



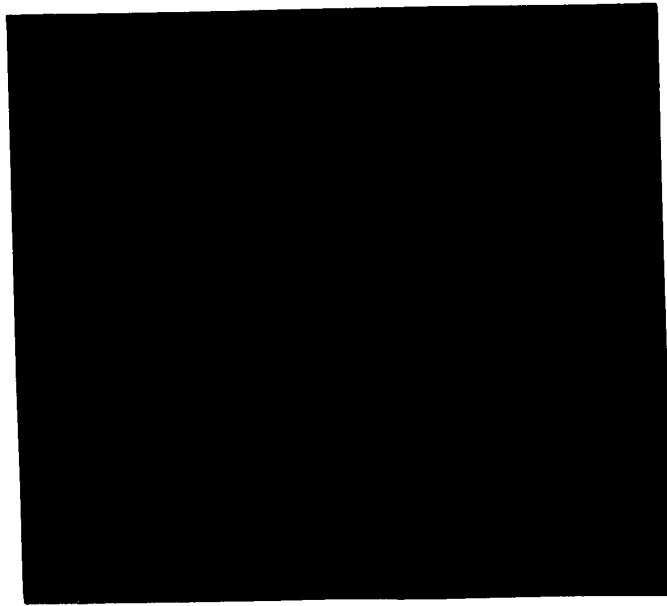
**INFORMATION ON
OBTAINING THE VIEWS
OF USERS WITH LEARNING
DIFFICULTIES**

**CONSUMER FEEDBACK
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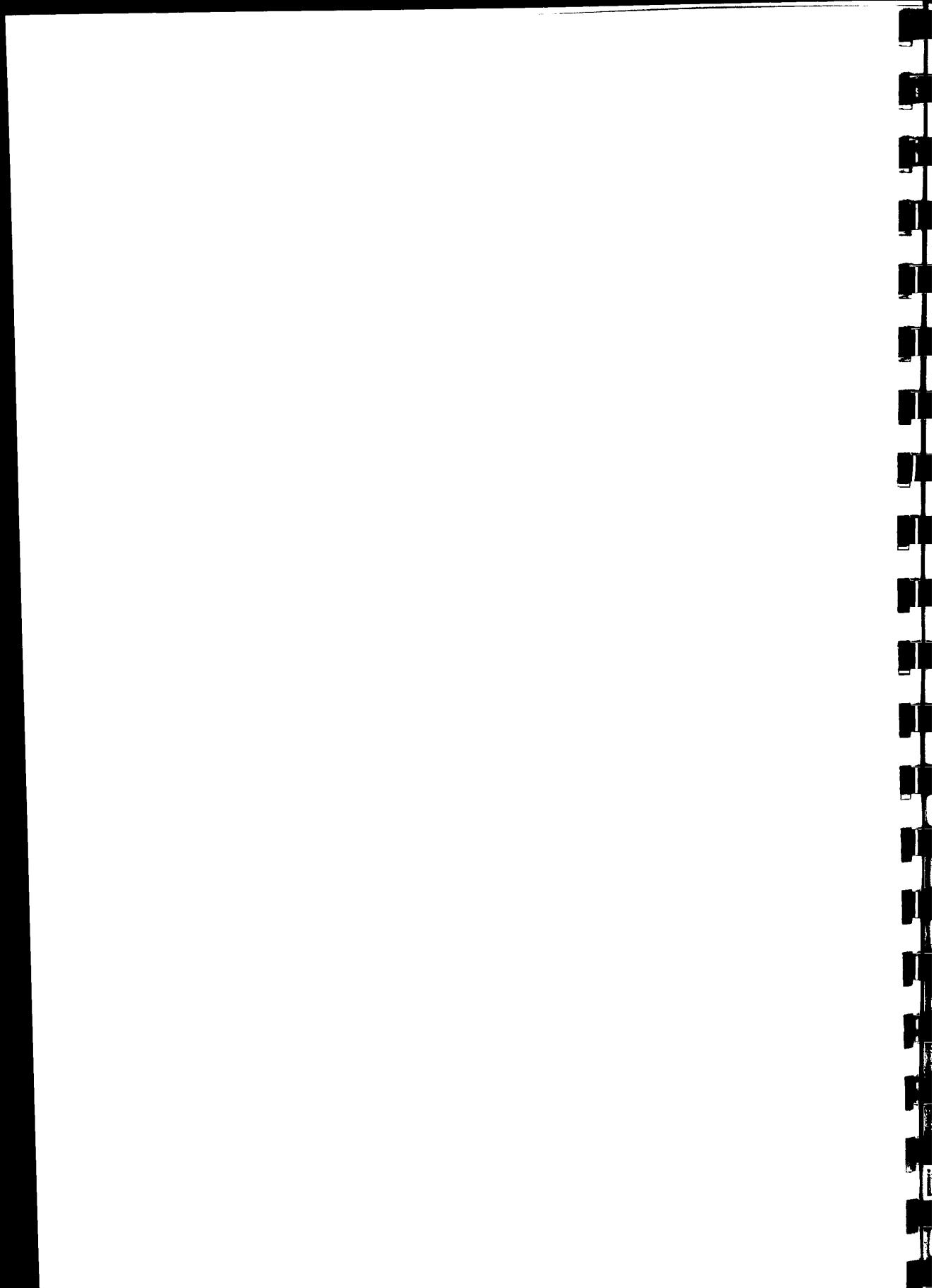
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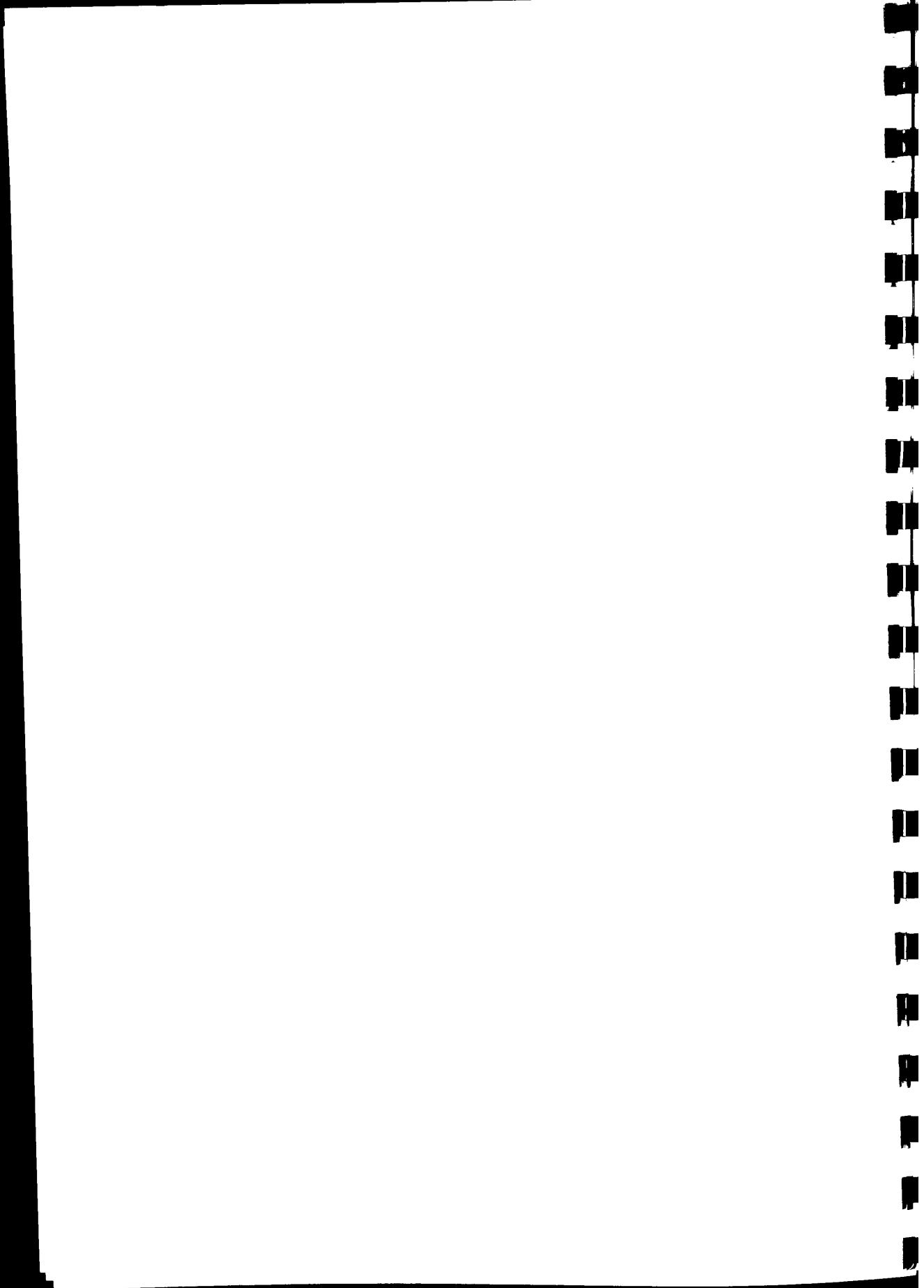


**INFORMATION ON
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INTRODUCTION

These information sheets will be of use to health service staff or Community Health Councils who wish to find out the views of users with learning difficulties.

The purpose of these sheets is:

- 1 to give some useful reading references for this field
- 2 to give details of some of the current major projects
- 3 to list some organisations which may be able to carry out research
- 4 to provide a checklist of what appear to be the most important areas for questions to ask users with learning difficulties.

Information on the use of feedback methods is available separately and is also provided in full detail in:

McIver S. *Obtaining the Views of Users of Health Services*. London: King's Fund Centre, 1991.

Details of any type of consumer feedback project using survey or non-survey methods are welcomed by the Consumer Feedback Resource so that we can develop advice on obtaining the views of users with learning difficulties. Please send the information to:

Shirley McIver
Manager
Consumer Feedback Resource
King's Fund Centre
126 Albert Street
London
NW1 7NF
Tel: 071-267 6111

July 1991

USEFUL READING REFERENCES

The texts in this list are chosen because they cover issues that arise in consumer feedback or quality improvement in services for users with learning difficulties.

None of the publications below has been formally evaluated but provide a guide to what is available.

King's Fund Centre publications can be obtained from Bailey Distribution Limited, Learoyd Road, Mountfield Industrial Estate, New Romney, Kent, TN28 8XU or to personal callers only from The Bookshop, The King's Fund Centre, 126 Albert Street, London, NW1 7NF.

The King's Fund Centre has a reference library which holds many of the publications mentioned. Photocopies of journal articles ONLY (not books or reports) can be supplied at 20 pence a page plus postage and packing. However you are advised to try your local library first.

Booth T, Simons K, Booth W. *Outward Bound*. Milton Keynes: Open University Press, 1990.

The experiences of groups of people moving out of long stay hospitals into the community are explored. The personal issues and policy implications of relocating people with learning difficulties in the community are addressed.

Le Touze S, Pahl J. *A Consumer Survey Among People with Learning Disabilities*. Centre for Health Service Studies, University of Kent, 1990.

46 people were interviewed to find out their views of the services they received. A conversational style was adopted as far as possible for interviews. The results of the survey formed the basis for two consultation workshops. The report includes an interview checklist.

Humphreys S, Evans G, Todd S (eds). *Lifelines: An account of the life experiences of seven people with a mental handicap who used the NIMROD service*. London: King Edward's Hospital Fund for London, 1987.

A case-study approach was used to illustrate the experiences of seven people providing insight into the lives of people with learning difficulties. The case studies are analysed in terms of several interwoven concepts – presence and participation in the community; relationships; competence; choice and status.

Wertheimer A. *Making Our Voice Heard: Strengthening alliances between people who use services*. London: King's Fund Centre, 1988.

Report of a one-day seminar for those who use services for people with learning difficulties, physical disabilities or long-term mental health problems. The participants included users of services, paid workers and individuals with a commitment to users of services. The report includes a summary of each of the following issues: what do we want; what are the barriers to achieving change; what has been successful in achieving change in the past; what possibilities are there for working together and what are the next steps.

Cameron Jo, Sturge-Moore L. Ordinary, Everyday Families. Under Fives Project, Mencap London Division, 1990.

Lists action for families and their young children with special needs, disabilities and learning difficulties. Contains information for families, policy makers, professionals, voluntary organisations, and a wide range of specific support services.

Baxter C, Poonia K, Ward L, Nadirshaw Z. Double Discrimination. London: King's Fund Centre, 1990.

Discusses the issues and services of importance to black and ethnic minority people with learning difficulties. It includes good working practices from around the country, references, resources, and further reading.

Whittaker A. Involving People with Learning Difficulties in Meetings. In: Winn L (ed). Power to the People. King's Fund Centre, 1990.

Whittaker A. Evaluation of Services by People with Learning Difficulties. London: King's Fund Centre, 1991.

This report looks at the innovative way that North West Thames Health Authority and Hillingdon Social Services gave support for people with learning difficulties so they could conduct their own evaluation exercise into the services provided for them. The report includes advice on how to carry through a similar project.

Community Living Development Team. Self Advocacy Resource List. London: Kings Fund Centre, 1991.

Lists books, films and videos about self advocacy.

Aylesbury Health Authority. Listen to Me, Part 2. Director of Consumer Services, District Head Quarters, Ardenham Lane, Aylesbury HP19 3DX, 1990.

This report of a follow-up study of the views of people with learning difficulties living in hospital and the community used taped interviews with 10 people.

CURRENT PROJECTS

These projects are ones that are funded to develop good practice in the field of consumer feedback or quality improvement in services for users with learning difficulties.

Sylvia Martin
Quality Assurance
West Surrey and North East Hampshire Health Authority
Northfield
Aldershot
Hampshire

Tel: 0252-311123 Ext. 258

The aim of this project was to produce a teaching package which would incorporate a series of faces showing a variety of expressions based on the 'oucher' system (Bayer and Byers, 1984). The piloting of the scheme has been completed. It has become a distance learning package which can be used to obtain the views of users with learning difficulties who have communication problems but have some level of comprehension.

Sheila Redfern
Researcher
Better Services Project
c/o 245 Royal College Street
London
NW1 9LT

Tel: 071-485 8177

A survey of users' views is being undertaken to find out whether users' expectations of services match the outcomes of services and to see whether the aims of the service outlined by service providers are being met.

Clare Jones
Clinical Psychologist
Llanfrechfa Grange Hospital
Llanfrechfa
Nr Cwmbran
NP4 2YN

The Clinical Psychology Department has been addressing the issue of consumer satisfaction for people with learning difficulties for two years. A questionnaire adapted from a general-purpose satisfaction questionnaire has been added onto a proforma for monitoring all referrals and is being used to obtain users' views.

ORGANISATION CONTACT LIST

This is a list of organisations offering advice and assistance to those seeking to obtain information from users with learning difficulties. This list is not comprehensive and inclusion does not imply endorsement by the King's Fund Centre.

Mental Handicap in Wales
Applied Research Unit
St David's Hospital
Cardiff
CF1 9TZ
Tel: 0222-226188

Mencap National Centre
123 Golden Lane
London
EC1
Tel: 071-454 0454

One-to-one
404 Camden Road
London
N7 OSJ
Tel: 071-700 5574

Community Living Development Team
King's Fund Centre
126 Albert Street
London
NW1 7NF
Tel: 071-267 6111

People First
Oxford House
Derbyshire Street
London
E2 6HG
Tel: 071-739 3890

AREAS FOR QUESTIONS

This list contains suggestions for areas which could be covered in a survey to obtain the views of users with learning difficulties. The list has been compiled from previous research into the views of users with learning difficulties but it is not intended to be exhaustive.

This group of users is one which is often thought of as having communication difficulties, and consequently as being unable to express views about service use. Research has shown that this is not the case and that useful information about service quality can be obtained from people with learning difficulties.

The questionnaire survey is probably the method least likely to succeed in eliciting information from this type of user, although West Surrey and North East Hampshire Health Authority (see Current Projects) is piloting a questionnaire based upon the 'oucher' system, which uses a series of faces showing a variety of expressions. More usual are interviews, such as the semi-structured interview schedule used by Aylesbury Vale Health Authority, Quality of Life Review Group in 1989. Advocacy groups also exist which help people with learning difficulties to speak for themselves. The Norah Fry Research Centre at the University of Bristol has a research project looking at people with learning difficulties involved in self-advocacy and citizen advocacy, as well as other projects involving this client group.

TYPE OF USER

One of the main issues for this group of users is to be seen as individuals with differing needs and not categorised under the same label. This means that it is important to use qualitative methods or methods involving the participation of the user. Books such as Double Discrimination (see reading list) detail the needs of different groups of users with learning difficulties. The sort of information that may be useful to find out in an interview is as follows:

- Age, sex, area of residence and ethnic group.
- Housing situation, e.g. living at home with carers, a hostel or a hospital.
- Day time activities, e.g. school, day centre, employed.

SOCIAL RELATIONSHIPS

This is an important area for this user group. Users may need help in maintaining existing relationships and developing skills to acquire new relationships or having the opportunity to meet new people.

- Friends – who are they; where does the user meet her/his friends; are there any difficulties in getting together; would the user like more friends?
- Do clients have the opportunity to meet able-bodied people?
- Hobbies – what does the user do in her/his spare time; does he/she get bored?

EMPLOYMENT OPPORTUNITIES

Users value leading as ordinary a life as possible. Many adults with learning difficulties use day care services and some of the issues that arise out of this are:

- Does the day centre offer opportunities to meet new people?
- Do attenders get paid for coming and if so how much?
- Do attenders have the opportunity to learn new skills?
- Does the day centre offer the opportunity to be employed outside the day centre?
- Are attenders given the opportunity and time to talk to staff?

ACCOMMODATION

This can be a source of tension in a person's life; in particular people may find it difficult to find a place where they can sit quietly if they wish.

- How many people does the user live with?
- Do users get on with the people they live with?
- Would users like to live elsewhere?
- Can they do what they want at home?
- Do users have a room of their own and would they like one?
- Is there a room for sitting quietly in?

ACCESS

- What transport is available to the user?
- What difficulties does the user have in using transport?

INFORMATION

Information may be needed about:

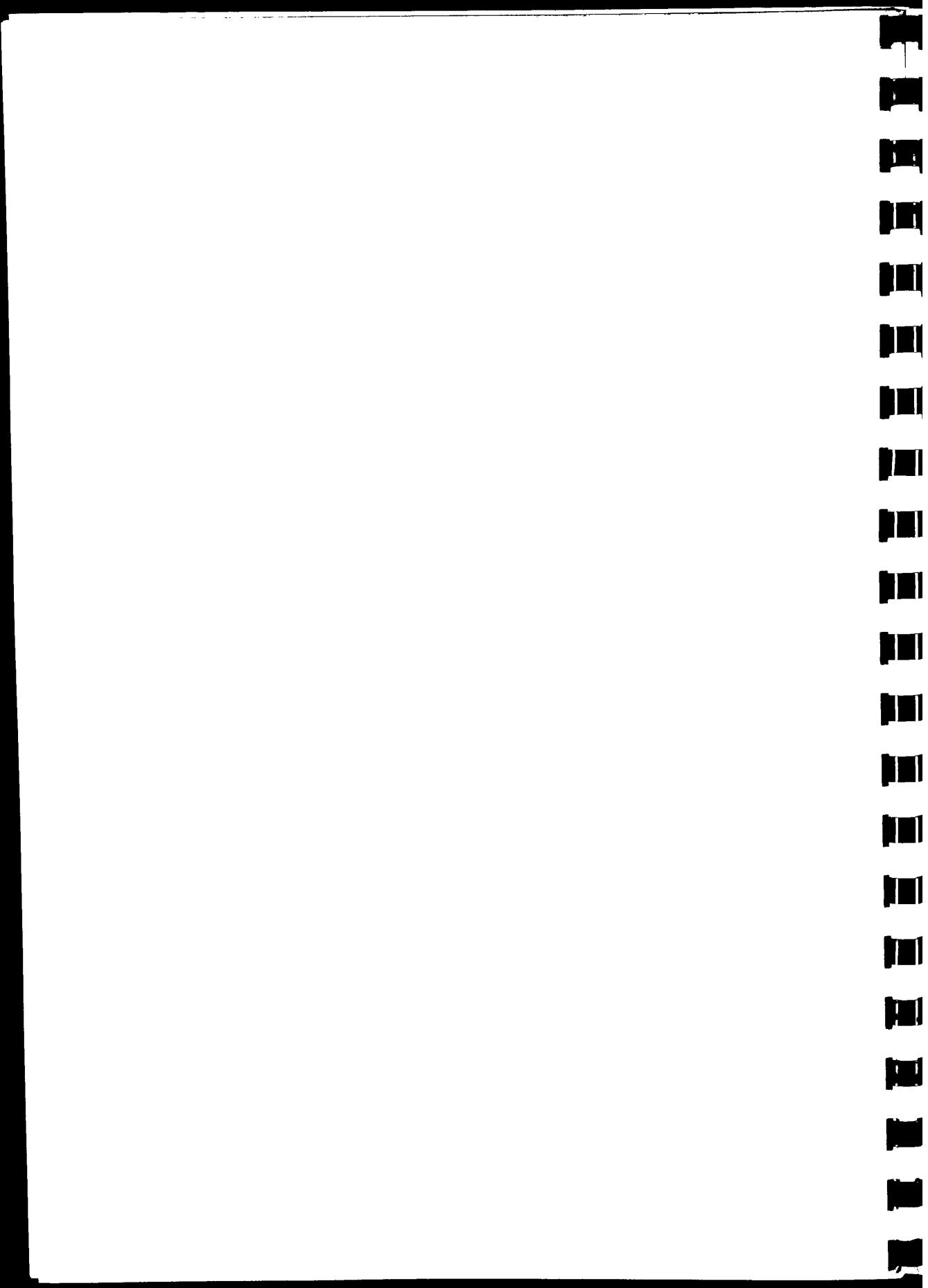
- The role of different service providers.
- The different services available.

ORGANISATION

- Are users involved in the planning and developing of the services they use?
- Do users have access to advocacy services?

CARERS

- Which services do carers find most useful for the person they look after?
- Are the views of the carer and user similar about different aspects of the user's life?



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The King's Fund Centre is a health services development agency which promotes improvements in health and social care. We do this by working with people in health services, in social services, in voluntary agencies, and with the users of their services. We encourage people to try out new ideas, provide financial or practical support to new developments, and enable experiences to be shared through workshops, conferences and publications. Our aim is to ensure that good developments in health and social care are widely taken up.