member or consultant who will ensure that it is carried out, and a 'co-ordinator' to keep the plan on track. Agree the messages the team wants to take to disabled people and prepare a written handout.

Practical arrangements

Attention to detail is very important. The difficulties encountered in holding a public meeting will be everyday problems for disabled people, and often form the first items for a shared action agenda from the meeting. Show by the choice of venue, support arrangements, refreshments, etc. that people's religious, cultural and dietary as well as disability / mobility needs have been considered. Make sure that practical arrangements are publicised in advance.

- **Venues** — Finding neutral and accessible venues is difficult but vital, particularly in rural areas. Often the only accessible venues are hospital units or day centres, but be aware that such settings put disabled people and professionals into patient / doctor, client / provider modes. Choose venues close to public transport and with parking spaces for orange badge holders; with level access and accessible toilets; good lighting; and sufficient space and tables for equipment. Major local employers or Training and Enterprise Councils (TECs) may be able to help with accessible rooms.
- **Transport** — Disabled people's ability to attend a public meeting will depend on availability of transport. Arranging or paying for transport for those who need it will be an important gesture of future intentions. Ask in advance about transport needs; publicise plans for arranging suitable transport.
- **Facilitation** — Arrangements for personal helpers, interpreters, signers, loop systems, and advocates at the meeting will also help convince disabled people that the team is serious about wanting to involve users, and will

make it possible for some people to contribute during the meeting who would otherwise be forced to take a passive role or be unable to attend. Advertise that help is available, or ask about personal assistance needs on invitation return forms.

- **Carers** — Anticipate problems if carers attend and speak for disabled people or about their own concerns. Independent advocates should be available to anyone who wants help in expressing his / her views. Plan to have a carers meeting next door at the same time. Make sure participants understand that this is an occasion for disabled people to air their own opinions.

Publicity

Devise a marketing strategy to encourage attendance of targeted participants. Prepare publicity material — handouts, journal articles, posters — well in advance, and arrange distribution through local information networks (see 'Routes to Disabled People', p. 21). Include a named person whom interested disabled people can contact during the daytime or evening. Provide materials on tape, in braille, and in minority languages.

Funding

Consider costs carefully before planning a public meeting. Fees need to be quantified for room hire and catering, transport, signers and interpreters, and personal helpers. Make sure promised help can be delivered if demand is high. Ideally, the service development team will already have a budget for such purposes, or access to funds through member authorities or Joint Finance. Voluntary groups, TECs and Further Education colleges may be able to help with accessible vehicles, venues, etc.

Programme

Structure the event to maximise its impact and positive feel; and keep to the agenda. All issues raised, however, even if not on the official agenda, must be taken seriously. If individual grievances are aired, use the occasion to explain how agencies' complaints procedures can be used effectively. Team members can support each other in not responding defensively, and in understanding the source of disabled people's anger, frustration or apathy (see Box 4, p. 10). Give participants an opportunity to indicate an interest in further involvement, joining a user group, etc.

Review and feedback

Make plans in advance for learning from the consumer meeting and for keeping participants informed. All disabled people (including non-attenders) who expressed an interest in the meeting or the team's plans should be sent a report of the day and updated regularly. Recognise that achieving genuine user participation takes time. Do not be disheartened by a small turnout at the first consumer event. If the team follows through — if there are small successes — both users and professionals will recognise the benefits of participation and more disabled people will want to become involved.

Living Options Checklist for Making Contact

MAKING CONTACT

✓ Explore ways to reach disabled people, considering:
- routes to getting in
- tactics to maximise results

✓ Plan a public meeting, considering:
- purpose
- participants
- action plan
- practical arrangements
- publicity / marketing strategy
- funding
- programme
- review & feedback

Chapter 5. Establishing User Groups

One of the aims of the public meeting is to identify individuals interested in forming a disabled persons' group to work in partnership with the service development team. This chapter looks at the key issues in establishing user groups, based on the experiences of Practice Localities where disabled people had little previous involvement in service planning.

Membership

Members of the user group will be those disabled people who, perhaps via the public meeting, wish to pursue the idea of joining together to work with the service development team. One locality-wide group, or a federation of community-based groups, may be appropriate. Numbers are not important — even three people is enough to make a start. Depending on interest, it may be necessary to form a small core committee, a larger working group of active participants, and a wider constituency or network of disabled people throughout the locality. Alternatively, the development worker may want to work individually with a few interested disabled people to explore benefits and needs before setting up a group. Links must be made with existing user groups whose aims may be different.

Membership issues to consider / tackle include the following.

- Decide which disabled people will be included in / represented by the group (e.g. only younger people with physical or sensory disabilities; elderly people; those who also have another disability). Existing services and consumer organisations for other client groups and age groups will affect the group's decision. Sub-groups — for example, of deaf / hearing impaired people — may be set up separately while maintaining links with the user group. Be sensitive to the pitfall of excluding those with multiple disabilities who fall between client groups. Recognise that, by the nature of disability, those who participate in service planning are likely to be more mobile and articulate people who depend less on services on a daily basis. They will need to find ways to ensure that the views of more severely disabled people are reflected through the group.

- Clarify the role of informal / family carers (see Note 1, Chapter 1). This must be decided according to local circumstances, but Living Options In Practice believes that the user group should comprise disabled people only — because carers' needs may differ from disabled people's needs; because carers often speak for the people they care for; and because the carers' lobby is often quite powerful locally. Carers should be encouraged to join local carers' associations. Independent advocates should be used where needed.

- Clarify the role of non-disabled people, whether as adviser, trainer, facilitator or speaker. Users may initially want team members to attend user group meetings, relying on them for support, knowledge about 'the system' and committee skills. Such requests should be respected, but the longer-term aim will be to develop a group with the confidence and skills to go it alone.

Aims

Everyone concerned must be clear about the aims and objectives of these early meetings of the user group. These might, for example, include:

- To meet other disabled people, share experiences and skills and discuss how to network more widely
- To learn more about local service development team plans and objectives
- To share local service needs, priorities and concerns about disability issues, and set broad agendas for future meetings
- To air possible differences between needs of different disability groups — e.g. physical vs. sensory, those in residential care vs. those in the community — and work towards shared agendas
- To explore how the group will be organised, and how it will work with the service development team.

Meeting Structures

The following guidelines are suggested for structuring meetings.

- Agree a schedule of meeting dates (at monthly or six-weekly intervals) and times (two hours) for the next six months. Choose times that suit most people — which may mean alternating day / evening, weekday /weekend meetings.
- Arrange venues that are informal, accessible, easy to find and near to where group members live. In rural localities, meetings based on local neighbourhoods may work best.
- Select a chairperson and note-taker for the first few meetings and set a few 'ground rules' about listening, respecting others' views, etc.
- Clarify group objectives, priority issues and speakers for the next few meetings.
- Circulate brief notes of the meeting — particularly action points — and consider how those not present can be kept informed (e.g. a regular news sheet).
- Ensure that action points are followed up. Action is vital so that group members, and the public, can see that things are happening.

'Mission'

At an early stage the user group will want to review the service development team's mission statement, aims and objectives, and agree with the team ways to achieve their common purpose. The team must be prepared seriously to reconsider its plans in the light of user group views.

Skills and Experience

Disabled people may need to gain confidence and experience of being part of a group. They may need space to be able to share their feelings about local services and to recognise that there is strength and power in sharing common problems and issues. The participation of Black and minority ethnic disabled people — who often feel particularly strongly that services are 'not for them' — will need to be encouraged. The group need to ensure that quieter members are asked for their views and opinions, and that the participation of those with communication problems is facilitated.

Some group members may already have skills such as chairing or note-taking, or specific knowledge of local issues that could benefit the group. Group members will want to do as much as possible for themselves, with appropriate support. Help may be provided by experienced local disabled people or other local groups, but formal training — in assertion, committee skills, and 'the system' — may also be required.

Public Profile

The role and expertise of the user group must be recognised by the service development team and local agencies as well as by local disabled people. There is a danger that a development worker acting on behalf of the group will be regarded as the sole representative of the user group; a disabled development worker may come to be seen as the 'acceptable' front for other disabled people, whom professionals feel uncomfortable about meeting face to face. The expertise of the user group can be developed, and its public image strengthened, if a group member accompanies the development worker on visits and at meetings. A leaflet setting out the group's aims and giving a contact point can help publicise the group's role and attract new interest.

Practical Support

The development of the user group will depend on the help they receive with practical difficulties. Funding and support for transport and personal facilitation, interpreters and signers will be needed until the group is firmly established and funded and members are able to arrange assistance themselves. Disabled people, many of whom are unwaged or on benefit, should not be expected to support the group's work personally. Some able-bodied help may make meetings run more efficiently — arranging the room, getting refreshments — but disabled group members will know what they require and be able to make their own arrangements provided they have the money.

Organisation

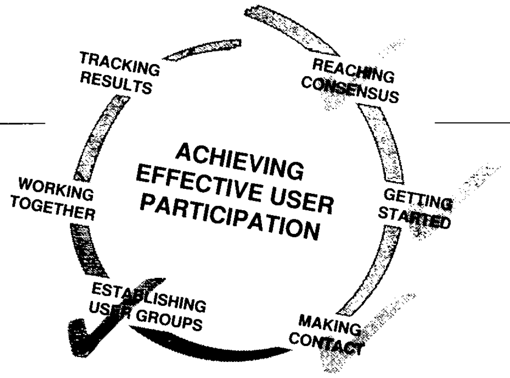
The next stage will be to put the user group on a sound footing for the future, considering the following points.

- Establish long-term objectives for the group and its joint work with the service development team.
- Clarify structure and legal status. The group will probably want to become formally established, with a constitution and officers. Depending on its objectives, however, the group may prefer to remain an informal association, working with the team on specific issues. Invite speakers from other successful user-run bodies to discuss possible structures, roles and responsibilities.
- Choose a name and 'livery'. Be aware that a group's name can affect image and confer 'authority' (e.g. User Advisory Group, Council of Disabled Experts).
- Firm up meeting schedules and practical arrangements. Setting meetings to co-ordinate with the service development team meetings would be useful.
- Clarify the process for selection of group members to join the service development team, considering availability, interest, skills and experience.
- Make arrangements for consulting with and reporting to the larger user constituency as appropriate — via newsletters, election of officers, occasional public meetings.
- Secure long-term funding for running costs. The service development team will bear some responsibility to demonstrate their commitment to user participation by helping to secure grants via Joint Finance or other sources (see Chapter 3, p. 18). But formalising the user group will enable it to seek and receive grants on its own behalf.

Living Options Checklist for Establishing User Groups

ESTABLISHING USER GROUPS

- ✓ *Agree group membership*
- ✓ *Clarify short-term aims*
- ✓ *Establish meeting structures*
- ✓ *Review long-term mission*
- ✓ *Share skills & experience*
- ✓ *Consider public profile*
- ✓ *Secure practical support & funding*
- ✓ *Clarify organisational & operational structures*



Chapter 6. Working Together

The previous chapters have traced the process of moving from commitment by a professional service development team to user participation, to the formal establishment of a user group. This chapter looks at how the team and group consolidate their relationship, goals and working practices as the culmination of their partnership. Through joint work in the service development team, service planners and users can set standards on ways of working that 'lead the field' and demonstrate working models to statutory and voluntary agencies and the community.

Team Membership

Considerable contact will be taking place between the service development team and the user group during the period of the group's development. The group will have discussed how user members of the team will be chosen, and group members may already be taking an active role on the team. It is important however that, when the user group is formally constituted, proper arrangements are agreed for the participation of disabled people on the team. There need to be at least two user members of the team; 25–50% disabled membership may be appropriate. A single disabled team member will feel isolated and 'token'.

Service development team aims for user membership of the team will need to be reviewed with the user group, and revised as necessary in light of new understanding and experience. Roles and responsibilities of team members — *all* members, not just user members — will need to be clarified in written 'membership guides' (see 'Guide to Membership', *Tracking Success,* p. 21).

Induction

Understanding of the aims and operation of the service development team should not be assumed. As with all new members, user group members require a proper induction into the background, purpose, structure and membership of the team. A team that has 'gelled' over a period of time may resent new (user) members challenging their ideas and plans. Some 'joining exercises' and early planned teamwork will help. New members can initially be paired with existing members to assist in settling in; or 'update' sessions prior to meetings can be arranged. Actually getting down to work together — perhaps in small task groups focusing on particular issues — will help break down barriers quickly and establish working relationships and respect.

Working Practices

Some of the difficulties encountered when 'professionals' meet 'users' results from lack of attention to common courtesies and clear procedural arrangements. The following checklist of good practice will get partnership teams off to a good start.

- Be consistent about protocol: e.g. ensure all team members are addressed similarly (first names, titles).
- Choose meeting times that are possible for disabled people: e.g. early mornings are often difficult.
- Ensure that venues are accessible and allow disabled people to work in the same way and in the same places as able-bodied team members (see Chapter 4, pp. 23–24).
- Build in 'natural breaks' to relieve signers, allow visits to the toilet, etc. without disrupting the meeting or embarrassing team members.
- Accept that people with sensory / communication impairment may need to work at a slower pace, and that some people may need shorter work periods, and build such considerations into meeting schedules.
- Give user members the same opportunity as other members of the team to place items on the agenda.
- Ensure that issues are understood and papers circulated in advance, and that there are no agenda items confidential to professionals only; professionals with more day-to-day involvement on issues may be tempted to raise matters without sufficient preparation.
- Make sure decisions are not made outside the team meetings if the issue is the legitimate business of the whole membership.

- Agree guidelines on language and jargon, labels and acronyms; and agree that the team will challenge anyone 'breaking the rules'.
- Choose a chair who will make all the above happen! Ensure that all points of view are aired and respected, and that everyone is clear about issues and decisions.

Action

The team must show that it is not just a 'talking shop' — that it can make a difference and deliver results. Set realistic targets and demonstrate real — if small — successes, avoiding over-commitment from professionals and disabled people who are not able to carry through on intentions. Make sure everyone is clear about the issue, the agreed action and the outcome. Success should be publicised and celebrated.

Achieving an effective user participation strategy, and the representation of disabled people on the service development team, will have been priority goals in the team's initial 'mission'. The team may now want to review these achievements and set new goals that move the team firmly towards improving and developing services.

Agreeing priorities and combining agendas can be controversial. User groups are more likely to be concerned about matters of practical value to disabled people — transport, access, personal assistance — while professionals may focus on service policy and implementation, community care strategies and organisational demands. Teams will need to negotiate action agendas which, while respecting all members' needs, acknowledge that solving practical problems empowers users to participate, and that the fundamental aim is to improve the quality of life of disabled people.

Training

Bringing disabled people onto the service development team will require a fresh look at the training needs of members. If the team has not had awareness / equality training previously, this will be an appropriate time for it. Some equality trainers prefer to train disabled and able-bodied people separately, while others work with a mixed group. The Living Options Teams used a variety of successful models, including one initiative in which the trainers first worked separately with disabled and able-bodied people, and then brought them together for a final session. Teamwork training will also be useful.

Partnership

Service development team members will want to confirm that they are now working as partners, checking for:

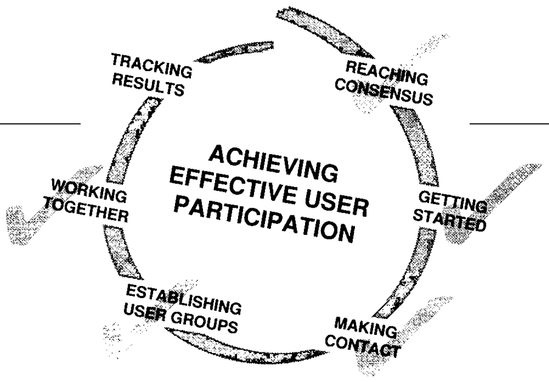
- Equality regarding roles and value, including accountability, access to information, and training
- Understanding, respect, trust and support of one another
- Recognition of each others' skills and experiences
- Willingness to listen and share, as well as to disagree.

The team will need to ensure that all local statutory and voluntary agencies acknowledge the status of user members of the team, and recognise that the strength of the team — and thus of local service planning — depends on partnership with disabled people.

Living Options Checklist for Working Together

WORKING TOGETHER

- ✓ Clarify selection & responsibilities of team members
- ✓ Plan induction & joining process
- ✓ Establish appropriate working practices
- ✓ Agree agendas & ensure action
- ✓ Consider training requirements
- ✓ Check partnership teamworking



Chapter 7. Tracking Results

Drawing on the work of the eight diverse Practice Localities, the previous chapters have presented a guide to achieving user participation in planning services. In order to confirm that their work has borne results — that effective strategies for involving users are in place — service development teams (and all those involved in planning and providing disability services) must review progress regularly. Based on the approach set out in the Living Options In Practice Project Paper 2, this chapter briefly reviews the process of 'tracking success' in achieving effective user participation.

Tracking Success proposes a regular planning–action–review cycle which — starting with Living Options principles — sets standards and detailed criteria for measuring action towards goals, leading to change based on regular feedback. The tracking approach offers practical ways to find out from disabled people and service planners whether strategies for involving users are making a difference, giving disabled people real influence over the way in which services are planned.

Service development teams will want to get feedback regularly from disabled team members and user group members and, occasionally, directly from a wider range of disabled people identified through public meetings and user group networking. Routine tracking will help the team and user group see that things really are happening, even when progress seems slow; and provide evidence to show to colleagues, senior managers and other disabled people. (Many disabled people will not wish to become directly involved in service planning, but the team will still want to test whether disabled people know how to make their views known to planners, and are able to do so.)

Following the process outlined in *Achieving User Participation* will ensure that service planners routinely learn the views of disabled people. But the service development team will also want to undertake simple, structured exercises to measure the impact of their partnership with disabled people.

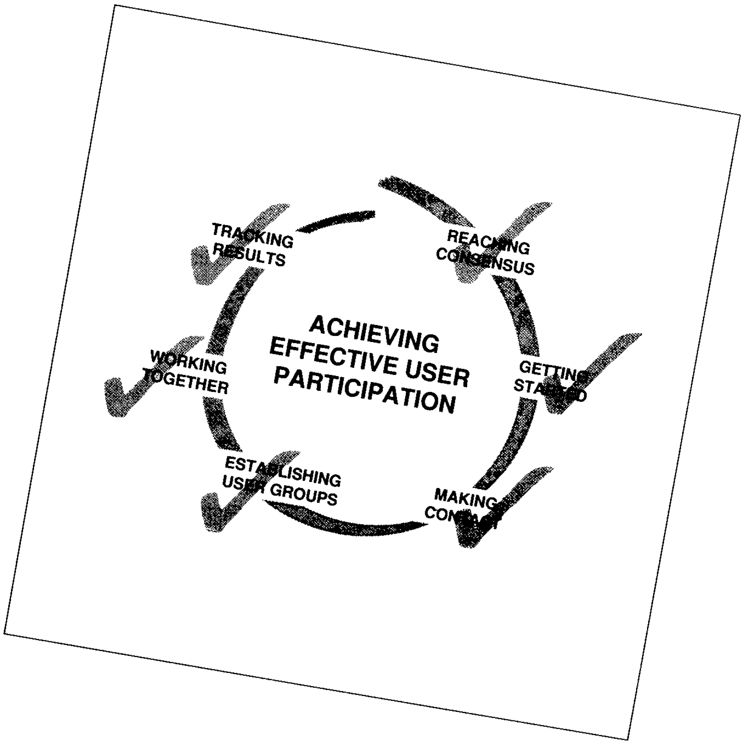
A variety of ways to obtain feedback ('tracking paths') are outlined in *Tracking Success,* Chapter 4, which also lists some sample questions to ask professionals and users that could be adapted for the service development team's review, and some 'Teamwork Questions' to check partnership working. Chapter 3 of *Tracking Success* suggests basic criteria for user participation, and the Living Options Checklists at the end of Chapters 2 to 6 of the present document will also help set criteria for each step along the path to achieving user participation.

Box 6 outlines a simple exercise that will help the team determine the tracking questions that need to be asked to measure the success of user involvement.

Box 6. Tracking progress towards Effective User Participation

- Decide exactly what you want to test, and prepare a list of precise, tangible criteria to use as measures of success, beginning with the goals for user participation agreed by the team and user group
- In small groups or pairs, brainstorm the questions that the team and user group members need to ask themselves to determine whether these criteria are being met; then feed back, discuss and review, and set goals for improvement
- Using these team questions as a baseline, prepare a list of questions to ask disabled people and professionals in the locality to establish the wider impact of the team's work on user participation; decide who will be asked, how and when
- Carry out the tracking exercise using these questions; discuss and review the results; and agree goals for change based on feedback

The Living Options In Practice Teams have pioneered a variety of ways to involve users in planning comprehensive, effective services. Other initiatives are developing different ways to ensure that services respond to users' needs. In a new phase of work, the Living Options Partnership (see p. 44) will be reviewing the Living Options experience together with other approaches throughout the country, to seek a common core of good practice that enables disabled people to have an impact on service planning.



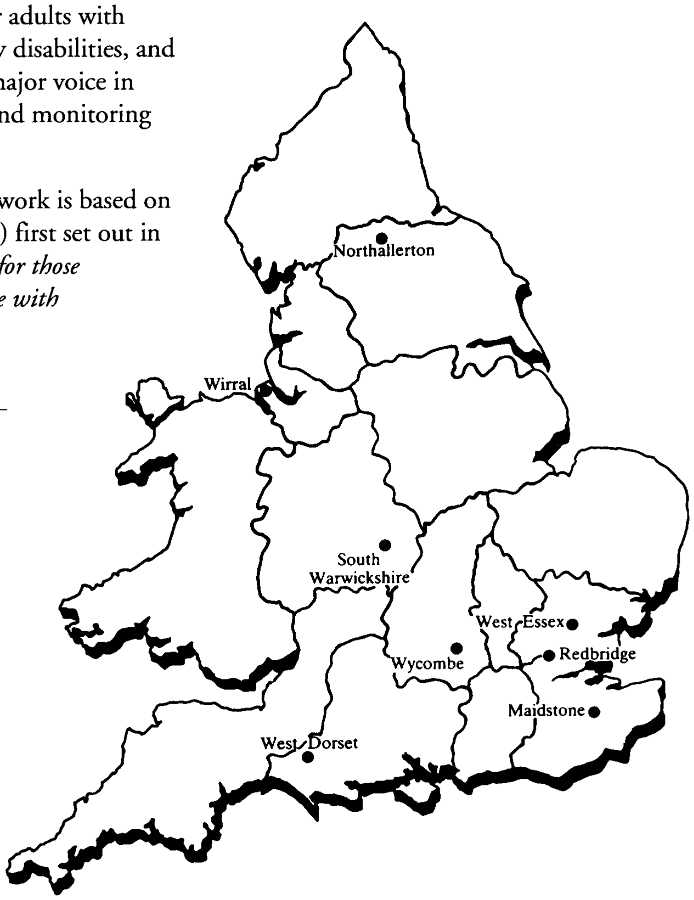
The Living Options In Practice Project

Living Options In Practice is the second phase of Living Options initiatives seeking to heighten awareness of the needs of people with severe physical disabilities and to assist the development of more and better service options. This work has been undertaken by a consortium of voluntary organisations (the Living Options Working Party), in association with The Prince of Wales' Advisory Group on Disability.

Funded through a three year grant from the Department of Health, with additional support from the King's Fund Centre, Living Options In Practice has aimed to encourage the development of local comprehensive services for adults with severe physical and sensory disabilities, and to enable users to have a major voice in planning, implementing and monitoring those services.

All of the Living Options work is based on a set of principles (see p. 2) first set out in *Living Options Guidelines for those Planning Services for People with Severe Physical Disabilities* (1985), and further developed in *Living Options Lottery: Housing and Support Services for People with Severe Physical Disabilities* (1988).

Between 1989 and 1992, eight Practice Localities have worked with the project to consolidate multi-agency teams, establish systems for user participation, and embark on action planning towards good practice services. To aid this work, Living Options In Practice published its first Project Paper, *A Framework For Action: Developing Services For People With Severe Physical and Sensory Disabilities* (1990), setting out the



● Practice Localities

Maidstone
Northallerton
Redbridge
South Warwickshire
West Dorset
West Essex
Wirral
Wycombe

The Living Options In Practice Project (continued)

elements of a comprehensive service structure, and a strategy for achieving effective services. Project Paper 2, *Tracking Success: Testing Services For People With Severe Physical and Sensory Disabilities* (1991), extended these ideas further, outlining a practical process by which planners and providers of services can test their progress towards building better services, against key standards. *Achieving User Participation*, this third Project Paper, draws on the varied experiences of the eight Practice Teams to analyse key steps in the process of developing effective user participation.

From June 1992 a new phase of work — the Living Options Partnership — will take the Living Options initiative forward. This new stage continues the association between The Prince of Wales' Advisory Group on Disability and the King's Fund Centre, with further funding from the Department of Health. The Living Options Partnership aims to support continuing development in the existing Practice Localities and to promote the Living Options approach in new localities around the country, expanding the role of disabled people in this work, and to track good practice in service development and user participation.

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Living Options Publications

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