

DEVELOPING COLLECTIVE ADVOCACY FOR
PEOPLE WHO FALL WITHIN THE REMIT OF THE
NEW MENTAL HEALTH (SCOTLAND) BILL

Final report

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Scottish Human Services Trust
1a Washington Court
Washington Lane
Edinburgh
EH11 2HA

Tel. 0131 538 7717
Text Tel. 0131 477 3684
Fax. 0131 538 7719
Email. general@shstrust.org.uk
Web. www.shstrust.org.uk

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FOREWORD

Context of this report - why advocacy is important, and how this study came to happen

Advocacy is a central part of ensuring that people who are at risk of not being heard get the services and other opportunities that they believe they need. There are several types of independent advocacy, and they are all important.

- Collective advocacy is where people with similar experiences or in similar situations come together, with or without external support, to make common cause, provide mutual support, and get their collective voice heard.
- Individual advocacy is when a paid or volunteer member of an advocacy project supports someone in dealing with a specific issue or problems, and the advocate will work with the person until the issue or problem is resolved.
- Citizen advocacy is when someone volunteers to act as someone else's advocate on a personal basis. These relationships may last over many years, and are likely to cover a wide range of issues.

All three of these forms of advocacy are independent of the formal service system and of organisations which provide care services, and they focus on the needs of people who are at risk of not being heard. There is more background on types of advocacy in 'Key Ideas on Independent Advocacy' (Advocacy 2000, 2000) and in 'Independent Advocacy: A Guide for Commissioners' (Scottish Executive, 2000).

In 2000, the Scottish Executive established the Advocacy Development Project, which was hosted by Scottish Human Services Trust (SHS). The role of the Development Project was to support NHS Boards and local authorities, along with their planning partners, to develop and implement advocacy plans. In early 2002 Scottish Executive funding was announced for two new bodies as part of a wider policy to extend the ways in which health services and other services focus on the people who use services, and to promote public participation.

The role of the Advocacy Safeguards Agency is to ensure that high quality independent advocacy is available to people where and when they need it. The agency has five main tasks: policy development and implementation; development support for the people in local areas

who commission advocacy; research; evaluations of advocacy projects; and complaints and dispute mediation.

The second new body is the Scottish Independent Advocacy Alliance, which brings together independent advocacy projects from across Scotland. It provides information, advice and support to local advocacy organisations; undertakes training on advocacy and related issues for agencies in the statutory and voluntary sectors; and ensures that the 'voice' of the advocacy movement is heard at national level to influence current and future practice and policy.

In early 2002 the Scottish Executive asked SHS to commission a research study into the extent of collective advocacy available to people who stood to be affected by the draft Mental Health legislation which was being considered, and since has become the Mental Health (Scotland) Act 2003. The focus was on people affected by the previous legislation – people who have mental health problems, people who have learning difficulties, and people who have dementia, - and for the first time people with a personality disorder. This report is the result of that research study.

The issues that the study has raised, and how these relate to other initiatives

The Discussion section of the report details the questions raised by the research. This foreword draws out some of the issues which highlight why collective advocacy is important and which are part of the continuing debate around how people participate and have their voices heard.

The people who are missing

The collective advocacy projects identified in this study did not reach all the groups of people who could benefit from their work. The people often missing were:

- older people;
- young people and children;
- people who live in nursing homes or residential care;
- people from the black and ethnic minority communities;
- disabled people.

If, for whatever reason, a collective advocacy project does not include all the people with a shared interest, it is not representing everyone. There will be some issues affecting people living in the situations which the group covers, which will not be raised and pursued.

For example, mental health collective advocacy groups rarely include people aged over 60 or 65. Some of the debate around the recent mental health legislation has focused on the safeguards for people receiving ECT. Yet the experiences and views of the people who are proportionately most likely to have received this form of treatment (older women) are among the least likely to be heard. How do we ensure that there are collective advocacy projects which welcome older people who have mental health problems? How do we ensure that the national standards and guidelines around good practice reflect the experiences of the full range of people who are affected?

Many people who are now leaving long-stay learning disability hospitals are moving to a nursing home¹. How do we enable the community-based collective advocacy projects to reach out and include people who are living in residential settings?

Services for people with mental health problems or with learning difficulties know that they tend not to reflect the needs of people from the minority ethnic communities. If the voices of those people are not being heard when the priorities for changes are being discussed, there is a risk that progress gets made first in other areas, and the gap between what people need and what is available widens.

The issues that people raise through collective advocacy

Access to good quality services is important. But services cannot address all aspects of people's health and well-being. Factors such as the environment people live in; their friendships and social networks; sufficient income and financial security; and how people look after themselves, are all significant in determining people's mental and physical well being.

We would have expected collective advocacy groups to be pursuing members' interests on all these matters – but the projects identified in this study tended to restrict their activities to health and social work

¹ Detailed updated information will be available later in 2003 through the Scottish Executive from work by the National Implementation Group for Same as You?

services issues. There were few examples of projects taking on the other matters that affect people's lives, such as employment, general housing issues, or transport to give members better access to more facilities. Where a project did raise these issues, there was little encouragement from the people who had commissioned the advocacy project.

There were also few signs of groups taking on the wider citizenship issues which can affect people as a consequence of the mental health legislation or of lengthy stays in hospital – such as encouraging members to be aware of the civil rights issues associated with compulsory treatment and care.

The channels which groups were using to promote members' concerns were also limited. The research found that one of the main activities of the groups undertaking collective advocacy is participation in the formal planning structures – the joint meetings established by the NHS Boards and local authorities. There were few signs of groups using the broader Community Planning mechanisms or the wider fora open to all citizens to take forward issues such as better transport for an area, or making links with networks such as the Social Inclusion Partnerships.

Taken together, these findings raise questions about how far groups undertaking collective advocacy feel able, or willing, or allowed to take on the full range of factors that will affect the health and well-being of the people whom they represent. One of the questions those commissioning collective advocacy projects could consider is how to encourage groups to make use of the range of possible routes through which issues could be progressed.

What helps support collective advocacy?

The research has confirmed that many of the collective advocacy projects are finding it difficult to survive. Some of the problems they are encountering – such as funding, and the availability of suitable premises and equipment - are similar to those experienced by many smaller voluntary organisations. But there also appear to be some issues that are specific to advocacy projects – such as finding useful ways to evaluate what they do and assess their level of activity.

Another finding is that most of the projects are heavily reliant on statutory funding from the NHS and local authorities – the bodies which a project will at some point be challenging as it represents its

members' concerns. This raises questions about what helps ensure collective advocacy projects are, and are perceived as, truly independent as well as able to address the full range of members' interests.

Many of the issues which the research has identified confirm what has been known for some time. So the question is: what are the reasons for these still being problems, and what can we do to make progress?

What happens next?

Over the coming year the Scottish Executive will be developing the Code of Guidance which will support the implementation of the Mental Health Act. Organisations which wish to contribute to the development of the Code may want to use the findings from this research, and the wider issues it raises.

Many of these issues will also be taken up by the Advocacy Safeguards Agency in its ongoing work with the people responsible for strategic planning and commissioning around advocacy, and by the Scottish Advocacy Independent Alliance and other groups with an interest in collective advocacy.

The issues will also become part of the work to improve the way all health services involve and reflect the circumstances of all the people who need to use them. In February 2003 the Scottish Executive launched the Health White Paper 'Partnership for Care'. It notes that: "An increasing proportion of NHS patients are older people and the service needs to ensure that it adapts and plans to meet this changing pattern of need. At the same time it needs to ensure that whatever the individual circumstances of people's lives, including age, gender, ethnicity, disability, religion, sexual orientation, mental health, economic or other circumstances, they have access to the right health services for their needs. This is central to our commitment to social justice and the need to bridge the opportunity gap for all."

One of the commitments given is the extension "of the principles set out in *Fair for All* [which seeks to ensure that the needs of ethnic minorities and of refugees are met] across the NHS to ensure that our health services recognise and respond sensitively to the individual needs, background and circumstances of people's lives."

SHS looks forward to continuing to work with the Scottish Executive, the Advocacy Safeguards Agency, the Scottish Independent Advocacy Alliance, the Scottish Development Centre of Mental Health and with the many other groups with an interest in collective advocacy to take forward the issues raised in this report.

Anne Connor
Head of Research and Policy
Scottish Human Services Trust

May 2003

SUMMARY

This report is the result of a research project commissioned by the Scottish Human Services Trust that studies collective advocacy for people who fall within the remit of the new Mental Health (Scotland) Bill.

The purpose of the study was to map existing collective advocacy groups in Scotland for people with mental health problems, those with learning disabilities, people with dementia or acquired brain injury. Also, to describe the issues currently faced by collective advocacy groups and the likely challenges and opportunities presented by the proposed new legislation; and, to identify the steps that might be taken to enable collective advocacy groups to respond effectively to the new Mental Health (Scotland) Bill and other recent legislation.

A framework was developed that enabled information to be gathered on the structure and function of collective advocacy groups. Information was collected on 54 groups across Scotland. The mapping exercise showed that a wide range of different types and sizes of groups undertake collective advocacy and that a wide range of collective advocacy work is undertaken. It also became clear that the term “collective advocacy” is not always used by groups offering a collective advocacy service.

Group interviews were then held with a sample of 16 collective advocacy groups in order to gather further information. A number of barriers to undertaking collective advocacy work were identified that focused on infrastructures and resources, capacity, awareness and attitudes, and links with others. Groups were also asked about supports and resources that they received or would like to receive. Groups also talked about issues around independence, representation and accountability and whether they felt listened to or not.

Two themes; coverage of the full age range of people, and the implications of the new Mental Health (Scotland) Bill for the development of collective advocacy were explored in further detail at two workshops.

The report concludes that it is important to take into account the breadth of collective advocacy functions. Also, that the fragility and vulnerability of much collective advocacy activity and the variable amounts of information and knowledge about legislative developments held by collective advocacy groups suggests that there is need for a considerable building of capacity.

I. BACKGROUND

The Scottish Development Centre for Mental Health (SDC) was commissioned in May 2002 to undertake two research projects on collective advocacy: developing collective advocacy for people who fall within the remit of the new Mental Health (Scotland) Bill; and, developing collective advocacy for people who have long-term contact with health or social care services. This report relates to the first project.

II. RESEARCH OBJECTIVES

The aim of the research was to inform the debate around what should be included in the new Mental Health (Scotland) Bill with regard to collective advocacy and to provide information about the capacity that currently exists to provide collective advocacy for groups who would fall within the remit of the proposed new Act. In addition the research was intended to enable the Advocacy Safeguards Agency to establish good practice in commissioning, developing and supporting collective advocacy groups.

Objectives:

- To map existing collective advocacy groups in Scotland for people with mental health problems, those with learning disabilities, and people with dementia or acquired brain injury
- To describe the issues currently faced by collective advocacy groups and the likely challenges and opportunities presented by the proposed new legislation
- To identify the steps that might be taken to enable collective advocacy groups to respond effectively to the new Mental Health (Scotland) Bill and other recent legislation.

III. METHODOLOGY

The research was undertaken as a series of linked stages.

- Stage One
Mapping existing advocacy provision.
- Stage Two
Perspectives from a cross-section of advocacy groups.
- Stage Three
Common themes and issues.
- Stage Four
Analysis and reporting.
- Stage Five
Feedback and verification.
- Stage Six
Final report.

Fuller details of the methods and approach used in the research are given in later sections of the report.

1. What is collective advocacy?

'Collective advocacy' has been described as 'a self-advocacy group or organisation offering mutual support, skill development and a common call for change' (Scottish Health Advisory Service, 1997), or as when 'people in similar situations come together - with or without external support - to make common cause, draw strength from each other and get their collective voices heard' (Scottish Executive, 2000). Collective advocacy is distinct from individual advocacy in that it seeks to effect change on behalf of and in the interests of a number of people who share common experiences, rather than for an individual.

Often implicit in definitions of collective advocacy are assumptions that the process of pursuing a shared cause engenders a stronger sense of mutuality and support and can combat the sense of isolation and powerlessness often experienced by people who are marginalised and excluded. In mental health, the development of the service user movement where individuals with experience of both mental health problems and of marginalisation have come together to argue for their

voices to be heard and their views respected at local and national level has been a powerful force for change.

It has been suggested that advocacy schemes can 'provide an alternative source of constructive intelligence and feedback about how well services are meeting the needs of the most vulnerable groups, and inform future needs and priorities thus assisting the systems of clinical governance within NHS Trusts, and of best value within local authorities' (Scottish Executive, 2000).

During both the mapping stage of the project and the subsequent group interviews, examples were gathered of the types of collective advocacy undertaken. The aim was, as far as possible, to collect information according to the definitions of collective advocacy used by those who were being interviewed.

Some people had an understanding of collective advocacy that fell in line with the definitions above. However, some people were initially not sure what was meant by the term 'collective advocacy'. And at other times, there was confusion between individual and collective advocacy. Others said that their organisation or group undertook what is known as collective advocacy, but that they would rather use other ways of describing their work, such as 'user involvement'.

2. Methodological challenges

The research was able to map a range of collective advocacy services across Scotland and to engage those involved in these services in discussion on the issues and challenges they face. This generated valuable information about the current practice of collective advocacy and about its possible future development in the light of recent and imminent legislative change.

However in considering the implications of the findings, it is important to bear in mind the limitations of the study. Several methodological challenges concerning both the mapping and group interview stages of the research project can be identified.

As with any mapping exercise, the mapping offers only a snapshot of the picture with regard to collective advocacy in Scotland at a particular time. In order to be meaningful to the development of collective advocacy across Scotland, such a body of information would require regularly to be up-dated.

The timescales of the research posed challenges for the collection of

information at the group interview stage, and many topics and themes had to be covered in the interviews. Difficulties were sometimes encountered in gathering all the information required whilst undertaking the interview at a speed that was comfortable for the people being interviewed.

Interviews were undertaken with groups of people rather than individuals. Undertaking research in this way always poses methodological challenges, particularly when interviewing groups of people who may have different viewpoints, or who are a mixture of service users and staff.

IV. STAGE ONE: MAPPING EXISTING ADVOCACY PROVISION

1. Introduction

A framework for gathering information was developed by the research team with advice from people working in collective advocacy in Scotland. The framework categorises collective advocacy groups according to the following information:

- Name of project/group.
- Contact details.
- 'Client group'.
- Region where based.
- Geographical coverage.
- Organisational status/type.
- Main source(s) of funding.
- Management structure.
- Number of people who are members of or use the project/group.
- Number of staff and volunteers.
- Who the group works with.
- Who the group doesn't work with.
- Other boundaries to work undertaken.
- Remit of the organisation/group.
- Main aim of the organisation/group.
- Collective advocacy - main or peripheral function.
- Examples of collective advocacy work undertaken.

Information on the organisations that could be contacted came from key informants from a variety of different organisations in each of the local areas. The people who provided the mapping information on each group were also asked if they knew of any other groups that undertook collective advocacy work in their area.

The information was gathered pro-actively by telephone. The questionnaire was designed so that the information could be gathered quickly over the phone. Another version was also drawn up that could be sent out to people to fill in themselves if they preferred this.

The mapping information came from a variety of different sources. One person was used as a main contact for each group. Who this person was depended on the contact details passed on by other organisations. The contact person tended to either be the person whose role was to co-ordinate the group, or to facilitate it.

The information was then centralised in a database using the Idealist database package, which allows larger amounts of text to be inputted than many other database packages, as well as allowing the information to be sorted by any category (and by a number of categories at the same time).

2. Groups that have been mapped

54 groups were mapped (see Appendix One). Two services cover people with mental health problems as well as those with a learning disability. Another two services are generic in terms of the 'client groups' that they work with. One group operates for people with mental health problems or dementia. 30 services cover people with mental health problems, 10 are for people with learning disabilities, two are for people with dementia, and seven are for people with a brain injury. Whilst the Bill also covers people who have a personality disorder, there is not presently a group that works with such people.

Some organisations that were mapped had collective advocacy groups that operated at different levels. For example, Enable had groups that operated at a local level that also fed into a national group. Detailed information was not gathered for each of these local groups. It should also be noted that inclusion in the mapping exercise does not imply that organisations are independent.

We recognise that there will be other groups whom we did not identify, as well as the groups which we contacted and which did not want to be included, because their members felt that they were not a collective advocacy group. Indeed, the findings in this report reflect the ways in which the groups interviewed have described themselves. On some other people might have used a different description.

3. What the mapping shows

3.1 Geographical base

Table 1 shows the geographical spread across Scotland of the projects mapped.

The majority of groups operate at a local rather than NHS Board level. Many of the groups operate within areas that reflect local authority boundaries. Some groups operate across more than one local authority area.

Table 1 Geographical base

Area	Number of groups
Argyll and Clyde	4
Ayrshire	4
Borders	1
Dumfries and Galloway	2
Fife	3
Forth Valley	7
Greater Glasgow	4
Grampian	5
Highland	1
Lanarkshire	2
Lothian	10
Orkney	0
Shetland	1
Tayside	3
Western Isles	1
National	6
Total	54

3.2 Organisational status/type

Table 2 shows that the groups mapped have a variety of different organisational set-ups. People who were contacted for information were given three options (plus the option of 'other'). Groups have been divided into three broad categories: those which are independent stand-alone groups or organisations; those which are stand alone groups, but which receive external support from another agency; and, groups that are operated in-house by another agency. One group used the 'other' category and described themselves as 'national'.

The majority of groups described themselves as 'independent'. Some groups were supported by another organisation through the provision of office resources or staff support. Other groups saw themselves as

operating within another agency. This agency was sometimes a service provider organisation and at other times, another advocacy project. Some groups were supported by, or operated within, another agency but had aspirations to become independent.

Table 2 Organisational status/type

	Independent	Supported by another agency	Operated inhouse by another agency	Other	Total
Mental health	15	10	5	0	30
Mental health/learning disability	1	0	1	0	2
Mental health/dementia	1	0	0	0	1
Learning disability	4	4	1	1	10
Brain injury	6	0	1	0	7
Dementia	0	0	2	0	2
Generic	1	1	0	0	2
Total	28	15	10	1	54

3.3 Main source(s) of funding

The people contacted for information in the mapping process were asked for information on the main sources of funding for the group concerned. Sources of funding were diverse. Many groups received funding from several sources. Some groups received no funding.

This suggests that the responsibility for financially supporting collective advocacy capacity in local areas is shared among a number of players. The data also indicate that only one in five of the projects mapped was supported by joint (health and social work) statutory funding and that one in five projects do not currently have funding to support their activity.

Reliance on service provider organisations for funding raises issues in relation to the independence of collective advocacy and the potential conflict of interest where the collective advocacy project may be representing the interests of its users / members and in doing so posing challenges to the organisation on which it relies for financial support.

Table 3 Main source(s) of funding

	Joint Statutory	NHS Board	NHS Trust	Local authority	Through service provider organisation	Statutory plus other	Statutory plus Scottish Executive	Scottish Executive	Mental illness Specific Grant	Charitable	None	Total
Mental health	5	3	3	0	2	2	1	1	3	4	66	30
Mental health/ learning disability	2	0	0	0	0	0	0	0	0	0	0	2
Mental health/ dementia	0	1	0	0	0	0	0	0	0	0	0	1
Learning disability	0	0	0	1	2	1	1	0	0	3	2	10
Brain injury	2	0	0	0	0	3	0	0	0	0	2	7
Dementia	0	0	0	1	0	0	0	0	0	1	0	2
Generic	0	0	0	0	1	0	0	0	0	1	0	2
Total	9	4	3	2	5	6	2	1	3	9	10	54

3.4 Management structure

The mapping sought to gauge the capacity of collective advocacy groups in providing a voice for the key groups affected by the proposed new mental health legislation. The management structure of the groups being mapped was included as a question on the mapping framework after several groups had already been mapped. Information is therefore not available for all groups. However, what is apparent from the information available is that collective advocacy provision appears to rely heavily on management committees made up of service users. This could have implications for the well being of those involved and for the sustainability of activity.

Table 4 Management structure

	Management committee all service users	Management committee all service users and carers	Management committee all service users and others	Various	None	No information	Total
Mental health	13	1	3	0	2	11	30
Mental health/ learning disability	0	0	0	0	0	2	2
Mental health/ dementia	0	1	0	0	0	0	1
Learning disability	1	0	0	1	0	8	10
Brain injury	1	1	0	0	0	5	7
Dementia	0	0	0	0	0	2	2
Generic	0	0	1	0	1	0	2
Total	15	3	4	1	3	28	54

3.5 Number of people who are members of or use the group/ organisation

Some groups had both a mailing list membership, plus a smaller, active group of members. If both were specified, the mailing list membership has been given in table five below.

Groups were a variety of different sizes. Some memberships were limited to service users and carers. Other groups had membership lists that were open to a wider range of people.

Membership also varied according to the type of organisation.

The mapping indicates that over half of the groups mapped have no more than a hundred members and one in three groups has a membership of no more than thirty. This is important in giving an indication of the relative fragility of some of the groups identified. It provides a picture of a mosaic of local groups involving relatively small numbers of people coming together on common issues.

Table 5 Number of people who are members of/use the group

	No fixed	1-10	11-20	21-30	31-40	51-100	101-200	201-300	501-600	901-1000	1001-2000	Total
Mental health	3	3	3	2	4	3	7	2	1	1	1	30
Mental health/ learning disability	0	0	0	0	0	0	2	0	0	0	0	2
Mental health/ dementia	0	0	0	0	0	1	0	0	0	0	0	1
Learning disability	0	2	4	0	0	2	0	0	0	1	1	10
Brain injury	0	0	2	0	2	1	1	0	1	0	0	7
Dementia	0	0	1	0	0	0	0	0	0	0	1	2
Generic	0	1	0	1	0	0	0	0	0	0	0	2
Total	3	6	10	3	6	7	10	2	2	2	3	54

3.6 Staffing and volunteers

Patterns of staffing were diverse, and reflected the organisational status of the group. Groups that were supported by another agency or operated in-house by an agency tended to have a small number of staff from the supporting or 'parent' agency attached to them. This arrangement was primarily on a part-time basis, with workers supporting groups as part of their remit. Groups that described themselves as 'independent' tended either to have no staff or to employ a small number of workers, often on a part-time basis. These workers were usually either development workers and/or admin workers.

In terms of the use of volunteers, experience was, again, diverse. Some groups relied on volunteers as an alternative to paid staff. Other groups employed staff or had workers attached to them (as part of the worker's remit), but also used volunteers. Some groups preferred to describe people who worked for the group on an un-paid basis as 'active members' rather than 'volunteers'.

3.7 Who the groups do and don't work with

Contacts were asked which people the group that they were giving information on did and didn't work with. The majority of groups only

worked with people who were aged between 16 (or 18) and 65, and didn't include children, young people or people over 65 in their work. The majority of groups worked with broadly defined groups of people, for example, people with mental health problems, or people with a learning disability. A few groups only worked with people who used particular services (such as tenants of a particular housing association), or who had particular experiences, such as hearing voices.

3.8 Is collective advocacy a core or peripheral function?

People were asked if collective advocacy was a core or peripheral function. The majority of groups said that collective advocacy was a core function. A few said that it was either peripheral, or a part of what they did.

Table 6 Is collective advocacy a core or peripheral function?

	Core	Peripheral	Total
Mental health	26	4	30
Mental health/Learning disability	2	0	2
Mental health/dementia	1	0	1
Learning disability	9	1	10
Brain injury	5	2	7
Dementia	1	1	2
Generic	2	0	2
Total	46	8	54

3.9 Remit and aims of the organisation/group

Groups undertook a range of activities and this was reflected in both the remit and aims of the groups. The remit and aims of a group were often similar, and when asked to list the aims of the group, many people referred to the remit that had just been noted. The majority of groups listed a remit and aims that were exclusive to collective advocacy work.

Groups for people with mental health problems

A variety of functions were included within the remit of mental health groups, including:

- User input into how mental health services are developed locally.
- To give users of psychiatric services a voice.

- To assist people in speaking up for themselves.
- To act as an avenue for consultation and involvement in policy and legislation.
- To progress mental health issues in the area.
- To improve local services.
- Lobbying/campaigning.
- To disseminate information.
- Challenging stigma.
- To support and promote all forms of advocacy for mental health service users.

The four mental health groups for which collective advocacy was not a core function listed slightly different remits and aims:

- To provide a social life to members to re-empower them back into society.
- To access funding to undertake activities within the project.
- To provide social activities to people who have experienced mental health problems.
- The provision of support to each other, sharing experiences, coping strategies and giving each other friendship.

Groups working with people with mental health problems plus others

Of the two groups that worked with people with mental health problems as well as people with learning disabilities, one of the project listed aims that were exclusive to collective advocacy work. The other group also listed aims that were relevant to advocacy for individuals.

The group that worked with people with mental health problems and dementia stated that its aim was the improvement of local mental health services, and that its remit was supporting people to be involved in the planning, development, monitoring and evaluation of mental health services.

Groups for people with learning disabilities

Remits of the groups for people with learning disabilities included:

- Organising a structure that will allow people with learning disabilities to have a voice and be heard.

- To monitor services and standards.
- For people to have control over their own services.
- To advise [the service provider] on issues that affect people with learning disabilities.
- To promote the views of people with learning disabilities.
- Self-advocacy and equality for people with learning disabilities.
- Campaigning for people's rights and changes in legislation.

The group for people with learning disabilities that had noted collective advocacy as a peripheral function, listed their remit as:

- Networking, consultation and socialising.

Groups for people with a brain injury

Remits of the groups for people with brain injury included:

- To promote understanding of all aspects of head injury.
- To provide information, support and services to people with a brain injury, their families and carers.
- To give service users a forum to discuss services and to give feedback on service developments.
- To make it possible for carers to meet together to share experiences.

The groups for people with brain injuries that noted collective advocacy as a peripheral function, gave the following aims:

- To help and support families to take control over their own lives in the community.
- To provide information, advice and support to people with brain injury, their families and carers.

Groups for people with dementia

The two groups for people with dementia had different remits, according to whether collective advocacy was a core function or not.

- Collective advocacy as a core function - to allow people with dementia to have more say within [the provider organisation].

- Collective advocacy as a peripheral function - to discuss feelings and experiences concerning dementia, to influence policy on technology and provide emotional and social support.

Groups that work generically

The two groups which work with a variety of different 'client groups' had different aims and remits due primarily to their different organisational status (independent and supported in-house).

The aims of the independent group were to see uniformity of services throughout the local area, as well as more openness locally in informing the public about services that are available. The remit of the in-house group was to represent all people who use services provided by the service provider, and to inform the service provider about their opinions and changes that they would like to see in the organisation. Their aims were to give ideas and opinions on standards and policies; attend conferences and workshops to listen to others; and, to give views on services that support people who have disabilities.

3.10 Collective advocacy work undertaken

The groups undertook a range of collective advocacy work.

In terms of work that was based locally, many groups were involved in local consultation exercises. Many groups were also involved with local planning groups, with representatives from groups attending local planning meetings. Groups also met with local practitioners and policy makers on a more one-to-one basis, such as meeting with the General Manager of the local hospital. Pro-active work such as campaigning for specific changes in services was also undertaken.

Some groups had a membership all of whom use the services of one agency, such as a voluntary organisation providing housing and/or support. Although some of these groups also undertook collective advocacy work at other levels, they focused their work on links with the service provider.

Involvement was sometimes on a national level. Groups took part in a variety of different types of national work:

- Involvement in forums that were concerned with policy formulation.
- Involvement with national campaigning initiatives, such as national anti-stigma campaigns.
- Involvement in national consultation exercises.

Other types of work were mentioned, such as attending and speaking at conferences, and involvement in staff training. Some groups also undertook various types of awareness raising, such as work with young people and children around the prevention of bullying (regarding people with learning disabilities).

The collective advocacy work that groups undertook related predominantly to health and social services. However, groups also undertook collective advocacy work around other issues such as community safety and public transport.

V. STAGE TWO: PERSPECTIVES FROM A CROSS-SECTION OF ADVOCACY GROUPS

1. Introduction

The aim of Phase Two was to identify a sample of different types of collective advocacy projects working with a range of client groups and in different parts of Scotland for more in-depth discussion and investigation.

The aim was to undertake group discussions with 15-20 projects across Scotland. Groups were selected so as to achieve an extensive coverage in terms of 'client group' and geographical area, as well as in terms of other categories mapped, such as organisational status and size. Interviews were eventually secured with sixteen groups (see Appendix Three).

The interview schedule was designed with advice from people working in collective advocacy on the key themes that could be explored. It was also designed with input from the research project team. The aim of the schedule was to cover the main issues identified, whilst allowing the interviewers to word questions appropriately.

Interviews were held with anything from one to eight people. The diverse nature of the discussions reflected the range of different types of group that took part in the research. Interviews were held with different combinations of:

- service users who were active but unpaid members of a group
- people who were service users as well as being paid workers with a group
- people who were employed to support a group, but whose use (or non-use) of services was not a defining feature of their job.

Of the groups interviewed, six were for people with mental health problems, four were for people with learning disabilities, two for people with learning disabilities and/or physical disabilities, three for people with brain injury, and one for people with dementia.

Some of the groups were stand-alone organisations with members from a particular geographical area, others were less formal groups that were for people who used services provided by a particular organisation (and these were all organisations that operated nationally).

The groups that were interviewed were based in nine of the NHS board areas in Scotland, or were groups that operated nationally.

The groups interviewed undertook a range of different functions – some related to collective advocacy, some not. Most of the groups had been set up specifically in order to undertake what they saw as ‘collective advocacy’; collective advocacy was their main purpose. Other groups, which tended to be those for people with a head injury or dementia, undertook collective advocacy as peripheral to their other functions, which were, for example, to provide people with the opportunity for mutual support, or to provide information and advice. These groups also undertook some work that could be seen as ‘collective advocacy’, but tended to have less awareness of the concept.

2. Barriers to undertaking collective advocacy

People were asked about the barriers that they faced when undertaking collective advocacy work. Responses fell into four main categories: resources and infrastructure; capacity; awareness and attitudes; and links with others.

2.1 Resources and infrastructures

Resources

Some groups mentioned a lack of resources as something that hindered them. A variety of resources were mentioned, including photocopiers, computers, access to e-mail and the internet, and funding for travel expenses (particularly for attending conferences). One group that operated within a service provider organisation mentioned that they would like funding for a newsletter in order to communicate with people within the service provider organisation about the role and activities of the group.

Funding

Issues around funding were mentioned by several groups. Issues were wide-ranging.

Inadequate funding was an issue. One group pointed out that only two of their workers were paid. Other people within the organisation undertook unpaid work that the group thought should be funded.

The amount of time spent searching for funding was also raised. Some groups preferred to seek non-statutory funding in order to remain independent, and this was a time-consuming process. The length of

time that funding is awarded for was also seen as an issue. After a lot of campaigning, one group that had been threatened with closure managed to obtain funding for three years; something that they hadn't received before. They felt that they only eventually received continued long-term funding because the NHS Board realised that local statutory services would not be in a position to provide alternative services if the organisation folded.

One group found that funding was not easy to obtain because funders were nervous about the fact that their management committee consisted entirely of people with learning disabilities (including the office-bearers such as the Treasurer).

One organisation pointed out that funding is often restricted to new projects rather than for core parts of an organisation. They said that it could be difficult maintaining the core of the organisation, and that living a 'hand to mouth existence' restricted forward planning. One group said that they found it difficult obtaining funding for the types of support that they required in order to undertake collective advocacy. They felt that trust funds and charities didn't want to provide core funding for such support. They were considering seeking local authority funding but were doing this reluctantly due to the restrictive conditions that would be attached to the grant. Another group also found that once funding for a specific project ended the organisation then had to either withdraw the service or draw on its own reserves, which impacted on the range of services that they could provide. They thought that funding that came directly from the Scottish Executive would be preferable to funding via a local authority, so that it didn't get 'lost in the pot'.

Some of the difficulties with funding mentioned above seemed to primarily due to the status of groups and organisations (as voluntary organisations) rather than due to the fact that they undertook collective advocacy.

However, it was also the case that some people felt that collective advocacy was something that was difficult to explain, and that funders sometimes struggled to understand. It was thought that individual advocacy was more readily understood and therefore easier to obtain funding for.

Space

Some groups mentioned a lack of office space as a barrier to undertaking collective advocacy work. This was particularly the case for

ensuring that meetings such as the management committee meetings could take place, as well as for general comfort for staff and volunteers. People from one national organisation that operated with local groups pointed out that some of their local groups had no funds for office or meeting space and that they relied on being able to obtain the use of local premises for meetings.

2.2 Capacity

Getting people involved

Several groups found that it was difficult getting people involved in collective advocacy work. Service users either came along to meetings and didn't say anything, or didn't get involved at all. The majority of the work that had to be undertaken in order to keep the group running and effective often fell to a few people. (And, as mentioned above, some groups highlighted the fact that this could then cause an undue amount of pressure and stress for the few people who were active within the organisation.) One group mentioned the vicious circle whereby it could be difficult getting others involved in collective advocacy work if external agencies got to know of a few individuals from the group and continued to liaise with them and invite them to meeting and events rather than anyone else from the group.

One group felt that many people needed quite a lot of encouragement to become involved, and that individual carers were in a good position to provide that encouragement. Another group thought that helping people become confident enough to be involved posed a challenge. Others felt that the culture of institutionalisation in mental health services in particular was a barrier to involvement. Long stay patients can become used to being directed by the 'system' and freeing people from this can be difficult. Both service users and staff can therefore lack impetus. One group felt that a lot more was needed to be done to encourage service users to become involved, for example, developing self-esteem and the skills for people to do things themselves.

Workload

The groups that were interviewed were asked about their workload and if it caused them difficulties. Some groups felt that this was not an issue. Others felt that issues around workload caused them difficulties.

One group felt that the more they were asked to do, the more work was generated for the group development worker. They asked at what point do you say 'No more!', bearing in mind that to stop taking on additional work may be to the detriment of others. They also identified

a tension between spending sufficient time with service users as well as in communication with service planners and providers.

Another group pointed out that the people who were actively involved with the group (as voluntary management committee members) were already active citizens in other ways, and that this caused difficulties for the group in trying to get everything done.

Workloads were also seen as a problem for another group in that a heavy workload was being shouldered by a few people. The group was concerned that if this continued, then people may become ill, which would jeopardise the future of the group.

Working to other people's agendas and deadlines caused difficulties for the management of workloads. One group pointed out that they have a plan on what they want to achieve during the year. But then a policy announcement is made which makes them angry, and to which they want to respond. Other work commitments then have to be put aside. Another group thought that working to other people's agendas and deadlines could be stressful. They coped with this by trying to make their meetings stress-free and fun - lots of breaks, sharing workloads, and agreeing more workable timetables.

Lack of support

Some groups had staff vacancies that caused them difficulties and a loss of momentum when undertaking their work. For one group, a staff vacancy meant that they couldn't meet when the current support worker was on holiday. Another group (which operated within a service provider organisation) found that the lack of a staff representative meant that there were difficulties in linking users and services. One mental health group felt that the number of paid workers in their office could be increased, rather than relying so much on voluntary workers. One national group felt that their local groups sometimes struggled to have the presence locally that they would like to have due to their lack of paid workers.

One mental health group in particular which had one development worker and no administrative support, felt strongly that they ought to have two development workers as well as have someone paid to provide administrative support. The feeling was that there should be at least two staff members (or at least a contingency plan and finance) so that the group could continue to function if a worker became ill or was on annual leave. The worry was that if someone went on sick-

leave, then a lot of good work would be wasted, and the group may not get off the ground again. It was also pointed out that if you are the sole worker in an organisation, you have more responsibility with less support and that it would also be good to have two workers in order to provide support to each other if things are not going so well. Further, a better service would be provided if a worker could be available at the office whilst the other worker was out at, for example, a meeting. The aim would be to encourage people to become more involved through being around to speak to them, and to not expect people to always leave a message on the group's answer-phone.

Another mental health group had a different experience in that the group had no paid workers, and voluntary management committee members undertook the bulk of the work. Workload fell on a few people, creating pressure for those who were involved. People then became ill and business was left undone which then caused more pressure. The group was trying to get more people actively involved in order to spread responsibilities.

Another group felt that it was very difficult for people on the management committee to stay well - many had to take time off due to illness. They thought that as a group they need to look at how they build in strengths to the group in order to be able to continue to cope when particular people are ill.

One group thought that a lack of local support from other organisations undertaking similar work was the issue that affected them most when trying to undertake collective advocacy. A lack of collaboration between local organisations and an unwillingness to work together caused difficulties. They felt that if local organisations were able to work together, then there would be a tremendous amount of collective support. It was felt that the situation was not helped by the fact that local organisations were all fighting for funding. Another group agreed, and suggested that local organisations were all building empires rather than working together, and that this way of working meant that it was difficult for the group to get their voice heard.

2.3 Awareness and attitudes

Lack of understanding about the role of collective advocacy

Not only did a lack of understanding about the role of collective advocacy cause difficulties when seeking funding, but another group also felt that some staff within the statutory agencies with which they worked thought that collective advocacy was about complaining rather

than about people working together. The group saw themselves acting as a forum for people to voice concerns, and did not think that they were about complaining and trying to make people's lives difficult.

Stigma and attitudes

Difficulties in obtaining funding due to the attitudes of people towards learning disability have already been mentioned. Groups also thought that public attitudes towards issues such as learning disability, brain injury or dementia caused a barrier when trying to undertake their work. 'A barrier to work in general is the general public's lack of knowledge of the condition and surrounding issues.' 'Stigma is a difficulty. People back away from dementia – can be frightened of it.'

The attitudes of professionals towards collective advocacy also caused problems. One group pointed out that the fact that the local psychiatrist did not recognise the need for collective advocacy was possibly to do with a lack of understanding about what collective advocacy is. Although there were local meetings at a strategic level that they were able to attend, it meant that they didn't have access to other forums at a practice level that they felt were also important.

Another group thought that some of the workers within the service provider organisation within which they were based saw user involvement as an add-on. The communication problems that this caused created a lot of extra work for them.

2.4 Links Communication

Issues to do with communication were thought to be a barrier to undertaking collective advocacy work. One group felt that their lack of knowledge of, and communication with, other groups similar to themselves was a barrier. Another group felt that a lack of knowledge (for example, about other channels of communication such as the avenues they could pursue for help and support) caused them difficulties. As lay people they felt they were unaware of the routes to NHS Boards and Scottish Executive. They also thought that voluntary organisations were not seen as 'professionals' and that this created barriers in terms of communicating with housing or social work.

Others felt that language could sometimes be a barrier. Professionals used terms and acronyms in meetings that were not always understood.

Another group also experienced a lack of the practical means by which to communicate. They had no computer, and therefore no internet access, and so were unable to send or receive e-mails. Although a local mental health service provided them with administrative support, it could sometimes take a while for their letters to be typed. They found the slow process of letter writing a real barrier to communication.

Geography

Several groups mentioned geography as a barrier to undertaking collective advocacy work. This affected groups that operated within national service providers, but also some groups that operated only within particular NHS Board areas.

The distances that people had to travel caused problems with people attending meetings; with encouraging members living in isolated areas to raise issues; with recruitment; and with the prohibitive expense of travelling. One group found the distances between where each committee member lived to be a challenge and felt that it would help if they could all be linked by e-mail. Another group found that it was very difficult for people to get to local meetings by public transport, and that they had to rely on volunteers to drive them to meetings. They felt that if they did not have these volunteers then it would be very difficult to meet. They were also aware that the local volunteers who helped them with transport were busy people who also undertook other voluntary work within their organisation.

One group also pointed out that a lack of proximity to the local Trust headquarters posed problems. They felt that telephone contact was not the same as face-to-face contact and that it is more difficult to get to know people if you are not based on the same site, or in the same building.

3. Supports and resources

Groups were also asked about the support and resources that they received and would like to receive. The support and resources that people found useful were various, and were provided through a variety of different ways.

3.1 Workers

Some groups had workers (paid or voluntary) attached to them who undertook a variety of functions – undertaking administrative work; helping a group to co-ordinate their activities; helping with meetings

and agendas; accessing training; and helping people to come along to and take part in meetings. Some of the groups employed the workers themselves, others had workers provided by their service provider organisation. The meetings that people received help in attending were various – the meetings of the groups themselves; meetings with local service providers; local planning groups and national policy groups. For example, members of one group for people with learning disabilities were heavily involved in national groups and committees concerned with the formulation of policy. Volunteer workers helped them by talking through the issues on the agenda with them beforehand, helping them get to the meeting, and then also attended the meetings with them. One person was also a co-chair of one of the national committees, and his worker helped him formulate agendas for the committee. The group agreed that if they didn't have such support, then they would be unable to be involved with national policy formulation in this way.

Some groups had workers (either paid or volunteer) who, as service users themselves, undertook a more developmental role, receiving support for administrative work from other organisations. One group that operated within a service provider organisation didn't have any staff attached to it, but mentioned staff as a support in that the people who worked in the organisation were supportive when the service user group asked for changes to be made.

3.2 Other key people

One mental health group felt that the local Primary Care NHS Trust had been very supportive. They met regularly with the local Commissioning Manager and General Manager and found that their attitudes towards collective advocacy were helpful. They also described their management committee as the 'backbone' of the organisation. And pointed out that being involved with the management of a group is a big responsibility for volunteers and that they are often not recognised for their work.

Another group suggested that locally there are one or two key motivated individuals, both staff and users, who are very supportive. They suggested that these people should be supported in trying to 'change the culture'. On similar lines, another group (that operated within a provider organisation) felt that the fact that some of the staff took an active interest in their activities was important. They also received positive feedback from the director of the organisation, and felt that this was also important.

Some groups mentioned the role that group members themselves could play in supporting each other. One group thought that encouraging each other really helps: another thought that the group members were really good at working in a team and supporting each other, particularly in a crisis situation.

3.3 Resources

Support also came in the form of resources provided either by a parent organisation (if for example, the group operated within a particular service provider), or from other sources.

Resources could come from, for example, the local Primary Care NHS Trust, other statutory agencies or local voluntary organisations. One mental health group received support from the local community mental health team: transport to meetings; support in letter writing and filling in forms; and accessing information. They also had the use of a meeting room, office space and access to a photocopier, fridge, storeroom, and TV and video system. Others managed to obtain resources (such as premises) through other routes (such as charitable funding), and as gifts. One group pointed out that access to adequate resources (in their case, the means by which to communicate: e-mail, their own letterhead and business cards) made them feel a lot more professional.

3.4 Training

Training was another resource that people spoke about. Some groups spoke about training from the point of view of what they had found useful in the past, but also from the point of view of what they would like to access in the future.

In particular, people mentioned training courses that enable people to enhance their skills in conducting and participating in meetings – training in the basics of ‘speaking out’, the language of meetings, chairing, minute taking, agenda setting and group-work in general. One group had also provided management committee members with training on leadership and authority in group settings.

Training in interview techniques for user involvement in the selection of staff was also seen as useful, as well as computer and IT skills. Training in stress management skills was something that one group said that they needed.

4. Independence

Most of the groups saw themselves as independent. The source of funding seemed to be the key to whether people felt independent or not. For example, one group for people with learning disabilities (a stand-alone organisation), said that it was important that they kept a broad spectrum of funders so that they weren't accountable to only one funder. They said that funders sometimes hinted to them 'remember whose funding you've got' but the group tried not to let it affect what they did. The control over the work of the organisation by funders was an experience that was shared by a mental health group. They saw themselves as independent, but they also felt answerable to the agencies that funded them.

Another group (that operated within a service provider organisation) described themselves as semi-independent because of the in-house status of the majority of their funding. They felt, however, that this way of working presented them with no challenges: 'We make quite a lot of our own decisions, and we stick to our guns'. The group preferred this rather than the challenge that they would be faced if they had to search for independent funding.

A mental health group that was not tied to a particular organisation felt that their independent status was due to the fact that they didn't have allegiances to any service provider or umbrella group. The group received funding from the local Primary Care NHS Trust, but they didn't feel that this affected their ability to undertake local collective advocacy work. They saw their role as working together with the Trust, rather than in opposition to it, and they felt able to voice concerns and work to their own agenda, as well as to that of the Trust. Another group that did receive support from an umbrella organisation didn't feel that this relationship compromised their ability to act independently. Again, another group who received various different types of support from an umbrella organisation, and which also had a service agreement with the local authority, didn't feel that this affected their ability to be independent in that they successfully worked to their own agenda.

One group didn't see themselves as independent, but wanted to be in the future. Project staff were currently employed by the local Primary Care NHS Trust, and the group run by an interim management committee. The group was aiming to develop the management committee so that in the future they could become fully independent.

5. Representation and accountability

Groups were asked about issues around representation – whose views they represented and how. Thoughts tended to be on the issue of whether you spoke at meetings (with, for example, service providers) about your own experiences, or whether you also tried to put across the experiences and viewpoints of others. One person suggested that when undertaking collective advocacy work you always have to ask yourself the question; ‘am I being invited to the meeting as myself, or as my ‘group self’?’ Another group acknowledged that it could be very difficult remembering that you are sometimes speaking on behalf of other people as well as yourself.

Some people felt that they were only able to give their own, individual, point of view. People involved with one group suggested that this was sometimes the only practical way of working. However, they also felt that a group member who was on the local hospital re-provisioning group was able to put across a wider range of viewpoints because the issues were talked about so much at group meetings. Two people who played a major role in running another group agreed that they could only represent their own point of view. They hoped, however, that by doing so, this still helped others. They also thought that it was important to acknowledge that different people do in fact have different views and different solutions.

Other people said that they tried to obtain the views of others so that they could then represent those views at meetings. One group had discussions and took votes on issues, so that it could be known if a point of view was one that belonged to the group, or whether it was the opinion of an individual. Another group wanted to ensure that the issues being campaigned on were what a majority of service users want. They felt that this would give their arguments greater weight.

Another group also tried to take the views of people on board and state them at meetings. They suggested that representing people can be challenging if you have not had shared experiences. The group therefore said they do not send people to meetings on the group’s behalf if they feel that the person is lacking in insight, and therefore only able to speak from their own point of view.

It was acknowledged by one mental health group that obtaining the viewpoints of different people is sometimes difficult, and at the best, you can only represent the views of people that you know. However, they felt that there are common threads and issues that can be identified that all service users identify with, and these wider issues can be represented at meetings.

6. Do they feel listened to?

When asked if they felt that they were listened to, groups came up with a variety of answers.

Some groups were satisfied with the extent to which people were willing to listen to them. One group raised issues that were of concern to them at all levels, and felt that they had managed to get issues such as user involvement on to agendas. One person suggested that trying to have your voice heard by other organisations took commitment, but that the effort was worthwhile.

Other people said that they felt listened to, but with qualifications. For example, they thought that other people wanted to hear their voice, but hear it on their terms, not on terms set by the group. One group for people with learning disabilities found that people wanted to hear what they had to say about care services, but weren't interested in hearing their point of view on transport. They also felt that Direct Payments was an important issue and had to raise this again and again. Another organisation found that items that they wanted talked about were placed on agendas and that it was possible to raise issues. However, they also spent a lot of time being involved with consultation exercises where they felt that decisions had already been made. A mental health group felt that it was easy for people to feel flattered by being invited to be part of a working group, but that they had to remember that they often had little control over the agenda.

Some groups felt that they were listened to by some people or organisations, but not by others. One group suggested that 'once someone's door was shut', it would be very difficult to make the person listen to them. They instead concentrated their effort on people who were willing to listen.

7. Links with others

Groups were asked about their links with other similar collective advocacy groups.

Some groups had links with other groups and felt that this was useful. One group felt stronger as a result, and found the exchange of information particularly useful. Other groups suggested that links with others helped them because they were able to learn from each other's experiences and mistakes.

One group did have links with others, but these links were often by telephone only, due to reasons of geography.

One group had no links with other groups or organisations and felt that it would be useful to visit other places to learn from the experiences of others. Another group agreed with this, and thought that it would be good to be part of a bigger voice on major issues such as stigma, and to be united with other groups across Scotland in campaigning on such issues. They also felt that it would be good to develop local links in order to work around local issues such as ward closures and cuts in services as well.

Another group had links with local organisations that they felt were not very helpful and that local groups could benefit from providing each other more support.

People mentioned links with other organisations, such as umbrella groups, the local Primary Care NHS trust and local authority, and suggested that these were equally important in terms of information sharing and advice.

8. Legislation

8.1 The Mental Health Bill

Some groups knew a lot about the Mental Health Bill, and were concerned that collective advocacy was seen as less important than individual advocacy, and that it may be under-represented or lost in any future Act. One person commented that they thought that the issue of user involvement had not been properly thought through. People also felt that advocacy (both individual and collective) should be properly funded.

Some mental health groups were not happy with compulsory treatment and felt that it will affect the work that they do. One group for people with a brain injury also felt that there were issues around treatment without permission and wondered how this would affect their clients (especially if they don't see themselves as having a problem). The group felt that there was a 'fine line' between mental health and brain injury.

One group was concerned that the legislation would increase people's awareness of advocacy (both individual and collective) and that there will be an unmanageable increase in demand when people become aware of what they are entitled to.

8.2 Adults with Incapacity

Other groups felt that the Adults with Incapacity Act was more relevant to their work, and that the Act was very complex and difficult for people to understand.

8.3 Human Rights legislation

One mental health group also mentioned Human Rights legislation, and thought that a users' guide to legislation would be useful so that people could find out how they might be affected by the new laws.

9. Achievements

The groups that were interviewed gave information on a variety of achievements. These examples give an illustration of the variety of collective advocacy work that is undertaken. Examples have been grouped into four categories: awareness raising and education; informing users of their rights and entitlements; staff recruitment and training; and service development.

Awareness raising and education

A group member gave a talk to carers (professional and informal) about, amongst other things, the problems of isolation for people with dementia who live alone.

We wrote up and distributed 'The Path' – a paper that described service users' dreams and how they could be realised.

We have raised awareness of advocacy by producing a video.

We have produced a video on bullying and have delivered workshops to children and young people to raise awareness of bullying.

Informing users of their rights and entitlements

We have provided information to service users on the procedure for Disability Living Allowance.

We have successfully requested internet access.

We have raised users' awareness of the welfare benefits that they could be applying for.

Staff recruitment and training

The group produced an induction pack for new staff in all departments of the organisation.

Group members will be interviewing staff for posts.

Members are involved with staff induction.

Members have been asked to sit on recruitment panels.

We are working with transport companies to improve staff training.

Service development

We are now being invited along to write consultation documents about the planning of services, instead of just being asked to comment on documents.

We developed a card for people with dementia to carry around that would enable them to seek help in difficult situations.

The group produced a questionnaire that asked users about the quality of the service and then helped to bring the ideas of service users to senior management.

We have two service users on the management committee of the organisation.

The organisation now employs a service user to develop in-house user-focused monitoring of services.

We undertook a survey of the views of patients and ex-patients that led to a change in the service.

We have influenced the design of the new local hospital.

The group is working with transport companies to improve the services given to people with learning disabilities.

VI. STAGE THREE: COMMON THEMES AND ISSUES

1. Introduction

The research included two themed workshops, to which were invited the collective advocacy groups identified in the early stages of the research, along with key people with an interest in the relevant theme. Taking account of the findings of the mapping exercise and the discussions with collective advocacy groups, two main themes were highlighted for further exploration in the workshops:

- Firstly, coverage of the full age range of people who fall within the remit of the new Mental Health Bill.
- Secondly, the implications of this legislation for the development of collective advocacy.

The first workshop was held in Glasgow and was attended by six people – one commissioner of services, and five people involved in a variety of ways with the running or support of collective advocacy groups. The discussion considered the extent to which current provision is geared to respond to the full age range of people covered by the Bill and what it would take to ensure that.

The second workshop was held in Perth and was attended by eight people – two commissioners of services, five people involved in a variety of ways with the running or support of collective advocacy groups, and one person from the Advocacy Safeguards Agency. The discussion considered the implications of the new Mental Health Bill for the development of collective advocacy.

2. The full age range of people covered by the Bill

2.1 Gaps

Various gaps in current provision were noted.

- There is little in the way of collective advocacy for younger people or people over 65 (for the groups of people who are affected by the Mental Health (Scotland) Bill).
- Individual advocacy for younger people or people over 65 is poorly developed.
- It is only just being realised that it is sometimes better to have an individual to help a young person speak up rather than the family doing this.

- Older people (for example, those who are living in residential care) are often without the safeguard of individual advocacy - someone there to help them speak out.
- Work needs to be done around involving people in different ways and in providing individual advocacy as well as tackling the gaps in collective advocacy.

2.2 Barriers

People at each end of the age spectrum are often not involved in influencing their own care:

- No-one talks to older people.
- For younger people with disabilities, it is often the family who has the voice rather than the young person themselves.

Many younger and older people are not used to speaking up for themselves, or being asked their opinion – they are often very disempowered. In addition, the way in which people use services can affect their ability to get together. For example, young people who use occasional respite services have little contact with each other or the service that they use.

A lack of information was another barrier to the involvement of younger and older people that was identified by those who attended the workshop. People often do not get involved because of a basic lack of information – there needs to be greater information sharing, and provision of information to individuals by service providers.

The tight timescales that, for example, the Scottish Executive and NHS Boards ask people to meet do not encourage the involvement of younger and older people. The involvement of people takes time, particularly if people have not been used to being involved.

Sometimes younger people and older people can be excluded by default from individual and collective advocacy initiatives because the initiatives are targeted at people who use particular services which younger or older people either do not use or do not have access to.

2.3 Capacity

Discussions at the workshop identified several issues around capacity that hindered the provision of collective advocacy, particularly for older and younger people.

- Not all workers who facilitate collective advocacy or who undertake one-to-one work have the skills and knowledge to work with the issues that particular people face (such as older people and issues around guardianship).
- For younger people, there may be 'mainstream' groups undertaking collective advocacy work, but it is not known to what extent these groups include people with mental health problems or learning disabilities.
- It needs to be recognised that there are also other groups of people who are very under represented in collective advocacy, for example, people from ethnic minorities, and asylum seekers.
- Collective advocacy groups and projects are often over-stretched, and are unable to take on additional work without additional funding. They currently do not have the time, capacity or the people to facilitate additional groups.
- Workers who are in support of developing collective advocacy need information to help them make the case that priorities should be changed, or additional funding provided.
- There are increasing difficulties for commissioners in funding groups that are not seen as totally independent – this could affect groups that are trying to set themselves up and get going.

3. Implications of the new mental health legislation

3.1 Issues for collective advocacy

Collective advocacy was perceived to have a vital role in a number of ways:

- It can provide checks and balances and is a means of identifying emerging issues and trends in the way that legislation is being implemented. Aspects of the formal monitoring of implementation could be undertaken by drawing on information routinely collected by advocacy groups.
- It can ensure that users' views and experiences are directly represented.
- Collective advocacy groups may be viewed with greater credibility by the service users for whom they speak than statutory bodies who have a watchdog role.
- Collective advocacy can also serve as a means by which experiences and information can be shared.

3.2 Nurturing and supporting collective advocacy

To be effective, collective advocacy groups and projects require:

- Information about current and proposed legislative measures, their implementation and the possible implications for individuals. Information needs to be user-friendly and presented in language and in a format which is comprehensible to lay people.
- Advice on the interpretation of legislation, its implementation and the possible implications of particular courses of action.
- Opportunity for collective advocacy groups to network and share information, expertise and experience.
- A national group or network which would act as a conduit to and from local groups, have a co-ordinating function and be able to take an active role in influencing policy and developments at national level.

The view was put forward that a set proportion of local mental health budgets should be earmarked for advocacy, including both individual and collective advocacy. For advocacy to develop and be effective, sustained local commitment is required in the mental health service to involve service users in their own care, as well as in the planning and development of services.

3.3 Responsibilities for developing collective advocacy

Organisations that support collective advocacy were asked to:

- Make available more accessible information available on legislation.
- Recognise that collective advocacy is not static but constantly evolving.
- Be prepared to review the way they work and their relevance and accountability to the current practice of collective advocacy.

The Scottish Executive was asked to:

- Promote the development of collective advocacy, but ensure that legislation is not the only or the main driver for this - to tie collective advocacy development to the implementation of mental health legislation would be detrimental.
- Support the development of a national network or body as a voice for service users.

- Further reinforce the expectation that local statutory bodies will support independent advocacy, building on the amended Performance Assessment Framework.

Local service commissioners were asked to:

- Make the case for protecting a set proportion of the budget (5%) for individual and collective advocacy.
- Use guidelines and other evidence on standards to argue for the need for greater prioritisation of investment in advocacy work.
- Recognise the capacity building that is needed to make advocacy effective and sustainable.

Advocacy groups were asked to:

- Get better at being able to set out what users want and at presenting this to service planners and providers.
- Share practice, build on what is known and what is effective, and demonstrate what can be achieved.
- Continue to develop structures and ways of working that can attract and retain new people, share responsibilities and develop people's confidence.
- Consider how they might get involved in professional training (pre and post qualifying) to challenge attitudes and raise awareness.

VII. DISCUSSION

The research project has raised a number of issues around collective advocacy that require further consideration, in relation to the capacity and capability of collective advocacy to respond effectively to mental health and related legislation.

Although many of the issues identified by collective advocacy groups are applicable to a wide range of small groups and organisations - issues relating to funding, infrastructure and support - these issues do have particular implications for the capacity of collective advocacy groups to function effectively to promote and protect the interests of those who fall within the remit of the Mental Health (Scotland) Bill.

In addition, the research also drew attention to issues that are of particular significance for collective advocacy work, including

- the lack of common understanding of what collective advocacy entails
- the limited knowledge of the potential implications of the proposed changes heralded by the new Mental Health (Scotland) Bill
- the variable recognition given to collective advocacy work in different parts of Scotland and for certain groups of people
- the fact that current collective advocacy groups include a number which are tied to service providers and are therefore not fully independent.

1. Variability

1.1 Definitions

- People who undertake collective advocacy do not always use the term 'collective advocacy'.
- While collective advocacy encompasses a range of core functions and activities, there is considerable variability in the focus and emphasis that collective advocacy projects / services take.
- The term 'collective advocacy' is confusing in its similarity to the expression 'individual advocacy'.
- The term 'collective advocacy' can be difficult to explain, and this can cause difficulties when trying to obtain funding or when working with service planners and providers.

1.2 The range of groups

- Collective advocacy is undertaken by a wide range of different types and sizes of groups and organisations, with a diverse range of organisational set-ups, staffing and funding arrangements.
- Collective advocacy tends to be undertaken more in relation to services for people who are over 18 and under 65 years of age, rather than for other age ranges.
- Collective advocacy groups operate at both national and local levels undertaking a wide range of work.

2. What helps and hinders collective advocacy work?

2.1 Infrastructure and resources

- Collective advocacy groups access their funding from a range of sources. In some cases funding is very insecure and minimal. This issue can be especially acute for those projects which are constituted as independent voluntary organisations.
- A lack of the minimum resources required to function effectively, such as office space, meeting space and equipment, can hinder the work of collective advocacy groups.

2.2 Capacity

- The fragility of the infrastructure on which much collective advocacy work is built makes it highly vulnerable. Inadequate support can cause difficulties, particularly when a group relies on one worker who may need to take sickness or annual leave.
- Inadequate support can cause undue pressure and stress for those (management, staff or volunteers) who run a project. A lack of support from other local groups and agencies can hinder the work of a group. The cumulative effect is to jeopardise both the effectiveness and sustainability of collective advocacy work.
- Groups can sometimes struggle in getting service users to be interested in undertaking collective advocacy work, due sometimes to a lack of confidence or of experience in being able to direct their own lives.
- Workload remains an issue for groups, both in terms of the amount of work to be done and the ability to organise a workload so as to allow the flexibility to respond to others' agendas and deadlines. This raises issues about the prioritisation of work, how this is

determined, and the extent to which it may be affected by the insecurity of funding insecurity and maintaining relationships with funders.

- The workshop discussions highlighted that nurturing and supporting collective advocacy needs to be accompanied by support for individual advocacy within a wider service culture of enablement and empowerment. Further, collective advocacy should be a feature of a comprehensive system of service provision and not 'cordoned off' and restricted to those who fall under the remit of legislative measures.

2.3 Awareness and Attitudes

- The attitudes towards people with learning disabilities can cause difficulties in obtaining funding.
- Attitudes amongst service providers towards collective advocacy work are key in enabling such work to be undertaken successfully.
- Training remains central: firstly to ensure that collective advocacy projects maintain and develop their capability to respond to the legislative agenda as well as maintain other areas of work. Secondly, there is the necessity of raising awareness among service planners and providers about the role of collective advocacy. Thirdly, it continues to be important to ensure that professional practice (whether that be planners, managers or service providers) values collective advocacy, listens and responds.

2.3 Links and contacts

- The rural nature of much of Scotland and the resulting distances between people and places can place particular challenges on groups in terms of their ability to both communicate and meet locally and across Scotland.
- Issues around communication can cause difficulties for groups in terms of the lack of means by which to communicate; lack of knowledge of communication channels; as well as being excluded through the use of difficult language.
- Advocacy groups are asking for more opportunity to share experience and information, build on good practice and demonstrate what can be achieved.

2.4 Representation and accountability

- Collective advocacy requires effective structures and processes to tap into the views and experiences of a range of people who use services. It goes beyond creating opportunities for individual voices to be heard. Collective advocacy services face considerable challenges in developing the mechanisms needed to achieve this, to ensure representation and to promote accountability. The research indicated the importance of time and of support to allow collective advocacy to develop the capacity to put forward the views of a body of people who use services and to remain accountable to them.
- Those who commission services want to know where to go to get access to the collective views of services users, not just the voices of a limited number of individuals.
- Accountability requires a continuing relationship and dialogue between collective advocacy groups and the statutory agencies. Collective advocacy projects expect to be given sufficient information and explanation and a response to the views they put forward.
- Local collective advocacy provision needs to be matched by the development of clear mechanisms at national level to articulate the voice of services users and to influence policy and planning.

3. Conclusions

The mapping exercise, while not exhaustive, indicates the variability of collective advocacy work, with differences emerging on a number of dimensions.

- Focus and coverage: most groups identified work with adults and not with children and young people, or older people (over 65). The majority of projects identified work with people with mental health problems.
- Function and role (see below)
- Representation: various different methods are used by collective advocacy groups to tackle the issue of representing both individual and collective experiences and points of view.
- Effectiveness: although groups were able to point to achievements and changes that had come about through their work, some groups reported that they did not feel that their views were given credence and or had an impact.

The research illustrated that although the function of collective advocacy projects varies from place to place, there remain a number of core functions, including:

- Involvement in and influencing local strategic planning and service development.
- Ensuring that user experiences are part of the processes for improving service quality.
- Influencing national policy and campaigning for change.
- Education and awareness raising.

In considering the steps that might be taken to strengthen the capacity of collective advocacy to respond effectively to legislative developments, it would be important to take account of the breadth of these functions, all of which relate in differing ways to legislation and its implementation.

It was striking that groups and projects appeared to have variable amounts of information on and knowledge about legislative developments that potentially affect the groups with whom they worked. Taken together with the findings which point to the fragility and vulnerability of much collective advocacy activity, this suggests that there would need to be considerable building of capacity to develop a baseline of provision across Scotland for those groups likely to fall within the remit of new mental health legislation.

Developing collective advocacy to ensure that groups can respond effectively would require action in the following areas:

- Awareness raising and training for mental health services about collective advocacy, what it entails and the implications for professional practice.
- Training and development for those involved in collective advocacy on the likely impact and implications of mental health and related legislation for individuals and for collective advocacy.
- Sustained commitment from health and social care agencies to support independent individual and collective advocacy, as part of the wider commitment to promoting involvement and influence of individuals in their own care and services.

- Supporting better communications and links within and between collective advocacy groups.
- Promoting mechanisms at national level to ensure that the voices of service users are heard.

APPENDIX ONE

Groups Mapped

Mental Health

Dykebar Patients Council, Paisley

Royal Edinburgh Patients Council, Edinburgh

New Horizons Borders

West Lothian Service Users Forum

Voice Advocacy Project, Ayr Action for Mental Health

User and Carers Group, Shetland

Mental Health Network Greater Glasgow

Mental Health User Network, Aberdeen

Stepladder, Fife

Continuing Care Service Residents Forum, Ailsa Hospital, Ayrshire

National Service Users Association, Richmond Fellowship Scotland

Highland Users Group, Highland

Involve (Inverclyde Mental Health Representative Forum)

Summertown Participants Group, Govan Mental Health Project,
Glasgow

CAPS, Lothian

Ailsa Hospital Panel of Reference, Ayrshire

Hartwoodhill Patients Council

User and Carer Involvement, Dumfries and Galloway

Aberdeenshire Mental Health User Reference Group

Stirling Users Group

Echo, Forth Valley

Fledglings, Forth Valley

Lanarkshire Links

Acumen, Argyll and Clyde

Fife Mental Health Survivors Group

Moray Mental Health

Edinburgh Users Forum

Augment, Angus
Scottish Association for Mental Health User Involvement Group
Stirling and District Association for Mental Health Members Group
East Lothian Involvement Group

Generic

Western Isles Carers Users and Supporters Network
Discovery Group, Quarriers

Mental Health and Learning Disability

Forth Valley Advocacy Service, Larbert
Lomond and Argyll Advocacy Service

Learning Disability

TVC Group, the Action Group, Edinburgh
User Monitoring Group, the Action Group, Edinburgh
Quality Action Group, Stirling
ACE National Committee, Enable
Surging Ahead, Edinburgh
Stick Up For Your Rights, Edinburgh
People First Scotland
Fair Deal (1 in 100), Glasgow
WIND, Fife
Key Housing Association

Brain Injury

Brain Injury, Grampian
Headway House Dumfries and Galloway
Headway, Perth and Kinross
ABICAS, West Lothian
Headway, Ayrshire
Headway, Tayside
Service Users Group, Brain Injury Vocational Service, Rehab Scotland,
Aberdeen

Dementia

Having Your Say, Glasgow

Joint Dementia Initiative, Forth Valley

APPENDIX TWO

Other groups that may also undertake collective advocacy work

Mental Health

Queen Margaret Hospital Patients Council

Stratheden Patients Council

Mental Health Reference Group, Aberdeen

Learning Disabilities

Partners in Advocacy, West Lothian

Advocating Together groups, Tayside

Brain Injury

Headway Fife

Headway Monklands

Headway Glasgow

Dementia

Differently the Same Project, Glasgow

APPENDIX THREE

Groups interviewed

Mental Health

Mental Health User Network, Aberdeen

National Service Users Association, Richmond Fellowship Scotland

Involve, Inverclyde

Highland Users Group

Royal Edinburgh Hospital Patients Council

Augment

Learning Disability

Quality Action Group

WIND, Kirkcaldy

Castlehall Action Group (Fair Deal)

Discovery Group, Quarriers

ACE National Committee, Enable

User Monitoring Group, the Action Group

Brain Injury

Headway Perth and Kinross

Headway Ayrshire

Brain Injury Vocational Services, Rehab Scotland Aberdeen

Dementia

Joint Dementia Initiative, Falkirk

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