A FRAMEWORK FOR ACTION

Developing Services For People With Severe Physical and Sensory Disabilities

LIVING OPTIONS IN PRACTICE

Living Options In Practice
Project Paper No. 1

THE PRINCE OF WALES' ADVISORY GROUP ON DISABILITY

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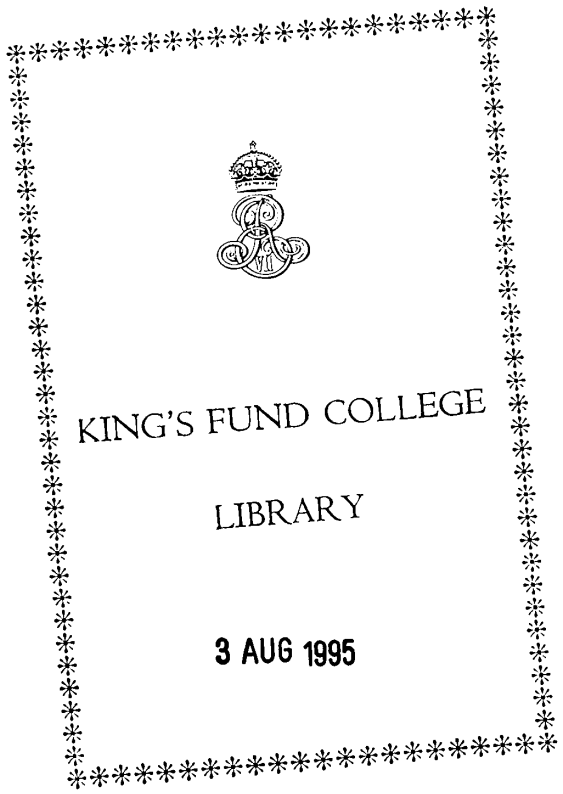

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Developing Services For People With Severe Physical and Sensory Disabilities

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Living Options In Practice is a collaborative venture between The Prince of Wales' Advisory Group on Disability, the Living Options Working Party and the King's Fund Centre.

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The Living Options In Practice Project

Living Options In Practice is the most recent of the 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 aims 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. These aims are being pursued chiefly through work with multi-agency teams in eight Practice Localities (see map). The project work will be documented through a series of Project Papers, as well as through the project newsletter *Network*.

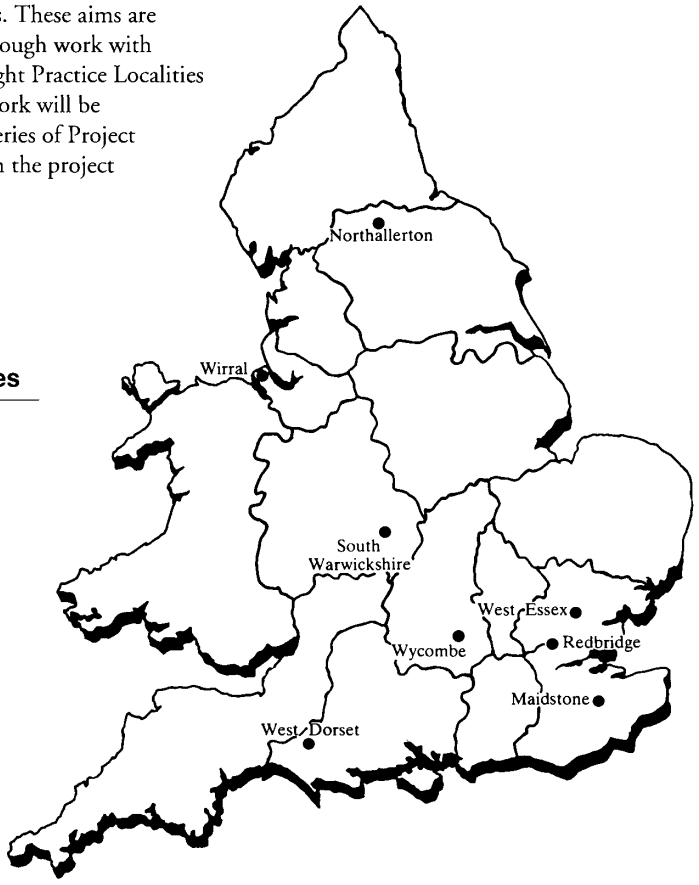
The work of the project is based on a set of values (see page 13) first set out in *Living Options Guidelines for those Planning Services for People with Severe Physical Disabilities* (1985), and further developed in *Living Options Lottery: Housing and Support Services for People with Severe Physical Disabilities* (1988).

Further information about Living Options In Practice, and copies of Living Options publications, are available from:

Living Options In Practice
126 Albert Street
London NW1 7NF

● Practice Localities

Maidstone
Northallerton
Redbridge
South Warwickshire
West Dorset
West Essex
Wirral
Wycombe



A FRAMEWORK FOR ACTION

Developing Services For People With Severe Physical and Sensory Disabilities

The Living Options In Practice project aims to help service planners and providers in statutory and voluntary agencies build effective and comprehensive services to meet the needs of people with severe physical and sensory disabilities. Multi-agency teams in eight Practice Localities are now working with the project to achieve this objective.

In order to provide a framework within which the Living Options In Practice Localities can consider their own local service provision, and service gaps, Living Options In Practice has developed an outline of the elements that should be encompassed within a comprehensive service system —

THE SERVICE STRUCTURE

and a strategy for getting there —

THE SERVICE STRATEGY

This document presents the Living Options *Framework For Action* as an aid for the localities and for others who are planning services for disabled people.

THE SERVICE STRUCTURE

The Living Options In Practice approach recognises that there are a number of different models of 'good practice' services, as well as different ways of achieving them. However, we believe that there are some basic components that are shared by any effective service system.

The Essential Elements of a Comprehensive Service System for People with Severe Physical and Sensory Disabilities

A comprehensive service system offers the disabled person:

- **A Response Point to Users' Needs**

A single point of entry to the service system, easily identifiable and easily accessible, offering information and advice on all aspects of disabled living, and help with the process of obtaining services through assessing, co-ordinating, and tracking requirements for, and delivery of, services.

- **A Place to Live**

A range of housing options to suit individual lifestyles and life stages, including individually adapted dwellings, shared or clustered accommodation with support, and residential facilities offering 24-hour on-site support.

- **Personal Support Services**

Appropriate, flexible and sufficient assistance with personal care and daily living tasks, domestic/homemaking duties and social/quality of life activities, enabling the individual to live as independently as he or she is able or wishes.

- **Access to the Community**

The opportunity to participate in all aspects of ordinary community life, including the availability of employment, education, leisure activities, transport and health care.

- **Specialist Services**

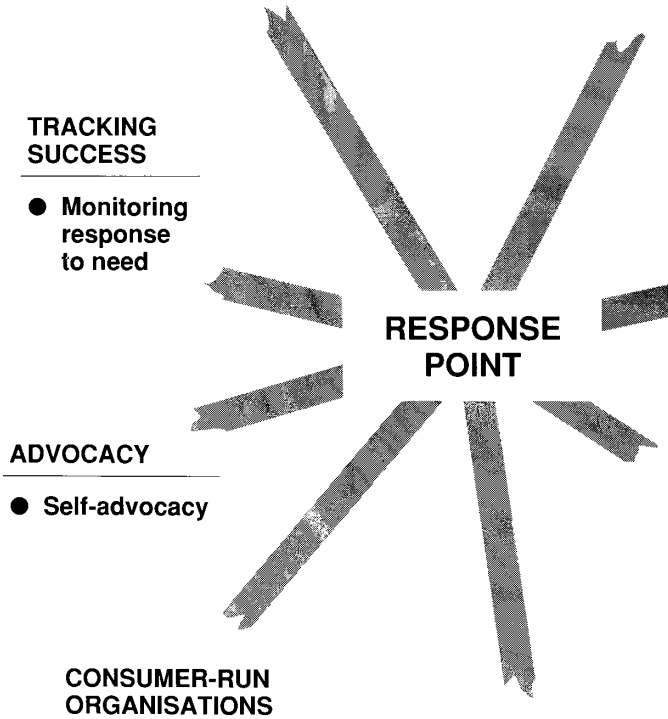
A wide variety of services to minimise or overcome physical or sensory impairment — services that supplement, and enable individuals to use, ordinary community services.

- **Opportunities for Personal Development**

Training, counselling and advocacy opportunities that enable individuals to aspire to and reach their full potential and take advantage of the opportunities available.

The following diagrams illustrate these six fundamental service elements, suggesting some of the possible options that might be included in each area. These are of course only a small sample of the full range of services disabled people may require, and their relevance and priority will need to be assessed locally in consultation with disabled service users.

A Response Point to Users' Needs



IDENTIFYING PEOPLE IN THE COMMUNITY

ONE DOOR TO SERVICES

TRACKING SUCCESS

- Monitoring response to need

INFORMATION AND ADVICE

- Financial
- Practical
- Personal

ADVOCACY

- Self-advocacy

ASSESSING INDIVIDUAL NEED

- Self-assessment

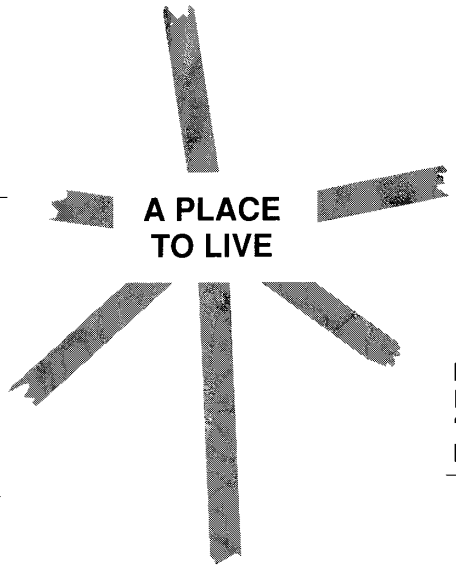
CONSUMER-RUN ORGANISATIONS

- Centres for Independent Living

SERVICE CO-ORDINATION AND DELIVERY

- Case / care management
- Service brokerage
- Individual service plans
- Direct funding / vouchers

A Place to Live



ORDINARY RENTED HOUSING

- Local authority
- Housing association
- Private sector

Adaptable

OWN HOME

- Mortgage access
- Equity share
- Improvement grants

ACCOMMODATION WITH 24-HOUR ON-SITE SUPPORT

- Residential homes
- Nursing homes

INDIVIDUALLY DESIGNED 'BESPOKE' HOUSING

SHELTERED HOUSING

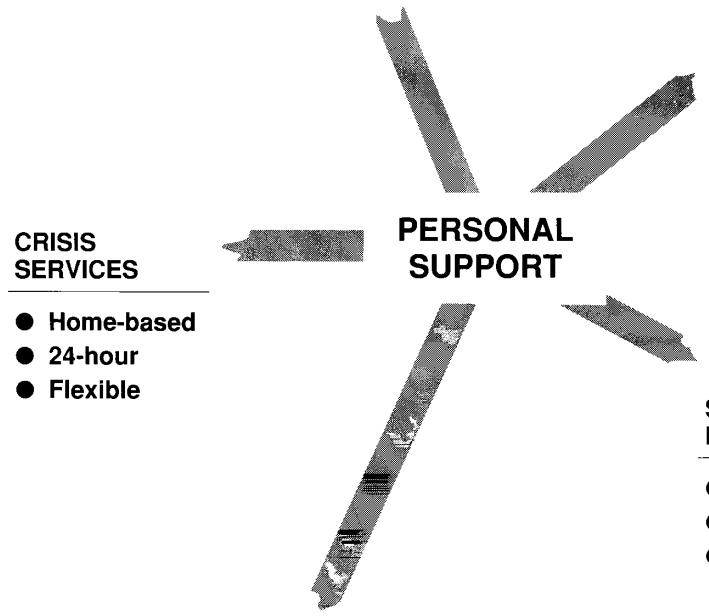
- Warden-assisted

'SPECIAL PROJECTS'

- Hostels
- Group homes
- Core-and-cluster schemes
- Half-way (move-on) housing

Staffed or independent

Personal Support Services



HELP WITH PERSONAL CARE / DAILY LIVING TASKS

- Care attendants
- Personal assistants
- Facilitators
- Enablers

DOMESTIC HELP

- Homemaking
- Home helps
- Shopping
- Meals

CRISIS SERVICES

- Home-based
- 24-hour
- Flexible

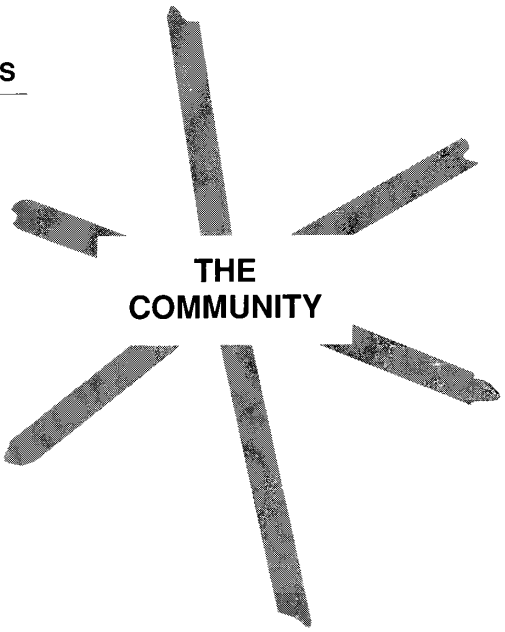
SOCIAL ENABLEMENT

- Entertainment
- Leisure
- Visiting friends

HELP FOR INFORMAL CARERS

- 'Respite' holidays
- 'Programmed care'

Access to the Community



TRANSPORT

- Public transport
- Taxis
- Driver training

EDUCATION

- Mainstream
- Adult
- Continuing
- Vocational

HEALTH SERVICES

- Accessible surgeries and hospitals
- Community nurses and therapists

EMPLOYMENT

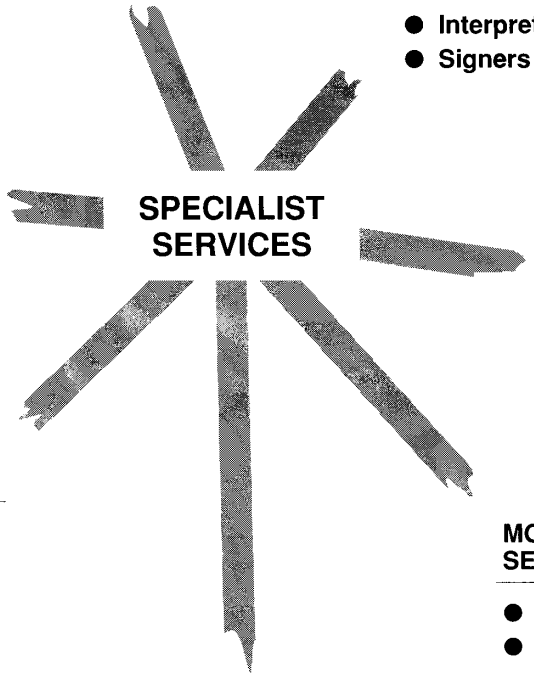
- Open
- Job training
- Supported placements

RELIGIOUS / CULTURAL GROUPS

LEISURE

- Sports
- Community involvement
- Volunteer activities
- Interests / hobbies
- Libraries
- Holidays

Specialist Services



ADAPTATIONS AND EQUIPMENT

- Communication aids
- Disabled living centres
- Car adaptations
- Telephone links
- Alarms

HEARING / VISUAL HELP

- Guide dogs
- Guide helps
- Interpreters
- Signers

WHEELCHAIRS / ORTHOTICS / ARTIFICIAL LIMBS

- DSA

USER-RUN SERVICES

- CILS
- DIALS

ACCESS TO EMPLOYMENT

- DRO
- Sheltered workshops
- Day centres
- Remploy

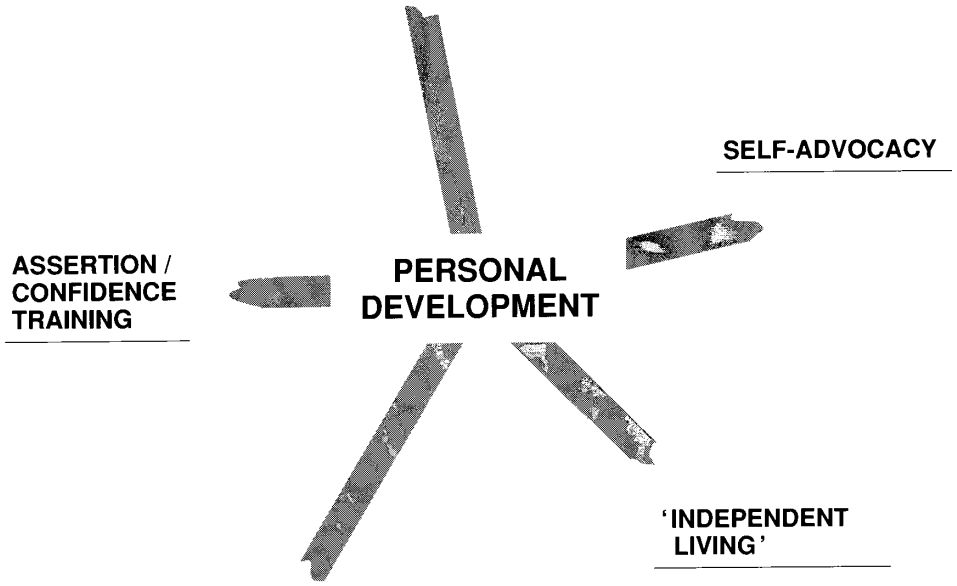
MOBILE SERVICES

- Health
- Personal assistance
- Libraries

REHABILITATION SERVICES

- Occupational therapy
- Physiotherapy
- Speech therapy

Opportunities for Personal Development



COUNSELLING / PEER COUNSELLING

- Personal
- Psychological
- Partnerships / relationships

SELF-ADVOCACY

ASSERTION / CONFIDENCE TRAINING

'INDEPENDENT LIVING'

- Training and encouragement

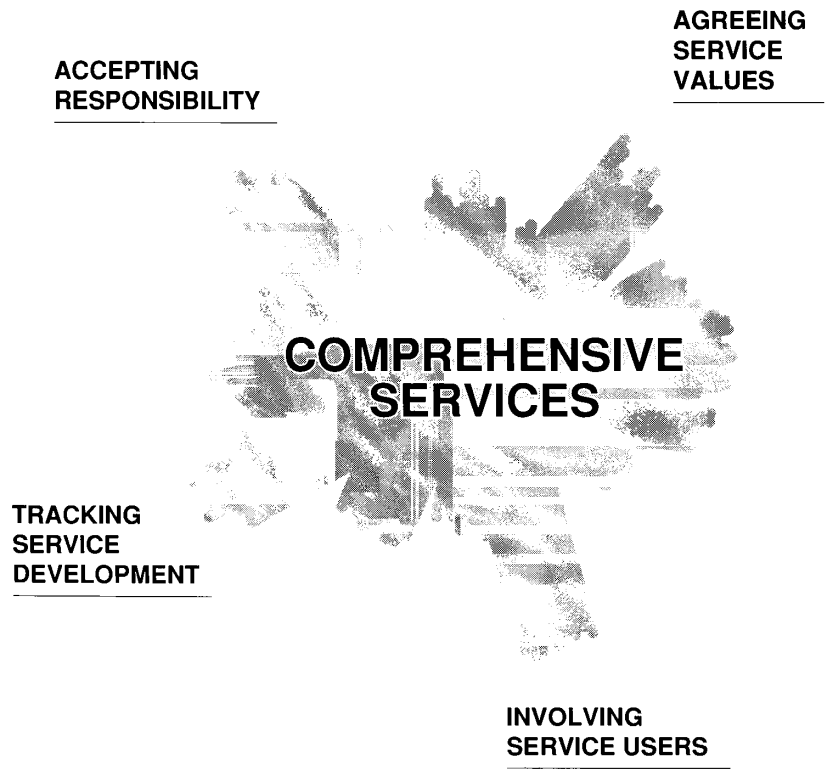
EDUCATION AND EMPLOYMENT ADVICE / TRAINING

THE SERVICE STRATEGY

The previous section of the *Framework* described a comprehensive service structure for disabled people. This section outlines the action strategy required to achieve that service structure.

Living Options In Practice has identified four requirements towards this end, and some practical measures that need to be taken to meet these requirements. These steps are neither entirely sequential nor separate, but need to be tackled as a whole — for example, service values will need to be agreed with disabled service users; and feedback mechanisms must be built into service planning.

Four Steps to Achieving a Comprehensive Service System for People with Severe Physical and Sensory Disabilities



Accepting Responsibility

Living Options In Practice believes it is unlikely that effective services will be realised unless social services, health and housing authorities accept responsibility for providing good services, and work in partnership with voluntary and consumer organisations, and other statutory agencies as required. Where such multi-agency service development groups do not already exist, Living Options In Practice has helped Localities form working teams to take the work forward.

TAKING ACTION

Accepting responsibility will require that the key agencies:

Set up a development group

A local service development group should be set up, representative of health, local authority (social services, housing, education, other relevant departments), voluntary agencies and service users, to take responsibility for planning services for people with disabilities. If there is an existing planning group with responsibility for physical disability, that group may need to review its membership to ensure a multi-agency approach.

Establish lines of accountability

Each service development group will need to establish appropriate lines of accountability. Where formal planning structures (e.g. Joint Care Planning Teams) exist, the role and relationship of the service development group will need to be agreed, to avoid duplication of planning functions. Where there is no JCPT for physical disability, the service development group may well take on that role. In either case, all statutory and voluntary agencies and planning bodies will need to be clear about the service development group and its work.

Designate posts

Service agencies should appoint specific officers to attend the service development group, and the commitment of these officers to the work of the group should be accepted as an integral part of their job. They should have authority to act on behalf of the agency they represent. Voluntary/consumer organisations will need to establish who should become members of the service development group. In some areas there will be existing 'umbrella' groups for voluntary agencies; in any case, organisations will need to agree consultation and report-back procedures for their constituencies.

Co-ordinate planning

In accepting responsibility for service planning, the service development group should identify all those agencies and professionals involved with physically disabled people, and determine ways of ensuring that they know about the work of the service development group. Ideally the service development group would become the focal point for planning and action for this client group, and would be looked to by all agencies as a source of ideas and plans for service development as well as a route to the consumer voice.

Ensure financial responsibility

Members of the service development group may not necessarily bring to the table new financial resources from their respective agencies. However, the group can ensure that existing resources are used more effectively by avoiding duplication of services among agencies and agreeing to target money jointly towards activities that will produce the best results. A persuasive case may need to be made for a higher priority to be given to services for physically disabled people. The group can also have a role in channelling funds directly towards disabled consumers.

Agreeing Service Values

All of the Living Options work is underpinned by the principles first set out in *Living Options Guidelines* and further developed by *Living Options Lottery.*

These principles — which place the individual disabled person at the centre of service planning — are as follows:

- **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
- **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

TAKING ACTION

In order to ensure that local services develop from fundamental principles, the service development group will need to:

Agree objectives

All those involved in service development for people with physical disabilities will need to understand and accept the above principles. Understanding the Living Options principles may require new ways of thinking for professionals, and they may need to get to know disabled people more closely as individuals. It will be necessary for those who

constitute the service development group to be clear about how far their present working practices fit with these principles, and about what needs to be done to bring local practice into line with the principles.

Produce a statement

Each local service development group will find it helpful to produce their own statement of intent, or mission statement, setting out service principles and objectives. Such statements need to be owned and understood by all the partners in the planning process. The statement should encompass the questions:

- What is the job to be done ?
- Why are we doing it ?
- Who is it for ?

In doing this it will prove helpful for copies of existing statutory and voluntary sector statements of policy or purpose to be tabled for consideration. The resulting mission statement should give a clear indication of the objectives of the local service development group. It is important that this statement informs planning documents for all individual agencies and joint development locally, so that those with responsibilities for physical disability services are not working to different and possibly incompatible service aims. All monitoring and evaluation systems that are developed locally should be based on local service principles and the local mission statement.

Inform others

It is important for the local service development group to ensure that its mission statement is widely circulated to all those working with people with disabilities, and is made available to professionals and staff working at all levels and in all agencies, so that they are aware of the existence of the service development group, the work it is doing, and — most importantly — the philosophy underpinning the work.

To ensure that information about the local service development group and its work is circulated and understood, the group will need to identify at an early stage all those in health, local authority and voluntary networks, at all levels, who should be aware of their aims and work, and who may potentially be allies — or present barriers — in taking the work forward. The group will need to determine ways of targeting information about their work to these contacts and ensuring regular progress reports.

The aims and objectives of the service development group should be reflected in development and training programmes for all staff working in the field of physical disability.

Involving Service Users

The full participation of disabled people in planning, designing, implementing and monitoring the services they use is fundamental to the Living Options In Practice project. Genuine user involvement results in better targeting of services. It ensures that the services ultimately delivered are those which disabled people want and need, and which are sufficiently flexible to change as circumstances alter.

TAKING ACTION

In order to achieve user participation, local service development groups will need to:

Consult local disabled people

Existing and potential service users will need to be identified and opportunities provided for service development plans to be shared and users' views learned. This includes disabled people from different races and cultures; and those who are less 'visible', less articulate or less able, and often spoken for by others.

Disabled people can be reached via media, special events, and individual (professional and consumer) contacts, as well as through consumer groups (run by users), local interest groups (e.g. Access Committees) and voluntary organisations. (The distinction between voluntary and user-run bodies must be recognised: while the former will have contact with disabled people, they may also provide services, represent carers, and/or support staff working with disabled people, and so may be reflecting views that conflict with those of service users.) The views of carers — whose requirements as users of services are often different from the needs of the person they support — must be taken on board.

Service development groups can work to ensure that consultation begins at the earliest stages of service planning, and that disabled people are encouraged to become involved.

Involve disabled people in formal planning systems

Each service development group will need to work towards genuine representation of disabled people on committees and working groups. A single disabled 'representative', an inexperienced representative, or a disabled person with no 'constituency' undermines effective participation.

Information and training relating to planning structures, committee 'culture', and negotiating skills, as well as assertion/confidence training, may be necessary. Practical support may be needed, too: for example,

- Accessible meeting venues
- Help with transport
- Committee papers in large print, Braille, or on tape; interpreters, etc.
- Personal assistants/facilitators
- Payment for time and expenses

Service development group members, and members of other committees/groups, may benefit from disability awareness training to ensure that consumer participation becomes effective.

Support user groups

Increasing demands on disabled individuals and their organisations can sabotage planners' intentions to consult consumers. If informed and representative input from disabled people is expected, consumer groups will require the resources to make that happen. Service development groups will need to help to identify funding for setting up and 'professionalising' user groups, including administration costs, premises, development workers, transport and training.

Living Options In Practice is exploring with the Practice Localities ways to encourage and develop genuine consumer participation.

Tracking Local Service Development

Living Options In Practice believes that it is essential to monitor the effectiveness and quality of local services. The service development group must take a lead in ensuring that mechanisms exist for tracking success and that action is taken where indicated.

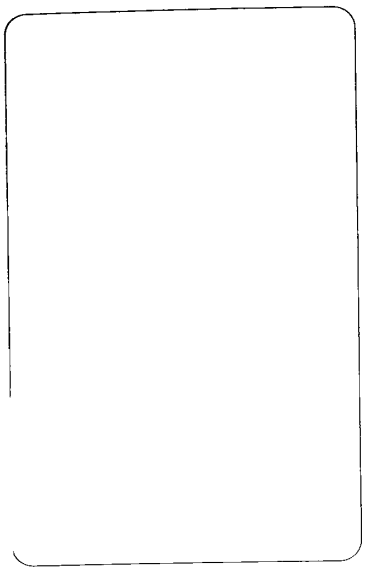
TAKING ACTION

There are a number of levels at which tracking needs to take place:

- Tracking progress towards comprehensive local services
- Tracking the experience of individual disabled service users
- Tracking strategies for achieving good services — such as consumer consultation

Service development groups may also want to track the effectiveness of their own work.

Service monitoring and evaluation can be time-consuming, disruptive and expensive — and the results are often not acted on. Living Options In Practice will be working with the Practice Teams to develop practical ways to Track Success that will contribute to informed planning, review and change.



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