Advocacy and People with Learning Disabilities: Local Authority Perceptions of the Scope of its Activity, Extent and Effectiveness

Final Report

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Advocacy and People with Learning Disabilities: Local Authority Perceptions of the Scope of its Activity, Extent and Effectiveness

Overview of this report

Advocacy schemes have been established throughout the United Kingdom (UK) but their evaluation by funders is varied. Inconsistencies in evaluation are increasingly untenable in view of concerns about public funding accountability and the need to assure outcomes meet their services’ stated intentions. This research is timely given the Government’s drive to improve and extend advocacy services for people with learning disabilities.

This report provides a literature review and research findings in respect of models of evaluation of advocacy schemes for people with learning disabilities. Part 1 describes the research methodology. Part 2 locates the policy and literature relating to advocacy for people with learning disabilities, considers the issues that arise in evaluation and analyses the advantages and disadvantages of six main evaluation models. Parts 3 and 4 describe the research outcomes. Part 3 details the findings of a survey sent to local authorities investigating the implementation of evaluation models and their outcomes. Part 4 describes the outcomes of interviews seeking stakeholder views regarding the effectiveness of advocacy, types of evaluation and recommendations for change. Part 5 details the main points identified at a seminar held to debate the research findings. The Discussion, Part 6, considers the research outcomes and the issues in respect of the scope and effectiveness of evaluation in response to the public funding imperatives, the aims and objectives underpinning advocacy in general and particular typologies, and commissioning arrangements. The discussion suggests that, although evaluation of effectiveness is accepted as increasingly important, it is not universally in place and available tools are considered to be inadequate for the task. The explanation of this may lie in the continuing debates over the meaning and purpose of evaluation and fears that it is one-dimensional. Part 7 outlines our conclusions and recommendations.

Introduction

The subject of lay advocacy has ‘moved to centre stage and … become a force for change’ since its more ‘fringe’ position in the late 1970s (Forbat and Atkinson, 2005; 325) when the movement in the UK began. The Independent Advocacy Campaign (ICA), comprising seven key stakeholders supporting people with physical, sensory, communication and profound multiple impairments, defined advocacy as:

“taking action to help people say what they want, secure their rights, represent their interests and obtain services they need”. (Lewington and Clipson, 2004; 4)

Core advocacy typologies can be identified as follows (Gates 1994; Teasdale 1999; Cantley et al 2003):
• **Legal advocacy**: usually describes the broad range of methods and activities by which lawyers and other skilled individuals help people to defend their rights, for example, lawyers engaged in scenarios such as mental health review tribunals and welfare rights appeals.

• **Class (also collective, corporate or group) advocacy**: when a group of people come together to speak up for and represent a larger group of people. For example, MIND, Mencap, Home Farm Trust, where not for profit organisations bring people with like concerns together to press for changes that benefit themselves and others.

• **Self-advocacy** where people with disabilities or who are socially excluded are empowered to speak for themselves. Self Advocacy projects facilitate this through providing them with opportunities to develop their skills, gain knowledge and confidence in order to be able to advocate on their own behalf.

• **Peer advocacy** where people with similar experiences speak for each other

• **Citizen (voluntary) advocacy** where a person, with learning disabilities for example, is linked to a volunteer to advocate on his or her behalf. Such relationships are often long-term.

Advocacy has been associated largely with the resettlement of long-stay patients in the community; however, it has evolved to include other people among whom social exclusion, marginalisation and disadvantage prevail. Whilst independence from public services remains an important advocacy principle, advocacy schemes are usually reliant on public funding (Henderson and Pochin 2001). Recent policy initiatives have enhanced the importance of service evaluation and monitoring to ensure efficient use of public money (DETR 1999). However, evaluation of advocacy is complicated by the diversity of advocacy schemes and their different aims and objectives (Henderson and Pochin 2001; Cantley et al 2003).

This study was carried out by a research team based at the Social Care Workforce Research Unit, King’s College London, in conjunction with Dr Jean Collins, Director of Values into Action, and her colleague Mark Brookes. Although this by no means was participatory research, this partnership enabled people with learning disabilities to influence the research, including involvement in refining the questions and messages. Throughout the research material has been made accessible and examples of this are included in Part 2 and the overall summary.
Part 1  Methodology

The broad aim of this UK-focused research was to examine how local authorities evaluated the outcomes of advocacy for people with learning disability and/or their carers (the prime focus being on people with learning disability). The research particularly focused on:

- How local authorities establish outcomes
- The sources of information used by local authorities to evaluate outcomes
- How local authorities respond to the identified outcomes.

The research used a social definition of learning disability and this included people who have complex needs or multiple disabilities. It concentrated on adults but also included services for those in transition between adults’ and children’s services.

The study comprised three main components: 1) establishing a knowledge base through reviewing published and unpublished literature, 2) a survey of local authorities in the UK and 3) a series of focused interviews with a range of key stakeholders involved in commissioning and providing advocacy services. The study took place 2004-5 and was funded by the Department of Health. The survey was approved by the Association of Directors of Social Services (ADSS) research sub-committee.

**Literature review**

The main aim of the literature review was to understand different methods of evaluating advocacy schemes and their different consequences within the UK context, including Scotland where advocacy strategies have advanced. It set out the models used, analysed their disadvantages and advantages and considered the implications for funders and also for advocacy schemes themselves of embarking on evaluation. The review was undertaken between July and December 2004 and updated at the end of the project. The review involved academic, government and voluntary group information sources and citation searches from the UK. The search terms used included: advocacy, autonomy, empowerment, evaluation, monitoring and review. Websites were extensively searched for up to date information. An accessible summary is provided on page 58. A paper outlining and discussing the review was prepared for publication and will be available shortly (Rapaport et al 2005).

**The survey of local authorities**

The primary purpose of the survey (see Appendix 1) was to investigate how local authorities (LAs) perceive the outcomes of advocacy schemes for people with learning disability and how they evaluate them. Self-completion questionnaires were posted to the Director of Social Services/Social Work Services of 189 LAs in UK using a list provided by the ADSS. Given the large numbers involved, limited resources and the short timescale it was not possible to mount an exercise to identify named staff responsibilities for advocacy development in each of the areas.
The survey asked respondents to provide information on up to two advocacy schemes for people with a learning disability that their LA supported and was divided into three sections. The first gathered information regarding:

- how each advocacy service was constituted and supported by LAs;
- the perceived reasons for support; ~ staffing of the advocacy service(s);
- the type of advocacy service(s);
- the target population(s) (vīz. generic or specific – ethnic minorities, young people, etc.); and
- the perceived outcomes of each advocacy service.

The second section focused on methods and processes of evaluating each advocacy scheme. The questions asked how the LA currently evaluated each advocacy service, as well as views about the best ways of evaluating services and future planning. This section also gathered information on any changes to advocacy schemes listed in the questionnaire as a result of the evaluation. The final section recorded the views of respondents and recommendations for change, respondents’ job roles and the urban, rural or mixed locations of the areas. Most of the questions were multiple-choice allowing for multiple responses with an additional category for respondents to include any other options not already covered. Respondents’ views about services and future directions were captured in open-ended questions.

Response rate
Significantly, a low response rate is usually anticipated where there are no incentives attached to participation (Edwards et al, 2002) and questionnaires are not sent to the person responsible for the specific topic under investigation, increasing the chance that they will either be lost or not sent to the relevant personnel. In the event, a total of 54 (28.6 percent) completed questionnaires were received by the research deadline. The responding LAs provided information on a total of 97 advocacy schemes for people with learning disabilities. Responses were fairly evenly spread although the South East of England had the highest response rate at 39 percent. Out of the total received; 17 percent were from Greater London, 13 percent from each the North West and the South East of England, and 11 percent from Wales. Most questionnaires were completed either by commissioning managers or directors of learning disability services.

Stakeholder interviews
Purposive sampling is held to be an effective way of understanding complex phenomena (Bowling 1997) and generating rich data for in depth study (Patton, 2001). We approached representatives of a purposive sample of statutory and voluntary agencies providing advocacy and other services, government departments and non-governmental organisations working across the UK. The majority of participants had extensive work experience and carried multiple roles - funders, commissioners, policy-makers, service providers, advocacy workers, service users and carers. Table 1 shows the work experience and job specifications of the participants taking part in the interviews.
At director and chief executive level, both statutory representatives were Assistant Directors of Social Services (England and Wales) and Social Work (Scotland). Voluntary representation comprised two chief executives, four directors of co-directors and one chairperson. Two of the managers worked for social work departments. Three of the managers from voluntary organisations worked for a Citizens’ Advice Bureau (CAB) and two for local charities. Another manager worked for a quasi-government consortium for learning disabilities. We also interviewed a researcher working for two voluntary organisations and the evaluation officer for a quasi-government body set up to promote advocacy development. Policy and advice representatives worked for a government department focusing on advocacy and related issues (the joint interview) and quasi-government bodies (three representatives) dedicated to advocacy development in England and Wales. One of the advocacy development workers was involved in promoting self-advocacy whereas the other was involved in developing and delivering a local advocacy service.

**Table 1 Current posts of stakeholders interviewed**

<table>
<thead>
<tr>
<th>Type of role</th>
<th>Statutory</th>
<th>Voluntary</th>
<th>Other</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Director; Chief Executive; Assistant Director; Chairperson</td>
<td>2</td>
<td>7</td>
<td></td>
<td>9</td>
</tr>
<tr>
<td>Manager</td>
<td>3</td>
<td>5</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Research; Evaluation</td>
<td>1</td>
<td>1</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Advice; Policy</td>
<td>1 + 1</td>
<td></td>
<td>3</td>
<td>4 + 1</td>
</tr>
<tr>
<td>Advocacy development workers</td>
<td></td>
<td>2</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Totals</td>
<td>6 + 1</td>
<td>15</td>
<td>5</td>
<td>26 + 1</td>
</tr>
</tbody>
</table>

Almost all participants were employed by national (16) or local (9) organisations. Only one person was employed by a regional body (a manager of a charitable Trust in the East of England). Of the 16 national organisations, three included Scotland, and several of the other national bodies had a UK-remit. Three participants employed by national bodies had a regional remit. Local organisations covered the North East (4), South (3), Midlands (1) and Scotland (1). Four of the local bodies covered urban locations and five an urban/rural mix.

All of the directors and managers carried leadership roles. Service provision was clearly reflected in thirteen roles followed by policy and practice development, evident in eleven roles. Three participants commissioned advocacy services and three were involved in research, evaluation and performance management. Two worked in provider services as advocacy development workers. One of these workers focused on the development of self-advocacy.

The employment experiences of those interviewed varied but were considerable overall. The majority of participants (11) had been in their current posts for between one and five years. Seven (including the joint interview) had been in post for under a year, four for between five and ten years and five for over 10 years. The majority (18) had worked in some form of social care including social work, probation, care work, project...
development and nursing. Four had backgrounds in the NHS. Two had been teachers in the past. There were individual examples of research, academia, finance, chaplaincy and the civil service. Five participants had experience of using learning disability or mental health services and at least one had personal experience of receiving advocacy services and was being supported by a personal supporter. Four had experiences of being a carer. One had been a volunteer advocate and another described a support role within an organisation dedicated to the needs of people with learning disabilities.

A semi-structured interview schedule (see Appendix 2) was devised in consultation with the Department of Health who funded the research and local authority staff in policy and evaluation sections. Most of the interviews were conducted over the telephone, although six were conducted face to face. In all, 27 people were interviewed (26 interviews – one interview was joint). They were given the interview schedule before the interview in advance. The interview data were analysed using thematic analysis (Flick, 2002) and the findings were debated at a seminar in April 2005. This consensus method, a modified consensus development panel or conference technique (Bowling, 1997) was undertaken to validate the interpretation of the findings of the literature review, interviews and survey and to place them in context. This discussion is detailed in Part 5.

In the course of this study, the green paper *Choice, Independence and Well-being* (DH, 2005,a) was issued and subject to a wide range of consultation. The relevance of this is raised in the discussion section. Also in 2005, the Social Care Institute for Excellence (SCIE) announced its own programme of work on advocacy for people with learning difficulties. This research (in draft) has been shared with SCIE and we have been invited to continue to work with SCIE after our own study has concluded (August, 2005). Findings from this study have been used in the Unit’s response to the Department of Health on the development of the Mental Capacity Advocate services (August, 2005).
Part 2  Policy and Literature Review

Advocacy, in broad terms pleading the cause of another, is predicated on the core belief that it plays an essential part in securing the rights and protecting the interests of socially devalued groups and individuals (Henderson and Pochin 2001). Although it has arguably been practised for centuries (Atkinson 1999), the roots of the lay advocacy movement lie in citizen advocacy that was developed and promoted in the United States in the 1960s (Gates et al 2000). Wolfensberger (1983) defined the purpose of the citizen advocate role as “meeting the instrumental and expressive needs of the partner” (the person being supported). In such a definition, ‘instrumental’ refers to practical needs and ‘expressive’ to the formation of a relationship based on friendship. It was the latter, the befriending aspect, that was said to be all-important in facilitating social links.

The closure of long-stay hospitals for people with mental health problems and learning disability (previously mental handicap) that took place during the 1980s and was largely concluded by the mid-1990s provided the mainstay of early advocacy work in the UK. The Advocacy Alliance was formed in the mid-1980s (Sang and O’Brien, 1984), comprising key national organisations representing mental health, learning disability and other relevant disability interests. A spread of local forums developed (Atkinson, 1999). Although advocacy is still not universally available, comparisons between two studies undertaken 10 years apart (Crawley 1988; Whittell & Ramcharan, 1998) suggests that the movement has continued to grow (Gates et al 2000). However, research also has suggested that advocacy provision for adults with physical, sensory, communication and profound multiple impairments in England is limited (NAS, 2003; Lewington & Clipson 2004). This is despite the fact that these groups “may be among the most in need of such support” (Lewington & Clipson, 2003; 4).

Government policy

Policy in England, in the White Paper Valuing People (DH, 2001), promised national funding for advocacy schemes, under the auspices of Values Into Action (VIA 2005) and the British Institute of Learning Disability (BILD), two voluntary organisations promoting the development of advocacy. It committed the government to setting up a national citizen advocacy network in every local authority area. Similar commitment was reflected in Scotland with funding to set up an Advocacy Safeguard Agency (ASA) and a Scottish Independent Advocacy Alliance, a confederation of advocacy organisations, to develop independent advocacy services for people with health problems, particularly mental health problems and learning disabilities (www.scotland.gov.uk). The ASA has a specific function to evaluate existing independent advocacy organisations (ASA 2003,a).

Although the UK has no comprehensive policy or legislative framework for the development of advocacy schemes for vulnerable adults (Cantley et al 2003), Valuing People (DH, 2001) outlined ambitious plans for improving advocacy services for people with learning disabilities. These were to be taken forward through the new structure of inter-agency partnership boards based on the findings of joint investment plans (JIPs),
introduced to drive forward the agenda of partnership working at local level (Ward et al 2004) and to ensure self-advocates were ‘genuinely’ equal partners in consultations about services used by people with a learning disability (Nicholl, 2004; 37). More recently the Valuing People Support Team Business Plan 2004/5 (www.valuingpeople.gov.uk/documents/BusinessPlanUpdat.pdf) promulgated a strategic plan to improve advocacy services throughout the UK. The right to advocacy under the Disabled Persons (Services, Consultation and Representation) Act 1986 has never been implemented, although government policy has supported advocacy in the context of community care and care management development (DH, 1991; Clements, 1996) and as a safeguard against abuse (DH, 1993; DH 2000).

However, legislative changes identifying new advocacy roles in special circumstances have recently been introduced in England. The Mental Capacity Act 2005 created new measures regarding essential substitute decision-making, based on the principle that people must be enabled to make their own decisions whenever possible. The proposed role of independent consultee (IC), introduced to consider decisions about serious medical treatment or significant changes of residence for people who lack capacity and have lost contact with family and friends was changed to that of Mental Capacity Advocate, following concerns that the ‘best interests’ focus of the IC conflicted with the underpinning advocacy intentions of the original proposal (Personal communication, 2005). The functions of the Mental Capacity Advocate have still to be clarified and further changes may occur (see Consultation on the Independent Mental Capacity Advocate Services, (DH, 2005,b)).

A new Mental Health Bill for England (Cm 6305 – 1) published in September 2004 introduced the role of the Independent Mental Health Act Advocate (IMHA advocate) to provide independent specialist advocacy to protect the rights of patients subject to care and treatment under compulsion. The IMHAA is to provide specialist advocacy to patients compulsorily detained. Although not identified in the Bill, the Government has thus far calculated that 140 IMHAAAs will be required.

More generally, advocacy schemes have also featured elsewhere in community care plans and charters (Henderson and Pochin, 2001). Support for independent advocacy is evident from professional sources (BMA and RCN, 1995). Mallick (1997) identified advocacy as a traditional role for nurses since they perceived themselves close to the patient and therefore in the best position to act and know how to advocate. Social workers also have claimed that advocacy fits social work core values of enabling people to achieve “self-fulfilment and to as much control over their own lives as is consistent with the rights of others” (BASW, 2002; 2).

Funding considerations

Public funding is the mainstay of most advocacy schemes. Whilst on the one hand vital to the survival of the advocacy movement, statutory funding potentially threatens the independence of schemes from authorities to challenge the delivery of public services (Cocks and Cockram, 1997, Gates et al, 2000, Henderson and Pochin, 2001). This threat
is compounded by public funding requirements of accountability that are particularly critical in the current climate of financial scrutiny. As Newman (2002) noted, this effort to consider ‘best value’ is not just a concern with efficiency, but central to the current government’s attempt to find out ‘what works’, especially in cross-cutting and complex areas. Yet insecure funding has seen many schemes come and go (Forbat and Atkinson, 2005) and schemes argue that they require secure, preferably independent funding and support, if they are to be viable concerns (Dunning, 1995; Wertheimer, 1998; Brooke, 2002; SDC, 2003). Therefore, if a reliable source of independent funding cannot be found, it is a challenge to deliver intellectual independence, loyalty to the client or partner and a commitment to justice and empowerment (Henderson and Pochin, 2001) while balancing these principles with obligations to a funding body (Gates et al, 2000).

**Best Value** requirements introduced under the Local Government Act 1999 required local authorities to:

“secure continuous improvement in the way in which they exercise their functions, having regard to a combination of economy, efficiency and effectiveness”. (DETR, 1999; para. 3).

Local authorities were required to undertake **Best Value** reviews of all the services that they provided either themselves or purchased from other providers. The underpinning principles of these reviews were summarised by Henderson and Pochin (2001) as:

- To challenge why and how a service is provided
- To compare performance with that of similar services
- To consult service users and tax payers to set new targets
- To use principles of fair competition to decide who should provide the service.

**Best Value** reviews potentially created conflicts for advocacy services particularly in terms of the aims and objectives of the various schemes versus the aims and objectives of the funder, and their suitability for reflecting the real value of a scheme.

In 2002 the **Comprehensive Performance Assessment (CPA)** was introduced in order to measure the overall performance of a local authority using best value performance indicators, best value inspection reports and audit reports (www.odpm.gov.uk). Whilst this represents a cultural shift from the focus on operational developments to strategic performance, local authorities are still largely left to their own devices regarding monitoring of services such as advocacy, which they commission, at times jointly with other bodies, such as a local NHS Trust, or which is funded as part of a service agreement with a voluntary organisation. Furthermore, tensions continue to arise regarding the most effective ways of evaluating services such as advocacy schemes - whether the focus should be on quantitative or qualitative outcomes - and problems in capturing the relationship and enabling process components of advocacy partnerships that are central tenets of advocacy traditions (Wolfensberger, 1983). This is in contrast to services such as child protection where performance measurement is also complex but firmly embedded into the requirements laid on local authority and health services by the UK government (see Tilbury 2004).
A plethora of different types of advocacy schemes offering generic and/or specialist services has developed since the early days of citizen advocacy. This has implications for the appropriateness of existing evaluation and monitoring techniques.

In addition to the core typologies identified in the Introduction, advocacy services include family advocacy involving a family member (Brandon, 1995), crisis advocacy for particular situations (Cantley et al, 2003) and professional casework advocacy where advocates are paid workers (Henderson and Pochin 2001), although not lawyers. The Services for People with Dementia in Wales Report (2003) and Henderson and Pochin (2001) also include volunteer advocacy where the scheme is organised by a paid co-ordinator but “staffed” by volunteers. Volunteer advocacy schemes are different from citizen advocacy as the advocate may have a number of clients and involvement may be short-term. Advocacy is also undertaken by nurses (Jenkins and Northway, 2002) and social workers (Gorman and Postle, 2003; Firth et al, 2004) in the course of professional duties, although conflicts can arise because of organisational and professional obligations (Killeen, 1996; Dunning, 1997; Atkinson, 1999; Forbat and Atkinson, 2005). The picture is complex and some schemes have developed multiple advocacy roles, see for example, CALL – Citizen Advocacy Lincolnshire Links (see Gates et al, 2000). People also may use different types of advocacy at different stages of a disability and their lives.

Some advocacy schemes are distinct whilst others are part of a wider movement for social change, or blend with advice and information services and befriending (Henderson and Pochin, 2001). Simons (1992; 23) observed that self-advocacy alone “means many things to those involved – it is a very diverse and plural phenomenon”. A new chat-line to support self-advocates and advocates (internatlinknet@yahoo.co.uk) adds to the increasingly complex picture. In addition to generic learning disability services, and dedicated schemes, for example, age-related projects (CALL in Gates et al, 2000; GOLD – Growing Older with Learning Disabilities – www.learningdisabilities.org.uk), specialist schemes help individuals who are victims of abuse and crime (www.anncrafttrust.org; www.voiceuk.clora.net; www.respond.org.uk) and also perpetrators of sexual abuse (www.respond.org.uk). MDAC (Mental Disability Advocacy Centre) is an international resource for service users, voluntary organisations and professionals focusing on the human rights of people with mental health problems and intellectual problems across central and Eastern Europe and central Asia (www.mdac.info). Schemes may be independently managed, either as registered charities or companies limited by guarantee or both, with their own elected boards of trustees. Some independent groups may align themselves with larger organisations or networks such as National People First. Others operate under local infrastructures, for example, Councils of Voluntary Service. Whitcher (1990) also found sub-sets of self-advocacy groups based in day services run by elected committees with staff or external advisers.
Evaluation

Advocacy per se is an under-researched topic and the available literature rarely attempts to address its effectiveness (Atkinson and Forbat, 2003). Furthermore, the literature suggests that an understanding of the effectiveness of existing evaluation models for advocacy is patchy. In addition, commissioners do not systematically collect or scrutinise the outcomes of the advocacy services that they fund (Hudson, 2000). There are many reasons why the case for research into the stage of advocacy services and how they are monitored is timely. These include:

- the complexities involved in exercising choice (Harris, 2003);
- difficulties experienced by disempowered groups in criticising the services that they receive (Atkinson and Forbat, 2003);
- the vulnerability of people with learning disabilities (Mencap, 2004,a) and those doubly disadvantaged from minority ethnic groups (Baxter et al., 1990); and
- the challenges faced by advocates in fulfilling their role (Tyne, 2001; Schwartz, 2002; Forbat and Atkinson, 2005).

Significantly, the involvement of people with learning disabilities in the evaluation and development of the support that they use has long been argued (Whittaker, Gardner and Kershaw 1990) and is arguably critical in respect of advocacy schemes as these purport to empower service users to attain the rights and services that they are evidently often denied. Acknowledgement of ways in which people with learning disabilities can and do participate in evaluation is not widespread and good practice does not appear to be widely disseminated.

The diversity of schemes and lack of clear identity beg questions as to the nature of advocacy, what should be measured in which type of scheme and the comparative value of different types of scheme. This lack of clear identity and abundance of diversity may have undermined attempts to develop good practice across advocacy schemes. There are no widely agreed benchmarks to test performance (Jones, 1999; Henderson and Pochin, 2001; Advocacy Across London, 2002; Forbat and Atkinson, 2005) and only a few such models currently exist. This has led to a tendency for purchasers of advocacy (usually statutory organisations) to impose their own individual monitoring regimes on advocacy schemes (Henderson and Pochin, 2001). Forbat and Atkinson (2005) suggest that effectiveness is usually judged through people’s stories about the value of their respective partnerships. However, in addition to information about process, the outcomes and changes that occur as a result of advocacy are also important (Wertheimer, 1998).

The different types of terminology used with reference to monitoring arrangements, viz. ‘evaluation and monitoring’, ‘audit’, and ‘research’ suggest different approaches derive not only from the diversity of advocacy schemes, but also different ideas about the nature of evaluation per se. Nevertheless, advocacy evaluation appears to be developing across agencies and service user groups. In one example, Mencap’s three-year strategy (Mencap, 2004,b; 20) aims to improve advocacy services and promises to support the development of advocacy schemes and “develop and try out a set of quality standards and
audit tools”. The Older People’s Advocacy Alliance (OPAAL (UK)) recommends that advocacy schemes and older people’s organisations develop nationally recognised quality standards and evaluation tools for advocacy for older people in hospital (Dunning et al, undated).

**Official guidance**

The Scottish Executive’s (2000) comprehensive framework, *Independent advocacy: a guide for commissioners*, proposed criteria applicable to all types of advocacy, provided examples of specific indicators for particular schemes and outlined the process of evaluation and what it involved. The Scottish Executive had the advantage of access to an existing, albeit relatively small, body of knowledge. In addition to citizen advocacy models and local audits this potentially includes co-operative inquiry action research (Booth and Booth, 1998), emancipatory disability research (Ward, 1998) and the use of case studies or individual case scenarios (*Services for People with Dementia in Wales* 2003). Key messages are that indicators of quality follow a clear understanding of the purpose of a project and that dialogue should take place with all stakeholders. The guidance is summarised in Table 2 below.
### Table 2: Summary of evaluation guidance (Scottish Executive, 2000)

<table>
<thead>
<tr>
<th>General criteria applicable to all types of advocacy:</th>
<th>Example of routine data collection: funders/projects agreement</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Should actively include groups most at risk of exclusion</td>
<td>• Type of enquiry – issues people want help with</td>
</tr>
<tr>
<td>• Should be firmly rooted in/supported by/accountable to a geographical community/constituency they serve</td>
<td>• Characteristics of people wanting an advocate – age/ethnicity etc</td>
</tr>
<tr>
<td>• Should be constitutionally and psychologically independent of govt/stat/vol service system</td>
<td>• Amount of staff time spent on direct advocacy</td>
</tr>
<tr>
<td>• Should have a robust process for management &amp; governance that helps them stay clear about their principles and goals</td>
<td>• Amount of time spent on recruiting, training, supporting Citizen Advocates (CAs)</td>
</tr>
<tr>
<td>• Should be clear about policy &amp; law</td>
<td>• Length of time people are in contact with the project/advocate</td>
</tr>
</tbody>
</table>

### Evaluation

**Planned process of**
- Gathering information
- Reaching conclusions
- Making recommendations

Who should do it and how?
Regular independent evaluation (e.g. CAIT) – when project is on its feet e.g. after 3 years.

Identify scope of evaluation – how being done and why – who wants it done – who is paying – who will get the report – what sort of actions might be taken as a result of the evaluation

### Between evaluations dialogue:

Need for **regular** cycle of face-to-face meetings – funders/advocacy agency – conduit for issues – information for Health improvement Plans (HiPs)/community planning etc and facility to hold in-between meetings as indicated to discuss issues.

### An example of scoping focus:

Developmental – using partnership process – what is working well – where improvements are needed

User focused – exploring the relationship between partners & advocates, experience/roles of advocates/issues taken up

Scheme-focused – work of office and co-ordinator, training & support to volunteers

Management-focused – management arrangements & role of the management committee

External support given by commissioners – what helps/hinders/could be improved

Relationships with providers – how perceived – impact on providers
**Who it involves** – all those with a stake in the project:
- People who need advocacy
- Paid and unpaid advocates
- Project staff
- Management committee members, funders, referrers etc.

**What it involves:**
*Activities* - Compliance with funding specification
Judgement about quality of what is delivered
Outcomes including relevance, what was done/could have been done.
Thinking about the purpose of the project
Balancing success/preventing worse from happening
Putting a value on relationships as well as results
Assessing impact of advocacy on policies and practice of service system
(individuals and in general)

*Could also evaluate accountability, robustness and sustainability of the agency.*
*Composition & renewal of management committee – how it reflects agency constituency?*
*How it addresses needs of most marginalised people?*
*Reputation of the agency in the community*
*Match between needs of people served and skills/resources of the agency.*

**Examples of indicators for specific advocacy purposes:**
E.g. project providing advice & assistance to large numbers of *people leaving hospital* – agreed indicators are likely to include:

- No. of people advised/supported
- Length of time between contact and someone being seen
- Quality of advice and support – e.g. by second opinion sampling of case files; assessing customer satisfaction from the referrer and people referred.

E.g. *collective advocacy* organisation – likely quality indicators:

- Growth & diversity of membership
- Breadth & depth of member involvement
- Development of leadership skills
- Evidence of managing group having consulted wider membership
- Extent of member influence

E.g. *citizen advocacy* – likely quality indicators:

- No. & diversity of partnerships supported
- Quality of match between advocates & partners
- Strength of relationship between advocates & partners
- Diversity of issues tackled
- Difference advocacy has made to people’s lives
The Advocacy Safeguard Agency (ASA) (funded by the Scottish Executive) subsequently produced a Resource Pack for Evaluators (ASA, 2003,b) detailing core questions for the management committee, administrators and support staff, funders and other professionals and interested parties in contact with the organisation. Specific questions are asked of specific groups of people involved in organisations that support 1) individuals and 2) self or collective advocacy groups. The evaluation is undertaken by a team of four or more people including a health or local authority commissioner, advocacy worker and a person who has experience of using an advocate. The questions are detailed and are designed to guide a structured interview and elicit qualitative information. As a general overview the evaluation investigates stakeholder perceptions on roles, how the aims and objectives of the service are being met, the difference advocacy makes to people’s lives, training, gaps in advocacy services and public awareness of advocacy. The resource pack largely reflects the Scottish Executive guidance (above).

Additional models of evaluation

Henderson and Pochin (2001) scrutinised three evaluation tools – CAPE (Citizen Advocacy Program Evaluation), CAIT and ANNETTE. In practice, organisations have tended to experiment and also use modified versions of existing schemes (for example, Gates et al 2000; Cantley et al 2003) and an approach used by Rethink (formerly the National Schizophrenia Fellowship). The nature, process, criteria and advantages and disadvantages are briefly described below and summarised in Table 2 (below).

MODEL 1

CAPE (O’Brien and Wolfensberger, 1978) was developed in the late 1970s to evaluate citizen advocacy schemes. Gates et al, (2000; 60) commented that CAPE is “the most widely known and used tool in the citizen advocacy movement”. CAPE studies specific criteria using a rating scale of 1 (low) to 4 (high). The required standards are:

- The independence of the scheme must be upheld
- Advocates must have primary loyalty to their partners
- Promotion of people’s rights must be through a relationship which is based on conviction and not money
- The rejection of the service approach; citizen advocacy must not resemble care services.

CAPE has several apparent advantages:

- It establishes the links between principles and practice
- It provides an objective measure of a scheme’s performance against a set of constant standards
- It highlights the way in which evaluation can be an integral part of a developing advocacy culture.
However, CAPE’s potential disadvantages include:

- Advocacy schemes in the UK usually obtain funding from statutory agencies rather than independent sources
- Its applicability to citizen advocacy schemes only (although it may inform other schemes)
- An inability to offer a measure of the scheme’s impact, this being related to the intrinsic nature of the citizen advocate partnership which is owned by the partner but not the scheme.

**MODEL 2**

CAIT – Citizen Advocacy Information and Training (Hanley and Davies, 1998) was produced after consultation with citizen advocacy schemes. CAIT followed the same principles as CAPE but was less purist in approach and more inclusive. It acknowledged the importance of local imperatives. Schemes are measured against their own aims as well as citizen advocacy principles.

A CAIT evaluation team is often drawn from other citizen advocacy groups. It meets eight citizen advocates and their partners of a particular scheme to explore how it is working in practice. The evaluation process involves a framework of interviews with advocacy partnerships, staff and managers. A format for feeding back and writing the report is also provided. The criteria under examination are:

- The range of people being helped
- The types of role advocates are undertaking *viz.* befriending, negotiator, information-gatherer
- How well partners have been prepared for their role
- How far partners are loyal to their partners rather than the scheme.

CAIT provides technical information and reports on the feel of the advocacy scheme. It focuses on:

- What the scheme is doing
- What the scheme is doing well
- How difficult areas can be improved.

However, its disadvantages include:

- Problems of measuring the value of particular partnerships
- People may be reluctant to participate in the evaluation because they fear a breach of confidentiality
- Failures to generate a sense of the scheme’s overall impact.
ANETTE (ANN, 1995; ANN, 2004), devised by Newcastle Council for Voluntary Service, has undergone considerable modification and is used regularly by the local advocacy service on a six-month cyclical basis. ANETTE focuses primarily on outcomes rather than principles and was developed in response to Best Value reviews.

The tool examines:

- The nature of advocacy issues and outcomes
- The number of advocacy hours under review
- The different types of role undertaken by advocates identified under six headings as mediator, troubleshooter, special friend, confidante, guide, lifeguard.

The tool uses tables to count up the tasks, time taken and different roles and there is also a place for some commentary.

ANETTE has several interrelated advantages viz;

- It is pragmatic and can accommodate a range of advocacy styles
- It measures process and benefit
- It allows for comparison between schemes
- It meets the objectives of the contract culture and is liked by funders.

However, its disadvantages include:

- Potential to overlook subtle successes
- The potential to prefer professional casework advocacy with successful outcomes over long-term partnerships with no obvious issues to address.

CALL – Citizen Advocacy Lincolnshire Link instituted a research evaluation project of its citizen advocacy project for young people who experienced social exclusion because of disability or other adversity, aged 18-25 living in Lincolnshire (Gates et al, 2000). CALL provides a number of diverse advocacy schemes and the 18-25 project was therefore a sub-scheme of a larger citizen advocacy initiative. The scheme was funded by the National Lotteries Board (NLB) rather than local service funders, which required periodic review. The evaluation adapted the revised short form of CAPE (O’Brien, 1987). In addition it uniquely incorporated a psychological personality inventory (the Minnesota Multiphasic Personality Inventory (MMPI-2)) (Butcher and Williams, 2000) to study the personality attributes of advocates for comparison with a control group of nurses and outcomes of a previous personality study of advocates (O’Brien et al, 1992). The method of evaluation incorporated a collaborative approach and examined both process and outcomes.
CAPE-revised was used to direct the content of the semi-structured interviews with 1) staff and 2) a small sample of service users. CAPE interviews usually specifically involve scheme co-ordinators. The 18-25 CALL project extended the interviews to include additional staff and also conducted a group interview. The content of the interviews involving the scheme’s partners was developed with the 18-25 project team and the advocates.

Quantitative data collection included:

- The demographic and geographic details of people using the scheme
- Referral routes
- Client groups and their locations.

The aims of the qualitative element of the research, the semi-structured interviews, were:

- To gather information on the specific roles of the project co-ordinators
- To discuss how each became involved in the advocacy movement
- To explore whether each person saw a future within advocacy
- To identify the support available within the organisation to the project co-ordinators
- To ascertain satisfaction with the role and working conditions.

Interviews with thirteen partners investigated:

- Partner satisfaction with scheme’s service
- An understanding of partner/advocate relationships.

Advantages of the CALL approach include:

- The adapted version of CAPE-revised widened the scope of the evaluation to provide an organisational context within which to interpret the co-ordinator interviews.
- Multiple methods strengthened research validity
- The project team and staff were involved in shaping the evaluation
- The interviews elicited perceptions about the scheme (happily “overwhelmingly positive”) (Gates et al, 2000;55)
- The outcomes validated the personality inventory as the personality characteristics of the advocate were seen as highly important.

Disadvantages include:

- The sample of partners interviewed was small (albeit larger than CAIT models) and therefore not fully representative
- Whilst over half of the referrals related to people with learning disability those who were interviewed were all described as articulate: whilst provision had been
made to help people with communication problems, the views of people who were not readily articulate were therefore missing

- The views of the advocates themselves appear to be missing
- Whilst use of the personality inventory was seemingly validated, the views of the advocates who were subjected to it are not known. It added a considerably time-consuming element to the research. In this regard the partner semi-structured interviews were not piloted because of time constraints
- It did not appear to attract additional funding from local funders.

MODEL 5

Cantley et al (2003) cited an example of a dementia service self-evaluation where a questionnaire was produced in consultation with an advocacy network. The questionnaires were sent to carers and professionals in contact with the advocacy project and investigated:

- Awareness of the dementia advocacy service
- Understanding of service aims
- Access to the service
- Frequency of contact with the service
- Reliability of the service
- The advocates’ communication skills
- The level of support from the advocate
- The advocacy outcome
- The impact of advocacy on the service user
- The impact of advocacy on the way professionals in other agencies worked.

There was also a clear intention to interview users of the advocacy service.

On the basis of the data the service was able to make improvements in the areas of publicity, working with carers and promoting professional understanding. However the approach was limited by:

- The limited response rate to the questionnaire (30%)
- The decisions taken by people with dementia, apparently for a variety of reasons, not to be interviewed.

MODEL 6

RETHINK severe mental illness provides advocacy services as one of a whole range of its activities. Schemes cater primarily for people with mental health problems, although some individuals may also have mild learning disability. Discussion with an advocacy co-ordinator (personal communication 2004) revealed three methods of evaluation have been used:
1. Questionnaire
2. Structured interviews
3. Focus group interviews of homogeneous groups of service users and advocates.

The questionnaire was described as “hopeless”. Focus groups were often difficult to arrange and required sophisticated analysis. The *structured interview* administered by trained and paid service users was described as the most effective and cheapest means of evaluation and the “classic” model used to satisfy funders.

The advantages of the structured interviews approach included:
- The use of service users as co-researchers facilitated the participation and engagement of users of the advocacy services
- It proved cheap to administer and obtains results
- It meets funders’ objectives.

Disadvantages include:
- The research process is not easily accessible for people with severe cognitive impairments
- The interview approach may not readily appeal to people with cognitive impairments (as suggested in Models 4 and 5)
- Absence of standardisation and independence of the evaluators.
<table>
<thead>
<tr>
<th>Model</th>
<th>Process</th>
<th>Pros</th>
<th>Cons</th>
</tr>
</thead>
<tbody>
<tr>
<td>CAPE – Citizen Advocacy Program Evaluation</td>
<td>Interviews co-ordinators • Uses rating scale to score standards • Assesses independence of scheme • Assesses loyalty of advocates • Assesses centrality of relationship</td>
<td>Pros: • Links principles to practice • Objective measure • Develops advocacy culture</td>
<td>Cons: • No assessment of outcomes • Funding patterns compromise principles • Only for citizen advocacy schemes</td>
</tr>
<tr>
<td>CAIT – Citizen Advocacy Information &amp; Training</td>
<td>Interviews with advocacy partnerships &amp; staff • Investigates: • Range of clientele • Advocacy roles • Advocate preparation • Advocacy loyalty</td>
<td>Pros: • As for CAPE • Acknowledges local issues</td>
<td>Cons: • Problems of evaluating partnerships • Barriers to data created by confidentiality • No sense of overall impact (for funders)</td>
</tr>
<tr>
<td>ANNETTE</td>
<td>Uses tables to count: • Numbers of tasks • Time taken • Different advocacy roles</td>
<td>Pros: • Can be used in a range of schemes • Meets Best Value objectives for outcome measures</td>
<td>Cons: • More suited to casework advocacy than long-term citizen advocacy partnerships</td>
</tr>
<tr>
<td>CALL – Citizen Advocacy Lincolnshire Links</td>
<td>Adapted CAPE-revised • Interviewed co-ordinators &amp; additional staff • Psychological testing of advocates &amp; comparative measures • Interviewed sample of partners</td>
<td>Pros: • Provided organisational context • Used multiple methods for validity • Recognised importance of personality characteristics of advocates</td>
<td>Cons: • Learning disability clientele not interviewed • Time consuming nature of psychological intervention • Unknown impact on funders</td>
</tr>
<tr>
<td>Dementia Service self-evaluation</td>
<td>Devised questionnaire in consultation with advocacy network. • Investigated: • Awareness &amp; understanding of the service • Access to the service • Quality of advocacy &amp; its effects • Interviews (planned)</td>
<td>Pros: • Scope of questionnaire • Obtained useful data</td>
<td>Cons: • Poor response to questionnaire • Service users declined to be interviewed</td>
</tr>
<tr>
<td>RETHINK (mental health service)</td>
<td>Used structured interview administered by service users</td>
<td>Pros: • Engaged service users • Cheap &amp; easy to implement • Satisfies funders</td>
<td>Cons: • May not be appropriate for people with cognitive impairments especially where the impairment is severe • Focus group unattractive to participants</td>
</tr>
</tbody>
</table>
Recent proposals and developments

Cantley et al. (2003) developed recommendations for evaluation and monitoring on the basis of a comparative case study of seven advocacy schemes. The recommendations, albeit for dementia services, broadly reflected the Scottish Executive guidance regarding routine data collection, thus suggesting the continuing evolution of advocacy development. However, they fleshed out core areas around joint working with health and social care agencies that advocacy services should consider including in their monitoring and evaluation arrangements. These included:

- Mechanisms to promote understanding between advocacy schemes and statutory services regarding respective objectives, pressures and constraints
- Identification of advocacy champions in other agencies
- Joint policy development viz. referrals, advocacy involvement and information sharing policies
- Development of inter-agency strategies to discuss policy issues and to promote advocacy planning and service development in the context of health and social care strategic planning.

The study also distilled good practice guidance that could be incorporated as standards against which to evaluate the content of advocacy training and support measures. The areas covered include:

- General advice such as preparation, approach, awareness, reliability
- Consent and other ethical issues
- Representation
- Working with families
- Working with practitioners in other services
- Handling boundary issues
- Managing endings
- Reflective practice and developing a reflective diary.

Booth and Booth (2003) broadly built on the aspirations of Brandon and Morris’ (2000) power audit related to people marginalised by mental health problems and often also drug and alcohol addiction. Booth and Booth’s study concerned a Supported Learning Project (SLP) providing personal support and development in self-advocacy to mothers with learning difficulties. They employed a programme of continuous monitoring to assess the empowering effects of the scheme.

More recently, Forbat and Atkinson (2005;328), using both quantitative and qualitative indicators, instituted a mixed-method approach, reflecting the available literature to evaluate the process, outcomes and scope of local advocacy services in Nottinghamshire. Significantly, they also adopted a two-pronged approach to identify unmet need. The first approach involved a systematic consultation with health and social care managers through email and telephone calls. The second involved ‘drop in’ observation and informal interview sessions with members of the public in hospital and GP waiting rooms.
to investigate understanding of advocacy and thoughts on where it could be found. This and other studies suggest the breadth and depth required of evaluation frameworks and the combined relevance of many currently available tools.

These recent studies have highlighted the importance of finding methods that elicit focused narratives about the advocacy experience and its expressive and instrumental effects. They also endorsed the value of using traditional research methods flexibly and sensitively (Wilkinson, *et al*, 2003) and on developing trust between the researchers and researched (Mills, 2003) in inquiries that involve seldom heard groups. The innovatory approach of Forbat and Atkinson (2005) to widen the scope of inquiry to incorporate the views of potentially interested parties and the public, adds to the investigatory armoury. The identified elements suggest the huge scope of the research topic and the relevance of currently available tools, often in combinations that are not confined to research, but can also extend to evaluation and audit.
Part 3 – Local Authority survey: outcomes and observations

As reported in Part 1, each LA was asked to identify at most two advocacy schemes used by people with learning disabilities that it supports. Part 1 also gave an account of how the 97 schemes (described below) were identified by the 54 respondents. Most of schemes (60 percent) had received support for 3 years or more. Only two advocacy schemes had been supported for less than a year. This indicates that in many areas there are well-established schemes, with presumably a record of transaction between the LA funder and the advocacy service. Two thirds of respondents were either commissioning managers (officer) or head/managers of learning disabilities services (66.7 percent), and general service mangers represented about a quarter (23.5 percent) of respondents, while other respondents included policy officers, planning and development officers and contract officers. This gave the research team some confidence that those responding were well acquainted with the schemes they outlined and their place in the systems of local authority commissioning.

Type of schemes

The majority of advocacy services were either self-advocacy (41.9 percent) or citizen advocacy (30.1 percent), followed by peer advocacy (12 schemes). Respondents were asked to indicate how each advocacy service was constituted. Figure 1 shows that 60.8 percent of schemes were a charity or trust, 44.1 percent were self-help groups (national or local), while 5.3 were in a network of local schemes. As mentioned, most of questions allowed for multiple answers, thus, in the figures reported below, total percentages are often higher than 100 percent.

Figure 1 Percentage of advocacy schemes by type (n = 24)
The survey sought information about who was undertaking advocacy for people with learning disability. About a third (35.5 percent) of advocacy services were described as having service users involved in delivering the service. Carers/supporters were involved in 14 percent of schemes. Very few schemes (4 schemes) included healthcare or legal professionals in delivering the service.

Most of the advocacy schemes were described as supporting people with learning disabilities in general. Nevertheless, 16 schemes were designed to support specific groups, such as adults, parents and carers, and people from black and minority ethnic groups. Interestingly, 12 of these specific schemes were funded by LAs situated in mixed rural and urban areas, while 4 were in urban areas, undermining any view that specialist advocacy is urban centred. The results do not show particular differences in the ways local authorities evaluate generic or specific services. The later might be due to the small number of specific services studied or because current evaluation methods are regarded by local authorities and schemes to be robust enough to be used for both types of services.

Reasons for support

Table 4 outlines how advocacy schemes were supported by local authorities and Figure 2 shows the reasons why LAs supported each scheme. The most frequently cited means of support was through service level agreements (77.3 percent) followed by partial (49.5 percent) or full (37.1 percent) funding of schemes. Some of the less frequently cited supports were: providing office accommodation; being members of management committees; providing administration; and secondment of staff. Ten schemes were helped by local authorities in their search for external grants while 16 schemes were offered some training for their staff. Moreover, the data suggests some changing patterns of support when looking at advocacy schemes that had been supported for less than 3 years and for 3 years and more. However, these results need to be treated with caution as the number of schemes supported for less than 3 years was only 41. They indicate a possible shift from partial to full funding among more recently supported schemes. Also more recent schemes are more likely to receive other forms of support, such as office accommodation, administration, training and secondment of staff, than schemes that had been supported for 3 years or longer.
Table 4: Percentage of advocacy schemes and type of support according to length of support

<table>
<thead>
<tr>
<th>How local authorities support advocacy services</th>
<th>Length of support</th>
<th>Percent of all schemes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>&lt;3 years</td>
<td>3 years or more</td>
</tr>
<tr>
<td>Commissioning service level agreement</td>
<td>70.3</td>
<td>82.1</td>
</tr>
<tr>
<td>Partial funding of scheme</td>
<td>35.1</td>
<td>57.1</td>
</tr>
<tr>
<td>Full funding of scheme</td>
<td>54.1</td>
<td>28.6</td>
</tr>
<tr>
<td>Seeking/secureing external grants</td>
<td>18.9</td>
<td>19.6</td>
</tr>
<tr>
<td>Expenses (e.g. travel)</td>
<td>21.6</td>
<td>17.9</td>
</tr>
<tr>
<td>Providing training</td>
<td>21.6</td>
<td>17.9</td>
</tr>
<tr>
<td>Attending committee meetings</td>
<td>24.3</td>
<td>12.5</td>
</tr>
<tr>
<td>Providing administration</td>
<td>13.5</td>
<td>7.1</td>
</tr>
<tr>
<td>Providing office accommodation</td>
<td>10.8</td>
<td>1.8</td>
</tr>
<tr>
<td>Other funding (e.g. case by case)</td>
<td>5.2</td>
<td>5.2</td>
</tr>
<tr>
<td>Member of management committee</td>
<td>8.1</td>
<td>3.6</td>
</tr>
<tr>
<td>Secondment of staff</td>
<td>10.8</td>
<td>0.0</td>
</tr>
<tr>
<td><strong>Number of schemes</strong></td>
<td><strong>41</strong></td>
<td><strong>56</strong></td>
</tr>
</tbody>
</table>

Respondents were asked about the reasons for supporting each advocacy scheme. ‘Policy initiatives’ were given as the main reason in almost three quarters of schemes (73.1 percent). A third (33.3 percent) cited changes in service provision, just over a quarter (26.9 percent) hospital closure programmes, approximately one fifth the outcome of a review (21.5 percent) and ‘tradition’ (19.4 percent), and 16.1 percent ‘campaigning pressure’.
Table 5 presents perceived outcomes of advocacy schemes: over three quarters (75 percent) were regarded as having the following outcomes: empowering service users; improving service user status and credibility; or meeting policy aims. Most, 60 to 75 percent, were seen to: promote independent living; make independent representation available; identify need/cause for concern; or improve service quality. Other perceived outcomes are: to improve family/carer understanding and attitudes (52.6 percent); to assist with decision-making in complex cases (48.5 percent); to improve inter-agency working (50.5 percent); and to improve service monitoring (53 percent). In respect of only 9 schemes it was reported that one of the perceived outcomes is to ‘fulfil legal requirements’. Interestingly, eight out of these nine were located in urban areas. These results mirror discussions of wider perception of outcomes of and reasons for advocacy services and whether they are mainly to empower service users or to implement policy and whether these perceived outcomes complement or contradict each other.
Table 5: Percentage of advocacy schemes perceived to have the following outcomes

<table>
<thead>
<tr>
<th>Perceived outcomes of advocacy schemes</th>
<th>Percent of schemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Empowers service users</td>
<td>85.6</td>
</tr>
<tr>
<td>Aligned with policy (e.g. <em>Valuing People</em>)</td>
<td>77.3</td>
</tr>
<tr>
<td>Improves service user status/credibility</td>
<td>75.3</td>
</tr>
<tr>
<td>Improves service quality</td>
<td>66.0</td>
</tr>
<tr>
<td>Promotes independent living</td>
<td>62.9</td>
</tr>
<tr>
<td>Independent representation available</td>
<td>62.9</td>
</tr>
<tr>
<td>Identifies need/cause for concern</td>
<td>60.8</td>
</tr>
<tr>
<td>Improves status/credibility of advocacy scheme</td>
<td>55.7</td>
</tr>
<tr>
<td>Improves family/carer understanding/attitudes</td>
<td>52.6</td>
</tr>
<tr>
<td>Improves service monitoring</td>
<td>52.6</td>
</tr>
<tr>
<td>Improves inter-agency working</td>
<td>50.5</td>
</tr>
<tr>
<td>Better commissioning decisions</td>
<td>50.5</td>
</tr>
<tr>
<td>Assists with decision-making in complex cases</td>
<td>48.5</td>
</tr>
<tr>
<td>Improves status/credibility of local authority</td>
<td>43.3</td>
</tr>
<tr>
<td>Cost effectiveness for local authority</td>
<td>26.8</td>
</tr>
<tr>
<td>Fulfils legal requirement</td>
<td>9.3</td>
</tr>
</tbody>
</table>

**Total number of schemes = 97**

*Current and planned Evaluation of Advocacy Services*

The survey asked how LAs evaluate or monitor the effectiveness of each of the identified schemes. Respondents were offered multiple choices and an open-ended option to provide this information. Table 6 presents the percentage of advocacy schemes that are evaluated or monitored through the listed methods. Use of service level agreements as an evaluation tool was mentioned in respect of 73 percent of schemes followed by receipt of the annual report for 53.8 percent. Discussions with service users, staff/volunteers of advocacy schemes, and at the partnership board were mentioned in around 39 percent of schemes. In only 6.5 percent was any accredited evaluation tool used. However, the latter was used more in urban areas (13.5 percent compared to 1.8 percent in rural or mixed rural and urban areas). Formal discussions with service user representatives and reference to complaints were mentioned for 27 percent of schemes. In respect of 3 schemes LAs felt they had no means of monitoring them.
The survey asked whether LAs planned to adopt any evaluation mechanism in the near future and 29.6 percent indicated that they were planning to do so. When asked to describe briefly the planned mechanisms, most respondents reported that this was still to be agreed. However, most indicated that they would involve service users and carers in the evaluation process. Some of the methods planned included: use of users’ satisfaction surveys; performance monitoring process; regular meetings with advocacy service providers; learning from other local authorities. One respondent suggested exploring the Quality Assurance Framework model (DH 2003).

Respondents were asked about their views on the best ways of monitoring and evaluating advocacy schemes for people with learning disabilities. Several interesting ideas were presented, mostly focusing on obtaining both service user and staff feedback. Face-to-face workshops, story-boards and qualitative stories of service users’ experiences combined with performance targets were also suggested. Some proposed approaching people who do not use the services to find out why they do not, in addition to listening to people who are using the services.

There were, however, some concerns about the difficulties of evaluating advocacy schemes in general and particular. Clear measurable outcomes of advocacy are difficult to define, making any evaluation process complicated. It was evident that respondents were aware that outcomes from the authorities’ perspectives often differ from those of service users, thus it is not always possible to standardise outcome evaluation. A number of respondents felt that any evaluation process might start by clear service specifications, based on identified service users’ needs and the local context, with flexibility to address

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Table 6: Percentage of advocacy schemes according to evaluation or monitoring method

<table>
<thead>
<tr>
<th>Evaluation/monitoring method</th>
<th>Percent of schemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service level agreements</td>
<td>73.1</td>
</tr>
<tr>
<td>Receive annual report</td>
<td>53.8</td>
</tr>
<tr>
<td>Discussion with staff/volunteers of advocacy organisation</td>
<td>39.8</td>
</tr>
<tr>
<td>Discussion with service users - general</td>
<td>38.7</td>
</tr>
<tr>
<td>Discussion at partnership board</td>
<td>38.7</td>
</tr>
<tr>
<td>Audit of advocacy service</td>
<td>26.9</td>
</tr>
<tr>
<td>Reference to complaints/compliments</td>
<td>26.9</td>
</tr>
<tr>
<td>Discussion with service user representatives - formal</td>
<td>26.9</td>
</tr>
<tr>
<td>Use performance indicators</td>
<td>19.4</td>
</tr>
<tr>
<td>Read committee meeting minutes</td>
<td>17.2</td>
</tr>
<tr>
<td>Use accredited evaluation tool</td>
<td>6.5</td>
</tr>
<tr>
<td>Audit of care plans</td>
<td>4.3</td>
</tr>
<tr>
<td>No means of monitoring</td>
<td>3.2</td>
</tr>
<tr>
<td>Benchmarking</td>
<td>0.0</td>
</tr>
</tbody>
</table>

Total number of schemes = 97

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( continue )
contingencies. Whatever the methods suggested, those interviewed considered that objectives should be decided through regular formal liaison with service users, parents and carers.

As the data reflects, most advocacy services were monitored through service level agreements. However, the use of evaluation tools or performance indicators to inform this process was modest. Involving service users and carers, whether formally or through general discussions, in the evaluation process was mentioned frequently both for current evaluation and future plans but there was generally no model to accomplish this.

**The potential for evaluation to influence change**

The survey asked whether LAs had ever modified any of the advocacy services they enumerated. Respondents reported that 49 advocacy services (52.6 percent) had been modified, 28 schemes of these had been modified as a result of an evaluation. Table 7 presents the type of changes that were made for all modified services: the most cited types of change are: expanding the service in volume (40 advocacy schemes); structural change (9 schemes); and the establishment of regular reviews (7 schemes). Other changes included expanding client groups (6 schemes); contracting the service by volume (4 schemes); and staff changes (3 schemes). Only one service was reported to have closed. While the survey focused on the current situation rather than the past, one interpretation of this data is that evaluation that is reportedly much feared did not lead to contraction of schemes in many instances.

Table 7: Percentage of advocacy schemes that have been modified and how

<table>
<thead>
<tr>
<th>Types of changes</th>
<th>Percent of schemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service expanded in volume</td>
<td>77.6</td>
</tr>
<tr>
<td>Structural changes</td>
<td>18.4</td>
</tr>
<tr>
<td>Regular review instituted</td>
<td>14.3</td>
</tr>
<tr>
<td>Service expanded in client group</td>
<td>12.2</td>
</tr>
<tr>
<td>Service contracted in volume</td>
<td>8.2</td>
</tr>
<tr>
<td>Staff changes</td>
<td>6.1</td>
</tr>
<tr>
<td>Service contracted in client group</td>
<td>4.1</td>
</tr>
<tr>
<td>Service closed</td>
<td>2.0</td>
</tr>
</tbody>
</table>

**Number of schemes modified = 49**

Table 8 present options open to LAs to influence change, regardless of whether they had modified any of the advocacy services they support. It reveals that many respondents felt that they could influence change, mainly through consulting stakeholders or through revising the agreement. They indicated that a second option would be to withdraw the agreement followed by consulting the local advocacy network.
Table 8: Scope of influence for local authorities

<table>
<thead>
<tr>
<th>Options to influence change</th>
<th>Percent of schemes reported to have each option</th>
</tr>
</thead>
<tbody>
<tr>
<td>Revise agreement</td>
<td>87.1</td>
</tr>
<tr>
<td>Consult stakeholders</td>
<td>86.0</td>
</tr>
<tr>
<td>Withdraw funding</td>
<td>69.9</td>
</tr>
<tr>
<td>Consult chairperson/equivalent</td>
<td>63.4</td>
</tr>
<tr>
<td>Consult partner organisations</td>
<td>60.2</td>
</tr>
<tr>
<td>Consult local advocacy network</td>
<td>39.8</td>
</tr>
<tr>
<td>Consult relevant national organisation</td>
<td>23.7</td>
</tr>
<tr>
<td>No means of intervention</td>
<td>0.0</td>
</tr>
</tbody>
</table>

Total number of schemes = 97

Summary

Whilst the survey response rate was low significant trends emerged regarding the evaluation and monitoring of advocacy services for people with learning disabilities. Service level agreements and annual reports were by far the most common means of monitoring and there was little evidence of other types of evaluation being used. Almost half of the responding authorities had instigated change, in over three quarters of cases to increase service volume. Policy shifts were largely held to be responsible for the recent development of advocacy services that were viewed to be important in empowering service users and promoting independent living. Although service users’ views were asserted to be an important component of evaluation and were apparently taken into account, the detail of how this was done was beyond the scope of the survey.

In order to make more detailed enquiries about evaluation from a broad range of interested groups, a series of interviews was undertaken and these are described in the next section.
Part 4 Stakeholder interviews: perceptions and recommendations

The many types of advocacy.

The interviews broadly confirmed the existence of the core advocacy typologies identified in the Introduction. According to those interviewed, the greatest ‘buzz’ of activity and current interest was apparent in the self-advocacy movement. Peer and collective advocacy were seen as extensions of self-advocacy, although those performing these roles were sometimes not aware that they had progressed to what others might see as advocacy. Citizen advocacy was identified as very important for people with complex or profound needs where it was essential to know the person well in order to ascertain their needs and wishes. However, in line with recent research (Atkinson and Forbat, 2005), a few participants mentioned that funders were favouring representational or issue-based advocacy over citizen advocacy schemes:

“A lot of advocacy that’s needed is when things go wrong – it now tends to be issue-based whereas previously there were citizen advocacy schemes. A lot of citizen advocacy schemes have extended their schemes now and have paid advocates to do short-term work – that’s not to say citizen advocacy is not needed for people with profound difficulties”. Manager, advocacy service.

Effectiveness of schemes

Interviewees painted a mixed picture regarding the effectiveness of advocacy services. Advocacy was seen as ‘more established’, ‘better understood’ and working well where national and local forums were having an impact. The contribution of self-advocacy was generally viewed very positively. A sense of service user appreciation was evident, as reflected in one service user’s response:

“Self-advocacy is going very well – it helps people to have a voice, develop in different areas … to have choices”. Self-advocacy development worker.

Those interviewed described representational advocacy in positive terms because it was easy to demonstrate the changes it made to people’s lives. However, the very independence of advocacy schemes that enabled them to challenge services could be adversely affected by the vested interests of the local authority and fear of resources being withdrawn:

“Independence of funding from services – this is essential … to avoid services having their funding cut, as reported to me … the whole point of advocacy is to fight officialdom – if the same officialdom is paying the money then there’s conflict”. Chief Executive, National Advocacy Charity.

In addition, a few comments were made that advocacy services were being ‘framed’ by the local government or health organisations that paid for their services, rather than by service users. For example, in some areas self-advocates were reportedly being asked to undertake extra consultancy by health or social services. This work was not always paid, could be outside the contractual arrangement and was at the risk of deflecting self-advocates away from their core work:
“There’s a lot of confusion and misunderstanding about advocacy. What tends to be in place is professional forms of subverted self-advocacy – not true self-advocacy, but a professional version of advocacy, people with learning disability undertaking a self-advocacy role framed by people and kept safe, rather than by people with learning disability speaking and acting for themselves”. Chairperson, National Advocacy Project.

Some reported that short-term funding hampered advocacy schemes’ effectiveness by preventing long-term planning. Many schemes were described as being on a ‘knife’s edge’ and they feared for their future survival. In some areas, advocacy services were identified as being in very short supply or non-existent. Finding advocates was said to be particularly difficult for people who also had mental health problems, autism, challenging behaviour and sensory impairments. In addition, people from minority ethnic backgrounds were identified as being poorly served.

The shortage of local schemes and lack of evaluation tools could hamper commissioners’ objectives to improve advocacy services. This represented the flipside to the controlling position of local authorities, mentioned above, and gave the advocacy scheme the ‘whip hand’:

“But it can work both ways – … – I was talking to a commissioner last week who was spending good money on advocacy – was saying that they get little clarity from an advocacy project about the advocacy role – the project is asking for increasing amounts of money – the commissioner feels [he] is being held hostage – there’s no competition – if you tender out there is rarely any competition – the commissioner feels held to ransom – there is no choice”. Regional advisor advocacy services.

**Partnership Boards**

In England, Partnership Boards, set up to further the aims of the *Valuing People* (DH, 2001) and to integrate planning and services, were identified as being centrally placed to further the position of advocacy:

“Partnership Boards … are supposed to be working under the *Valuing People* objectives – all the people who want it have access to advocacy … and there will be citizen advocacy in every area … it’s a performance indicator”. Regional advisor advocacy services.

However, in spite of policy objectives, views that the Boards were a ‘very mixed bunch’ formed the bedrock of responses. Very few informants reported favourably and a slightly higher proportion gave entirely negative responses about the capacity of Boards to ensure advocacy was promoted and sustained. Boards were generally viewed to be working well where democratic processes were followed, membership was inclusive of people with leaning disabilities, people with learning disability were properly supported and the meetings were not too large:

“The Partnership Boards that are working well have joint chairs – people with learning disability and people without learning disability – those who haven’t aren’t working well – it’s very variable. The Valuing Support Team should be supporting the Partnership Boards in local areas – where this is working well it has resulted in good involvement of people with learning disability and their families”. Policy-maker.
“The Partnership Board is helping and not helping – half and half. There are good things but they need to do more work on reviewing on a regular basis how people with learning disability are being involved – you shouldn’t have the person from the local authority speaking all the time – they should make it an equal share – easier access for people with learning disability – more choice in how the partnership board is running. The language must be accessible for people to understand. I’m on the Partnership Board – my supporter goes with me and I support people to go on it. They have a morning meeting and workshops. People with learning disability go to that”. Self-advocacy development worker.

An advocacy service manager observed that the diverse representation of the Boards could help to protect advocacy schemes from the vested interests of local authorities, as more people were aware of what was going on. However, the breaking down of meetings into smaller groups was generally appreciated and many commented that this helped service users to have their voices heard. Partnership Boards were also reported as offering opportunities to advocacy schemes to broadcast their effectiveness to commissioner ‘movers and shakers’.

**Evaluation**

A few interviewees were completely unaware of the existence of evaluation mechanisms (similar to the lack of knowledge displayed in Part 3 Table 4). While there was considerable concern about evaluation, in line with the findings of the survey sent to local authorities (see Part 3), the evidence suggested that either a range of semi-appropriate tools was being used or nothing was happening at all. Although advocacy networks were trying to develop common standards, there were major stumbling blocks. These included the different views of stakeholders regarding what constituted a successful outcome, the problem of deciding what was being measured, and resentment amongst some schemes, particularly those aspiring to the purist position of total independence, of the intrusiveness of evaluation:

“A real issue – people are judging on reputation – but the reputation is in the eye of the beholder. If the commissioner is having a hard time from the group this can colour their attitude. There is little that is objective …”. Manager, advocacy project.

“A lot of schemes don’t monitor and review their work – a lot of schemes think they can be independent but not accountable for money …” Policy performance manager.

Citizen advocacy was considered to be the most difficult to measure because of the central importance of the quality of the partnership, whilst representational advocacy was the easiest. Although tools principally designed for citizen advocacy have been in existence for some time (see Part 2), these were not mentioned as working models. However, in some cases, informants indicated that the quantitative elements of these tools were being incorporated in a range of approaches:

“But how do you measure long-term advocacy? What are you measuring? It's very time consuming – the development of the relationship. The partnership may go on for years – it’s difficult to pin down what you’ve achieved. You need evaluation that will evaluate the relationship to the partner … helping someone to have a fuller meaningful life – an extra person in their lives is very difficult to measure – but they may be very important to that person.” Chief Executive, National Advocacy Charity.
Among measures used to monitor advocacy were reliance on ‘reputation’, instituting an audit, assessing against the contract, holding regular reviews and reading the annual report. Tensions were apparent between the appropriateness of quantitative and qualitative approaches, tools that measured systems, procedures and process versus those that measured the elusive quality of the partnership and approaches using self as opposed to independent assessment. ‘PQasso’ – Priority Quality Assurance System – was identified by one interviewee as a generic tool that measured a comprehensive range of operational systems. Its major disadvantages were reported to be its self-assessment approach and systems focus:

“PQasso … covers services, structures, user-centred development, committee, office and staffing, networking, monitoring and evaluation and complaints – you assess against key indicators … it’s slightly out of fashion now because of self-assessment and bias. I was shocked at how groups had an over-inflated view of themselves – it’s not robust”. Director, advocacy network.

The Community Legal Service Quality Mark (CLSQM), reported to be increasingly required by some funders, did provide a level of independent scrutiny. However, this scheme was designed for law centres and similar and focused on systems, procedures and working practices rather than outcomes. Like PQasso, the CLSQM was viewed to be inadequate by those interviewed who knew of it because it failed to address the impact of advocacy.

ANNETTE (ANN, 2004, see above) and the model devised by the Scottish Executive (2000) and promoted by the Advocacy Safeguards Agency (ASA, 2003) are examples of approaches specifically designed to evaluate advocacy services. ANNETTE, instituted to meet Best Value objectives (Henderson and Pochin, 2001), uses tables to count the number of tasks undertaken, the time taken to complete the tasks and the nature of the different advocacy roles. Whilst the approach is viewed to be more suited to representational advocacy rather than long-term citizen advocacy partnerships (Henderson and Pochin, 2001), one person indicated that it was deeply appreciated by funders. However, as her service was well aware of the limitations of the model, a six-monthly ‘follow-along’ review had been instituted whereby the advocate and partner were seen by a service co-ordinator to assess the effects of the relationship. This part of the evaluation included personal criteria, for example an assessment as to whether the confidence of the person being helped had increased. The resulting information was quantified as a measure to reflect the qualitative component.

Scottish informants pointed to guidance developed by the Scottish Executive (Independent advocacy: a guide for commissioners, 2000) and the Advocacy Safeguards Agency (ASA) (Resource Pack for Evaluators, (ASA) 2003b). One informant involved in policy development extolled its comprehensiveness. The guidance identifies both core criteria applicable to the evaluation of all forms of advocacy and specific criteria related to particular case scenarios, for example, schemes set up to assist in hospital resettlement programmes. It spells out the advocacy process, scope of the evaluation and whom it should involve. Regular independent evaluation, self-monitoring and a regular cycle of face-to-face meetings between the funders and the advocacy scheme to agree the evaluation criteria and inform community planning were also promoted. However, the
guidance was heavily criticised by another informant, also working in the policy field, who described a complaint made by a service user-led organisation that service users could not understand the questions set by the evaluation. As a consequence, people with learning disabilities were apparently unable to participate properly in the evaluation. This informant further argued that an attempt to standardise evaluation across different types of advocacy was insufficiently flexible for the task and claimed that ‘there were currently a lot of unhappy advocacy schemes’ as a result.

**The potential effects of new legislation on advocacy schemes**

Whilst England and Wales were in the throes of pre-legislative developments in respect of the Mental Capacity and Mental Health Bills at the time of the research (2004-5), in Scotland parallel legislation was already statute, although the new Mental Health (Care and Treatment) (Scotland) Act 2003 had not yet been implemented. The responses were therefore speculative and there was considerable uncertainty about how the new legislation would operate in practice alongside existing advocacy services.

Positive comments regarding the introduction of the Independent Consultee (IC) and lay advocacy in law concerned the potential to raise the profile of advocacy, especially if services were to be financed to do the work. In addition, advocates undertaking the new roles would have the right to be present at meetings without fear of being dismissed and targeted groups at least would have the legal right to have an advocate. One Scottish service commissioner expressed the hope that the introduction of a tribunal in place of the court system would reduce the legally based nature of the work. In this regard advocates were being sought to support people in the tribunal setting.

However, there were also concerns that the new legal measures would lead to divisions within the advocacy service, a two-tier service of professionalized versus non-professionalized advocates with the ‘super’ official advocates being listened to and the others liable to be dismissed. There were fears that the officially funded advocates would lose their campaigning edge. A senior policy-maker who had supported a person with learning disabilities commented that paid advocacy would remove the friendship qualities underpinning the advocacy role and said there was evidence to suggest that people with learning disabilities valued this element highly.

In addition, some informants were concerned that the new roles were confined to the smallest groups of people. In respect of learning disability, conflict was generally most evident amongst people whose families and friends were deeply involved in their lives, not among those who were isolated. Furthermore, once a person had been identified as lacking capacity would that remain their default status? In England and Wales the Independent Mental Health Act Advocate role (IMHAA) was planned to be restricted to people who were detained under Mental Health Bill proposals but to exclude those about to be detained and the *de facto* detained (see L v Bournwood Community and Mental Health Trust, ex parte L. [1998] 3 WLR; 107) among whom the needs for advocacy were likely to be high. People with both mental health problems and learning disability, and those with other disabilities such as autism, could fall through the gap. Frequent
reference was made to the current dearth of advocates to meet existing needs, a factor that would have human resource implications in respect of the new roles and increased demand for advocacy. Scottish services were described as being particularly under pressure because advocacy under mental health legislation was open to anyone, not just those who were detained. Services were said to be ‘running scared’ because of the scarcity of advocates and looking to commission ‘scatter gun’ advocacy (professional advocacy) contrary to guidance that suggested one to one advocacy (Scottish Executive, 2003). However, the proposal that 140 IMHAAs would be able to provide the necessary advocacy in England and Wales was greeted with ‘hysterical laughter’, as ‘too small’, and ‘farcical’, particularly as there were 150 or so local authority areas. The numbers were too few and would change the nature of advocacy:

“140 – I think that’s impossible – it’s changing what you mean by advocacy. If it’s speaking up for that person how could you do it for that person if there are only 140?” Co-director, national charity.

One participant who managed a small citizen advocacy project and representational service was ambivalent about the specialist focus of the IMHAA. Whilst an IMHAA would be highly knowledgeable about the workings of legislation, there were also dangers that the wider social elements, essential to facilitating discharge, might be lost or spread across a range of other specialist advocates. The specialist service could be positive but it could also be a retrograde step:

“I suppose it could create differences between advocacy services. It could be confusing for the person with the mental health problem if they have two different advocates, one person only works with that issue. Does it really separate out? Would you have for example specialist housing advocacy? But if you don’t have separate advocacy it could mean advocacy took on loads of issues – separating out advocacy into specialist areas could be a benefit. But if the Mental Health Act advocate is confined to health issues who is going to pick up the other stuff? There are places that don’t have advocacy still. There are people who have small every day issues that are really important to them. If you have crises smaller things go awry – maybe. … mental health issues may be very interrelated with other issues, for example housing and aftercare”. Advocacy development worker.

Towards the end of the fieldwork, the proposed Independent Consultee (IC) under the English Mental Capacity Bill (now Act 2005) was changed to the role of Independent Mental Capacity Advocate (IMCA) thus ending speculation regarding the intended nature of the role and its relationship to advocacy. Concerns had been expressed that the term advocacy had not been used and that the ‘best interests’ focus and what might ensue, conflicted with the advocacy role of representing a person’s wishes. The role of the IC was potentially awesome:

“The IC … best interests and partial to the person – I think that’s extraordinarily dangerous. The life support ‘Charlotte’ case – the parents were asking the Trust to intervene – the Judge needed the wisdom of Solomon – took into account every bit of relevant policy and the nature of the intervention which was very painful. Best interests was very sensitively handled, but it was at odds with the parents. Who is going to take on these roles because they are so onerous? There is a place for the IC role – but that should rest with the judiciary?” Chief Executive National Charity.
However, one person registered concerns that under current proposals there was a danger that an IMCA might work independently and not as part of a team of advocates where he or she would be monitored and supported to do the work.

**The future of advocacy and recommendations for change**

Informants expressed mixed views about the future of advocacy. Some were optimistic that it was at the ‘crossroads’ and on the brink of developing. Others thought there would be little or no change, only ‘incremental steps’. Fears were also expressed that advocacy would at some point cease to have a high political profile. One senior policy manager commented that advocacy was not a national health target and argued that public apathy about the plight of vulnerable groups lay behind official inertia. One person was doubtful about the continuance of Partnership Boards. Another considered that volunteer advocacy was likely to be replaced by casework advocacy because paid workers were easier to control and were more accountable. There was a strong consensus of opinion that regulation was likely to increase. A prediction was made that smaller advocacy schemes, often the more fragile user-led schemes, would be likely to disappear because they would be unable to sustain the extra costs of regulation unlike the larger ones that would probably grow.

In respect of recommendations for change, improved access to advocacy, funding arrangements and policy development featured on ‘wish lists’. General points were made that attitudes needed to change, not only to promote advocacy to empower service users to change their lives, but also to enable planners and commissioners to use advocacy more effectively to improve services:

“Partnership Boards and local authorities still have a perspective – I’m being very general here – that of you involve advocacy you’ve done the consultation and you’ve involved people. They are missing the fundamental principle – advocacy is a process to move things along but it is not an end in itself. It would be helpful if people who were responsible for developing services would use advocacy as a means of helping to develop better as opposed to ‘we’ve consulted’ and tick the box. … The role advocacy can make in changing planning and developing services has been missed to date”. Regional advisor advocacy services:

Against a likely growth in quasi-legal advocacy arising from new legislation, informants wanted advocacy to cover a full range of need:

“Advocacy to cover all the issues – not just big ones and legislative ones”. Advocacy development worker.

**The right to advocacy**

There was consensus that every person with a learning disability should have a right to advocacy. Several participants also pointed to the specialist advocacy needs of people with severe impairments, people with challenging behaviour and those with allied disabilities such as autism and recognition so that while self-advocacy might be ideal it was not always possible. More generally, those interviewed considered that additional advocacy was required not only to meet specialist needs but also to avoid the current ‘postcode lottery’. They wished that the advocacy clauses of the Disabled Persons
(Services, Consultation and Representation) Act 1986 Act should be invoked: advocacy should be formalised: advocates should have the right to be heard. Resources should reflect the need for advocates ‘to really get to know people’ in advance of the event triggering the advocacy request. Advocacy should be recognised by services on an individual’s statement of need as part of person-centred planning. Local user-led initiatives should be retained. Furthermore, local authorities should be legally required to provide advocacy for everyone for whom they provided services:

“The right of the person to have an advocate – I don’t think this would have a massive funding impact. Most people with learning disability won’t want advocacy all the time – they will only need to exercise their rights from time to time – but it would make a huge difference to people’s lives”. Chief Executive National Advocacy Charity.

A few participants promoted the need for carer advocacy and recognition that the autonomy of the person with learning disabilities needed to be balanced within the context of interdependency. It was also suggested that some staff attitudes towards carers needed to change.

Funding

Concerns related to the amount of funding allocated, funding arrangements and ways of managing conflict of interest:

“I should like to see a commitment for funders to fund independent advocacy. I’d like to see more clarity and expectation about independence and what that means”. Regional advisor advocacy services.

Everyone wanted more funding for advocacy. The more tortuous issues concerned conflict of interest and how funding arrangements could be designed to protect the independence of advocacy schemes from funders and give schemes sufficient stability to plan and develop. Various ideas were proposed:

- Funding administered centrally through the Department of Health or a national independent organisation e.g. British Institute for Learning Disabilities (BILD)
- Funding administered locally through local government, but not the social services department, e.g. the legal department or a regional commissioning structure
- Core funding administered from a central body with specialist initiatives locally funded
- Services seek multi-source funding
- Funding allocation without any strings attached.

Two senior managers viewed that there should be better understanding amongst commissioners of the importance of advocacy in promoting change and progress. An advocacy manager gave a robust example of ‘the county council … paying to bite the hand that feeds us and that’s clearly understood’. The importance of promoting the local context was highlighted in a few responses. The development of collective community
advocacy was also described as providing a more powerful lobbying voice to effect change.

**Policies and strategies**

Informants wanted a strategic approach in respect of advocacy development at national and local levels. There were calls for a national agency to promote a coherent advocacy plan and an assessment of advocacy need. In respect of policy, the need for an advocacy code, official guidance and standards developed by advocacy organisations in consultation with Government, featured in responses. Two participants specifically mentioned the importance of a conflict of interest policy to protect the independence of advocacy schemes.

Safeguards to ensure people were receiving quality advocacy to improve services, tackle bullying and address minority ethnic needs were also identified as necessary. Steps should be taken to ensure people with learning disability were integrally involved in setting up and managing local advocacy services. Training to develop representational skills should be instituted. Finally, whilst most acknowledged that it was difficult to capture the essence of advocacy and evaluate social care outcomes, tools that reflected the quality of services and the human impact of advocacy on people’s lives needed to be developed.

**Summary of the interviews**

The findings broadly confirmed the main advocacy typologies. The greatest development was in the self-advocacy movement, although crisis advocacy was also viewed to be increasing, possibly in some areas at the expense of citizen advocacy. The service level agreement and annual report featured as the main means of monitoring and the use of existing evaluation tools was patchy and haphazard. Fears of interference from funders and withdrawal of funding were reported, although particular case scenarios appeared to be more likely triggers rather than the consequence of formal evaluation. The importance of the service user voice in developing advocacy services was recognised and there was evidence that in some cases this was being honoured. However, one advocacy spokesperson considered that service users were being required to meet funders’ needs rather than their own. Although partnership boards were viewed to be an important element of service development, they were commonly reported to be a ‘mixed bunch’, in some areas working well and in others not so well. There were fears that the new advocates enshrined in law would create a two-tier advocacy service, although informants generally viewed that the movement as a whole would grow. The development of common standards and a funding framework to address accountability for public funding and safeguard the objectives of schemes were held to be of utmost importance.
Part 5  Consultation Seminar

A consultation event was held in April 2005 to discuss the above findings. The seminar was attended by 17 participants representing a range of groups such as people with learning disabilities, advocacy organisations, service providers and social work practitioners (see Appendix 1 for a list of participants).

The Importance of Advocacy

There was a general agreement on the importance of advocacy as a way of improving service users’ experience and as part of implementing policy. Box 1 presents some of the points expressed by the groups as to why advocacy is important for people with learning disabilities.

<table>
<thead>
<tr>
<th>Box 1 Points of agreement about the importance of advocacy</th>
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<tbody>
<tr>
<td>- It makes a positive difference to people's lives</td>
</tr>
<tr>
<td>- It is part of policy (e.g. Valuing People)</td>
</tr>
<tr>
<td>- New roles for advocates are emerging</td>
</tr>
<tr>
<td>- New policies (such as individualised budgets) may promote advocacy</td>
</tr>
<tr>
<td>- It is independent of services</td>
</tr>
<tr>
<td>- It can reflect people with learning disabilities' wishes (not solely taking a best interests approach) and some schemes represent the view of carers.</td>
</tr>
</tbody>
</table>

The Need for Evaluation

Given the importance of advocacy services there was a general consensus that it is equally important to be able to evaluate such services. Box 2 presents some of the reasons expressed by the group for the need to evaluate advocacy services in general and for people with learning disabilities in particular. However, there were also some concerns that a rigid evaluation mechanism may be too controlling of schemes and may reduce their effectiveness and detract from their main aims.
Box 2 Points of agreement about the need for evaluation
Advocacy schemes accept the need for and importance of evaluation because:

- It can help counter criticisms of not being representative
- It can help 'prove' it works and isn't a waste of time and money
- It provides evidence that it is running properly (self regulation)
- It can help funders measure one initiative against another, or against other service choices
- It can help clarify the definition of advocacy
- Networks in Scotland (ASA), Wales and England are considering standards and practice. In England there are several umbrella groups and thus a range of initiatives
- Advocacy schemes accept that while they are not the same as user involvement or public consultation - they can help with this but this is not their function
- This can include the process as well as the outcome of the advocacy relationship
- Advocacy schemes acknowledge that less is known about the evaluation of self-advocacy than other types.
- If advocacy is to attract new worker/volunteers it needs to say what it wants of them and what type of individuals it hopes to recruit and the outcomes it expects.

The Scope of Evaluation

When discussing methods and scope of evaluating advocacy schemes, in particular in relation to perceived outcomes and whose perspective should determine them, seminar participants felt that advocacy schemes should work with commissioners to agree the most appropriate type of evaluation and that a mix of methods is more effective. Box 3 presents some of the discussion points around the scope of evaluation of advocacy schemes for people with learning disabilities. Advocacy schemes were said to accept the need to convince people that they are working well and efficiently but that judgements about this need to be made by the people using their services as well as funders.

Box 3 The Scope of Evaluation
Advocacy schemes need to be judged by a range of people, especially those it serves because:

- Independent evaluation can be useful
- Although involving people with learning disabilities is not simple - it can be done
- A narrow or single approach can be limited, for example, sometimes people want to evaluate friendliness or approachability, or just cost
- Self assessment is not independent but is an important part of monitoring
- This will also make good use of evidence available from records, interviews, and assessment tools, a mix of methods
- Some people who might benefit from advocacy do not get the chance to use it because they never hear of it (as some schemes don't advertise as they could not cope with extra numbers)
- We need to evaluate how well and how commissioners tell people about advocacy.
Evaluation can help with self-regulation and accountability but is wider than this in being a process of development and learning. Those consulted also drew attention to the detail of evaluation and the need to ensure that specialist schemes and differences between schemes are acknowledged (see box 4).

**Box 4 Consensus and concerns: the factors underpinning evaluation**

Advocacy schemes want to know how decisions about evaluation are made and what is taken into account because:

- Advocacy is currently fashionable but for how long?
- Representational advocacy can appear to have clearer or more substantial results or outcomes than other forms of advocacy
- Specific advocacy schemes want to be differentiated from general schemes so that their special features are acknowledged
- Decision making is not always clear and criteria are not always well developed
- An advocacy charter may help agree the 'core' functions of a service and what is expected as a minimum.

**Summary**

The seminar broadly confirmed the issues highlighted by the literature review, survey and interviews. Evaluation mechanisms were seen as an important aspect of service development and particularly crucial in sustaining growth and credibility. However, the problem of what should be evaluated, how and by whom, taking into account the different perspectives and objectives of all the stakeholders and also the variety of advocacy schemes had still to be resolved.
Part 6   DISCUSSION

Advocacy outcomes are difficult to measure because of the range of schemes available and their different aims and objectives. Henderson and Pochin (2001) highlighted a common challenge: the aims of a scheme are blurred with the rules describing how a scheme will go about achieving its aims. They further acknowledged that whilst advocacy aspires to commitment, conviction and social change, assumptions are made that it has something to offer but efficacy cannot be automatically assumed. Whilst evaluation may seem to threaten the independence of advocacy schemes, overlook the success stories of long-term partnerships and favour time-limited focused advocacy, services need reliable sources of funding to survive and thrive, and they need to be publicly accountable.

The pioneering evaluation approaches of citizen advocacy schemes focused on principles at the expense of outcomes and were primarily addressed to people inside the advocacy movement. ANNETTE (see Part 2, model 3), whilst arguably a more versatile tool, fostered the disadvantages associated with the contract culture. The Scottish Executive guidance (Scottish Executive, 2000) attempted to combine the advantages of citizen advocacy and outcome-focused measures and also addressed their potential pitfalls. This guidance highlighted the importance of stakeholder involvement, indicators that relate to the purpose of the scheme, regular dialogue between funders and advocacy schemes, and the quality of the relationship between the advocate and service user. The challenge of drawing up criteria to measure the effectiveness of long-term citizen-advocacy partnerships where there may be prevention of harm or no obvious issues to address, as well as the short-term focused schemes, was also addressed. However, the literature and findings of this study suggest that the Scottish model has so far had little influence in England and Wales.

Whilst a range of evaluation models exists, all possess advantages and drawbacks. Consideration of their implementation and available options is timely given the introduction of lay advocacy roles in new and proposed legislation and the government’s consultation initiative regarding the role of the Independent Mental Capacity Advocate (DH, 2005,b).

Although the survey was limited in terms of the low response rate, this had been anticipated and it was not intended to be a census of the field. While confined to local authorities, any future scoping exercise to map all advocacy services would need to include services funded through multiple sources. What the survey adds is a picture of commissioners’ perceptions about the evaluation processes, formal and informal, of local advocacy schemes. Most other research provides accounts of individual schemes and their chosen evaluatory approach (for example, Forbat and Atkinson’s study of five advocacy schemes in Nottinghamshire, 2005). The survey and the seminar discussion in which its findings have been contextualised by experts in the field indicate some emergent trends in commissioning. The results show that advocacy services for people with learning disabilities are increasingly supported through service level agreements, as indicated by the interview findings (below). Proposals to introduce individual budgets
(DH, 2005,a) may also raise the profile of advocacy in that service users may wish to challenge decisions and criteria. In the schemes considered by respondents there had been some shift in support according to the length of services, with more recent services (those supported for less than 3 years) reported to be fully funded rather than partially funded. Respondents stated that the main reason for supporting advocacy schemes was because it was a policy initiative (73 percent). This was mirrored by other responses, when asked about perceived outcomes 77 percent of schemes were perceived to be ‘aligned with policy’. This may suggest that those who are seeking to establish an advocacy service, or to expand one, may find that this argument, rather than revelations of unmet need, is a more persuasive lever to funders.

Survey respondents noted the importance of service users’ and carers’ input in current and planned evaluation. For example, discussions with service users, whether general or formal, were used in monitoring by 65 percent of schemes. In contrast, the use of evaluation tools or performance indicators to inform the evaluation process was modest. These factors were reflected in discussions at the feedback seminar, as participants felt that a rigid method of evaluation may not be attractive due to the possibility of over controlling schemes as well as difficulties in their application to different types of schemes. The views collected in the survey and expressed in the interviews and seminar suggest that it is important to evaluate both the process and outcome of advocacy services and to include the views of different stakeholders in the evaluation process. Self-assessment of schemes, commissioners’ evaluations and data collection about unmet needs among those who do not use services need to form different cornerstones of any evaluation. The significance of different evaluation methods for different schemes has been raised in research about other types of advocacy (Barnes et al, 2002).

Some studies suggest that some groups of people with learning disabilities might benefit particularly from targeted advocacy due to different reasons, for example, people from black or minority ethnic groups (Beattie et al 2005; Adamson 2001) and people in the autistic spectrum, in particular those with Asperger’s Syndrome (Broach et al, 2003). However, most of the advocacy schemes reported in the survey were described as supporting people with learning disabilities in general. The survey results did not reveal any variation in the way generic or specific services are evaluated. This might be due to the small number of specific services captured by this survey (16 schemes) or because local authorities regard current evaluation methods as sufficiently robust to be used for both types of services. The latter is in contrast to the views of the interviewees, participants at the seminar and other research (e.g. Chapman 2003) where it was considered important that any evaluation should acknowledge differences in types and roles of specific services. However, it seems more likely that local authorities are struggling to get a grip of what should be evaluated and how, both for generic and specific services.

The stakeholder interviews were limited in that those interviewed had volunteered to talk about the subject and may have held atypical views. As discussed above, many of those interviewed had interest and involvement in advocacy schemes. This type of study cannot claim to present generalisable information, rather it provides a rich source of experience
and insight of ‘social phenomena’ (Bowling 1997) such as advocacy. The research findings broadly identified a hierarchy of advocacy typologies with the greatest growth and development most evident in respect of self and peer advocacy. This growth, as also suggested by the survey findings, appears to be in line with policy direction. Yet representational advocacy was a developing area and described as being preferred by funders over citizen advocacy because the more tangible outcomes of crisis intervention were easier to evaluate than the benefits arising out of a long-term relationship, especially where the person being supported had profound dissibilities. Whilst citizen advocacy was upheld as an important model and self-advocacy was clearly developing, there were also concerns from within the user movement that commissioners and service planners were creating the framework for advocacy rather than service users themselves. Some authorities were commissioning advocacy intentionally to ensure robustness of services for people with learning disability and appeared to be open to criticism. There remained considerable fear, however, that schemes’ support would be withdrawn if they upset funders, although these concerns appeared to relate to the impact of advocacy in certain case scenarios rather than as an outcome of an evaluation or monitoring process.

The interviews broadly reflect the underdeveloped picture of evaluation tools highlighted by the survey. There appeared to be no overall cohesion regarding the types of evaluation used by funders of advocacy services identified by the informants of this sample, although significantly the contract featured as an important tool to assess performance. The findings suggest that in some cases no evaluation was taking place at all and that funders were relying on ‘reputation’. In other cases evaluation covered numbers of tasks undertaken and people supported, for example, often with reference to citizen advocacy models and also included a number of stories illustrating particular case scenarios. The dynamics of a successful outcome from service user, service provider and commissioner perspectives continued to be an unresolved issue. There were no attempts to assess whether advocacy schemes were reaching their target populations, as exemplified elsewhere (Atkinson and Forbat, 2003). Amongst the English examples evaluation appeared to be variously applied with no particular pattern emerging in respect of what suited which type of scheme best, although Scotland had developed core and specific criteria to flexibly accommodate its wide range of advocacy schemes, based on an extensive search of available models.

Whilst there was general agreement regarding the importance of advocacy evaluation, the interviews revealed a haphazard picture of multifarious approaches that were variously recognised as being cumbersome, partially adequate or inadequate for the task. Some respondents did not know of any of the tools for evaluation that are used in the UK (see Part 2 Table 3). Among those who were aware of the range of tools, even ANNETTE and the Scottish model, though accredited and comprehensive, did not escape criticism by those interviewed. There was more general agreement, despite limited evidence from evaluation, that advocacy services played an important role in helping people with learning disability to attain their rights and were potentially well placed to influence service improvements (see Part 2 Table 2; Part 5 Box 1). This confidence in advocacy’s benefits helps to explain why, despite limited evidence and trust in evaluation’s abilities to measure outcomes, many argued the need for more advocacy services and identified
areas of particular gaps, such as the patchiness, both geographically and for people with particular needs, the greatest deficits reportedly occurring in relation to people with multiple and profound difficulties and reportedly from black or minority ethnic backgrounds. In spite of strong support for universal rights to advocacy and new legal imperatives, there was general consensus that advocacy was always likely to be under-resourced.

The stakeholders who participated in this study were aware of difficulties in both defining advocacy and its outcome. These challenges and complexities of monitoring and evaluating advocacy work are well acknowledged elsewhere (Chapman & Wameyo 2001, Chapman 2003). Such complexities are mainly due to the difficulties in establishing cause and effect of an advocacy initiative as well as the difficulties in defining an ‘outcome’. Moreover, in complex human systems, where advocacy usually operates, it is difficult to establish which part of the process has caused a specific impact. Another important aspect is agreeing on what to be considered as the desired outcome. Complete fulfilment of a person’s wishes may rarely occur as a result of advocacy but it may be the compromise and process of achieving an outcome that is satisfactory to the user (Thomas 1998).

Competition for scarce resources and legislative requirements sharpen the necessity to find effective ways of evaluating advocacy. The development of quasi-legal advocates paid, specially trained, and with clearly defined functions suggests that the advocacy movement, in consultation with government (not just the Department of Health but also other government departments) needs to define its role and how it should be measured to guard against the emergence of a two-tier system of ‘superior’ and ‘inferior’ advocates. The advocacy movement was launched on the ideals of independence and befriending. Political developments and the movement’s heavy reliance on statutory funding suggests the need for timely pragmatism to develop standards that address the public policy needs in terms of accountability and protocols to safeguard independence.
Part 7 Conclusions and recommendations

Whilst much has been written about the threat of controlling by funders, little is known about the use of evaluation tools and if there is a causal link between funding decisions and evaluation. Fears that funding objectives may be influencing the recent growth in casework advocacy in favour of citizen advocacy also exist. Whilst at a national level we have not been able to confirm that this is so, the findings suggest that policy imperatives were by far the largest determinants of change and that expansion of services was a more likely consequence of monitoring by funders, rather than contraction or closure. However, while a range of evaluation models exists these are not easily accessible and decisions about evaluation are not being taken in full light of the existing evidence base.

This research has established that many local authorities do not systematically collect or scrutinise the outcomes of the advocacy services they fund and, except in a minority of cases, there is an absence of a cohesive approach to evaluation in general. Local authorities appear to be using contractual arrangements as a means of commissioning, monitoring and review. Monitoring and evaluation tools are not well developed. The seminar and consensus development process generally validated these conclusions. However, it also highlighted the desire by advocacy schemes to be evaluated: clearly a measure of confidence among those who know about advocacy that it will be able to convince funders of its worth if given the opportunity to undergo evaluation that is inclusive, proportionate and process as well as outcome oriented.

The outcomes of the local authority survey, the stakeholder interviews and workshop consultations largely confirm the position of advocacy services as described in the current literature. People using the service, those involved in funding, service planning and delivery, and professionals generally value advocacy. However, there is no coherent advocacy framework on which to structure further development and there are fears that the movement may suffer if and when advocacy ceases to be a policy priority. Information obtained from the interviews suggests that advocacy schemes are scattered unevenly throughout the country. Both the survey and interview elements indicate that the service is stretched and there are areas of unmet need. Although overall services appear to be developing, there were also comments that short-term funding arrangements and inadequate funding were restricting service development. Furthermore, there is little independent funding available. Most schemes are dependent on public money for their funding and are conscious that their independence to challenge services may be threatened. Evaluation tools to demonstrate the effectiveness of an advocacy scheme could potentially help a local project to survive local authority challenge. However, although various models are currently available, they are little used. Partnership Boards, comprising key stakeholders, would appear to be strategically placed to highlight effective advocacy and promote evaluation, but views about their effectiveness in this regard were mixed. There was little doubt in the minds of the participating stakeholders that advocacy services and supporting infrastructures should be improved, reflecting their partial orientation, an acknowledged limitation of the study.
Recommendations

**Government and key national organisations**

This research has highlighted findings in a hitherto untapped area of research viz ~ the centrality of policy in promoting advocacy development (Part 3 Figure 2) ~ perceptions of the empowering effects of advocacy (Part 3 Table 2) ~ and the role of evaluation in modifying service development (Part 3 Tables 4 and 5). However, in view of the short time-scale the study has of necessity only covered certain areas. In this regard the outcomes suggest that government, through the Care Services Improvement Partnership (CSIP), the Valuing People Support Team, the Association of Directors of Social Services, Association of Directors of Social Work and National Advocacy Networks should work collaboratively to enable:

- local authorities to agree the outcomes of the advocacy services they commission (in partnership or alone) for people with learning disabilities in their area.
- local authorities to have easy access to sources of information to assist them in evaluating advocacy service outcomes.
- local authorities to respond to the outcomes of advocacy service evaluation.
- local authorities to consider the most effective types of evaluation in general and/or for particular types of scheme.

The research findings also suggest that further national debate is required to strengthen and develop the advocacy infrastructure, in particular:

- To develop a national advocacy strategy to promote an advocacy plan, core principles, standards and outcomes taking into account the range of schemes.
- To suggest a framework of outcome measures for local adaptation and how each should be evaluated.
- To suggest appropriate areas for self and independent evaluation for local adaptation.
- To develop an Advocacy Code of Practice that also addresses ‘conflict of interest policies’ and funding arrangements to safeguard public funding accountability and the independence of schemes.
Local authorities

The research identified the importance of Local Authority awareness of the range of evaluation mechanisms available to inform effective service monitoring. Local authorities should take into account the advocacy evidence and work collaboratively with local stakeholders:

- To ensure every service they support is subject to regular evaluation that satisfies public funding accountability and stated aims and objectives of a particular scheme. The research suggests that the most likely mechanism through which to reach this objective would be through service level agreements or contracts.

- To promote dialogue and agreement between funders and service providers on outcome measures and how these should be measured.

- To review the aims and objectives of the advocacy schemes which they support and assess the effectiveness of any current evaluation mechanisms.

- To assess the capacity of the evaluation to assess performance, safety for staff and service users, accessibility factors, service capacity, unmet need, signposting and publicity taking into account the different stakeholder perspectives and range of advocacy contexts, including those projected under legislative change.

- To carry out any changes that may arise out of evaluation.

- To assess the strategic position of Partnership Boards to assist in the development of appropriate evaluation tools for the range of advocacy services in the local area and ensure service users are fully supported to contribute.

- To promote advocacy within person-centred planning.

- To develop mechanisms to identify and respond to areas of unmet need particularly in respect of people with severe impairments, special needs such as autism and also people from minority ethnic groups. Wider consultation with the general public may be relevant to assessing the support for advocacy and the extent to which it is generally known.

- To help develop and comply with conflict of interest polices and funding arrangements that satisfy public funding accountability and safeguard the position of advocacy services to act independently on behalf of the service user.

- To promote the benefits of advocacy emerging from outcome measures to policy-makers, services, advocacy schemes and the public.

- To ensure practitioners are trained in the appropriate use of advocacy and mechanisms for quality assurance of the service.
While this research focused on local authorities, these recommendations may also apply in respect of other funders, such as the NHS.

**Providers of advocacy services**

Local service providers should recognise the importance of evaluation in terms of keeping the service on track, identifying changing areas of need, promoting good practice and achieving accountability to their funders. In this vein they should work closely with their own agencies and collaboratively with local funders, commissioners and service providers:

- To identify and implement the most suitable evaluation programme for their particular schemes, help develop appropriate outcomes and outcome measures taking into account the different range of stakeholder perspectives, collective needs, diversity of schemes and their stated aims and objectives.

- To cooperate with regular evaluation, promote the importance of evaluation with service users, volunteers and advocacy workers and ensure these groups are supported through the process.

- To ensure safeguards are in place to observe service user confidentiality.

- To help develop and comply with conflict of interest polices that satisfy the aims and objectives of their schemes and also public funding accountability.

- To engage in regular meetings with funders to report on progress, highlight areas of unmet need and any collective concerns about the services used by people with learning disabilities.

- To participate in training of local staff regarding the importance of advocacy and mechanisms for quality assurance of the service.

**Acknowledgments**

This research was funded by the Department of Health. The views expressed here are those of the authors and do not necessarily reflect those of the Department of Health. We are very grateful to all those who agreed to be interviewed, to those who responded to the survey and to those who attended the feedback seminar in April 2005, and to Mark Brookes and Jean Collins of Values into Action for chairing the feedback seminar. We should also like to thank Martin Stevens (SCWRU) and Paul Dolan (Birmingham Social Services) for their comments on the survey draft.
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Advocacy and People with Learning Disabilities: the Scope of its Activity, Extent and Effectiveness

Questionnaire for Local Authorities and Partnership Boards

This survey relates to research commissioned by the Department of Health and being carried out by the Social Care Workforce Research Unit, King's College London.

The main aims of the research are to investigate:

how Local Authorities (LAs) and Partnership Boards (PBs) evaluate the outcomes of advocacy services/schemes funded and/or supported by them that are used by people with learning disabilities (PLD) and/or their carers/supporters, in particular:

• How LAs/PBs establish outcomes
• The sources of information used by LAs/PBs to evaluate outcomes
• How LAs/PBs respond to outcomes

Although the survey appears to be long the multiple-choice format has been used with the intention of making completion quick and easy. Please answer as many questions as you can. We should also be grateful if you could direct us to any evaluation models used by yourselves or local advocacy services. All replies will be anonymised.

Please return the survey by 24th January 2005 to: Dr Joan Rapaport, Social Care Workforce Research Unit, King’s College London, Franklin Wilkins Building, Stamford Street, London, SE1 9NH – or FREEPOST SCWRU

If you wish to complete the survey electronically please return the completed version to the Social Care Research Workforce Unit: scwru@kcl.ac.uk

If you have any queries about the research or questionnaire please contact Joan Rapaport, Tel: 0207 848 3753, email: joan.rapaport@kcl.ac.uk

If you would like a copy of the final report please let us know.

Thank you for taking the time to complete this questionnaire.
**Section 1  About advocacy services**

*Please note: the research focuses on services/schemes for people with learning disabilities (PLD) of adult age and young people in transition and/or their carers/supporters.*

1.1) **Does your LA/PB support any services that provide advocacy for people with learning disabilities and/or their carers?** *Please note: support could be many things - e.g. providing accommodation, administration, secondment of staff, travel expenses etc.*

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

*If the answer to 1.1) was no please go straight to Section 3*

1.2) **Please list the advocacy services/schemes used by people with learning disabilities and/or their carers/supporters funded and/or supported by your LA/PB.**

1.3) **Please identify two advocacy services listed in 1.2) prioritised according to those you consider receive the most support from your LA/PB.**

<table>
<thead>
<tr>
<th>Service 1</th>
<th>Service 2</th>
</tr>
</thead>
</table>

*If you wish to provide more information about how you defined “most support” please explain briefly below:*

Service 1

Service 2

1.4) **For the above services please indicate for how long each one has been running.** *Please identify each service using the no. as in 1.3 here and throughout the survey where indicated.*

<table>
<thead>
<tr>
<th>Number of years</th>
<th>Service 1</th>
<th>Service 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 1 yr</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 yr to under 3 yrs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 yrs &amp; over</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
1.5) Please indicate how each advocacy service is constituted. [Please tick as many options as appropriate]

<table>
<thead>
<tr>
<th>Constitution options</th>
<th>Service 1</th>
<th>Service 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Charity/Trust</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Multi-agency partnership</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Local branch/national organisation*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-help group/national org**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-help group/local organisation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-help group - no affiliation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Network of local schemes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don't know</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please describe)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*E.g. Citizens Advice Bureau  **Mencap

1.6) Please indicate how your LA/ PB is supporting each of the above services. [Please tick as many options as appropriate]

<table>
<thead>
<tr>
<th>Support systems</th>
<th>Service 1</th>
<th>Service 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Commissioning/service level agreement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full funding of scheme</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partial funding of scheme</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other funding e.g. case by case</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seeking/secureing external grants</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Expenses (e.g. travel)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attending committee meetings</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Member of management committee</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Providing office accommodation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Providing administration</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Providing training</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secondment of staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don't know</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other – please describe</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
1.7) Why does your LA/PB support these schemes? [Please tick as many as appropriate]

<table>
<thead>
<tr>
<th>Examples of reasons to support advocacy schemes for people with LD</th>
<th>Service 1</th>
<th>Service 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Part of hospital closure process</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Changes in service provision</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outcome of review</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pressure/campaigning pressures</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Policy initiative</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tradition</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don't know</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please describe)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1.8) Please indicate who provides advocacy in each of the above services [Please tick as many as appropriate]

<table>
<thead>
<tr>
<th>Service delivered by:</th>
<th>Service 1</th>
<th>Service 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paid co-ordinator &amp; volunteers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paid co-ordinator &amp; paid staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Voluntary co-ordinator &amp; volunteers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Service users</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carers/supporters</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professionals (healthcare)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professionals (legal)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don't know</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1.9) Please describe the type of advocacy offered by each of the identified services.

<table>
<thead>
<tr>
<th>Types of advocacy</th>
<th>Service 1</th>
<th>Service 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-advocacy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peer advocacy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Citizen advocacy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professional (healthcare)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professional (legal)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don't know</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other – please describe</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
1.10) Are these services catering a) for a **generic** population (including PLD) or b) for a **specific** group or groups of PLD (e.g. women, adolescents, people from minority ethnic communities etc? Please indicate a or b in the space provided.

<table>
<thead>
<tr>
<th>Service 1</th>
<th>Service 1</th>
<th>Service 2</th>
<th>Service 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) generic</td>
<td>b) specific</td>
<td>a) generic</td>
<td>b) specific</td>
</tr>
</tbody>
</table>

If a) applies to both services please go straight to 1.12

1.11) Please identify which specific groups are catered for:

Service 1

Service 2

1.12) In general, what are the perceived outcomes of each of the advocacy services? *[Please tick as many as appropriate]*

<table>
<thead>
<tr>
<th>Perceived outcomes</th>
<th>Service 1</th>
<th>Service 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Empowers service users</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improves service user status/credibility</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Promotes independent living</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improves family/carer understanding/attitudes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Independent representation available</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assists with decision-making in complex cases</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identifies need/cause for concern</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improves inter-agency working</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Better commissioning decisions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improves service monitoring</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improves service quality</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improves status/credibility of advocacy scheme</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improves status/credibility of local authority</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fulfils legal requirement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aligned with policy (e.g. Valuing People)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cost effectiveness for the local authority</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don't know</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please describe)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Section 2 Evaluation of advocacy services and LA/PB role

2.1) How does your LA/PB judge (evaluate/monitor/assess) the effectiveness of each of the identified services? [Please tick as many options as appropriate]

<table>
<thead>
<tr>
<th>Evaluation/monitoring systems</th>
<th>Service 1</th>
<th>Service 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use accredited evaluation tool*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Use performance indicators**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Audit of advocacy service</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Audit of care plans</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reference to complaints/compliments</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Service level agreements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benchmarking</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Receive Annual Report</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Read committee meeting minutes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discussion with service users - general</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discussion with service user representatives - formal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discussion with staff/volunteers of advocacy organisation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discussion at Partnership Board</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No means of monitoring</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don't know</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other – please describe</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*If an evaluation tool is used – please identify below

**If performance indicators are used – please identify below

2.2) Who in general undertakes the tasks identified in 2.1 in your LA/PB? [e.g. a group of people, delegated person(s), monitoring officer, external agency etc]

2.3) Are you planning to adopt any evaluation mechanisms in the near future?  

Yes  No

If no please go to 2.5

65
2.4) Please describe briefly the evaluation mechanisms you plan to adopt.

2.5) In your view what would be the best way of monitoring the outcomes of advocacy services for people with learning disability and their supporters?

2.6) Has your LA/PB ever modified or changed any of the identified services? [e.g. service expanded; client group changed]
   
   Yes   No
   
   If no please go to 2.9

2.7) Did the modification/change arise as a result of an evaluation outcome?

<table>
<thead>
<tr>
<th>Service 1 - yes</th>
<th>Service 1 - no</th>
<th>Service 2 - yes</th>
<th>Service 2 - no</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

2.8) What kinds of changes were made to any of the advocacy services? (Please tick as many as appropriate)

<table>
<thead>
<tr>
<th>Types of changes</th>
<th>Service 1</th>
<th>Service 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service expanded - in volume</td>
<td></td>
<td></td>
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<tr>
<td>Service expanded in client group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Service contracted in volume</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Service contracted in client group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Service closed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Structural changes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff changes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regular review instituted</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No changes were made</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don't know</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other - please describe</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

66
2.9) Whether your LA/ PB has made any modifications or not to the above services, what options are open to your LA/ PB to influence change? [Please tick as many as appropriate]

<table>
<thead>
<tr>
<th>Options to influence change</th>
<th>Service 1</th>
<th>Service 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consult stakeholders</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consult chairperson/equivalent</td>
<td></td>
<td></td>
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<tr>
<td>Consult partner organisations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consult local advocacy network</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consult relevant national organisation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Revise agreement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Withdraw funding</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No means of intervention</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other - please describe</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Section 3 Views and recommendations

3.) Is there anything else that you would like to tell us about assessment and evaluation of advocacy services for people with learning disability and/or their supporters/carers?

Section 4 Please tell us about yourself

4.1) What is your role title?

4.2) Please give a brief description of your role

4.3) How long have you been in your present post? years
4.4) Are you a member of the Local Authority Disability Partnership Board?

Yes  No

4.5) Please identify your LA/PB

4.6) Does your LA/PB cater for:

Urban areas  Rural Areas  Mixed urban/ rural areas

Please return this form by 24th January 2005 to:

Dr Joan Rapaport
Social Care Workforce Research Unit
King’s College London
Franklin Wilkins Building
Stamford Street
London
SE1 9NH

Or by Freepost; no need to write anything else on the envelope, only as follows:

FREEPOST
SCWRU

Or email:
scwru@kcl.ac.uk

Thank you for completing this questionnaire.
Appendix 3

Advocacy and People with Learning Disabilities: Commissioners’ perceptions of its Activity, Extent and Effectiveness

This topic guide forms the basis of the interview. It has been sent to you in advance to give you an idea about what I would like to talk to you about.

Explanation about the research

Brief explanation of project – aims and objectives

Confidentiality and anonymity

Final report

Would you like a copy of the final report?

About your position

What is your position?

Who is your employing authority?

Is your post: UK/national? Regional? Local?

Please give a brief description of your role.

How long have you been in post? years

Are you (also) a service user/carer/supporter

What is your professional/work background?

Which geographical areas do you cover?:

London and South East South South West West Midlands
East Midlands North West North East Wales
Scotland Northern Ireland

Urban Urban/rural Rural
Questions

1. How do you see the main forms of advocacy nowadays? [peer, citizen, self, carer support, legal, professional]

2. What are your perceptions on how these are working?

3. How do you think people are judging the effectiveness of advocacy schemes? [Formal or informal ways – formal – accredited evaluation tools, performance indicators etc versus informal or less formal – verbal and other reports, “reputation” etc]

4. Are you aware of any additional ways of judging the effectiveness of advocacy schemes?
   [Have you used any of them?]

5. Do you have a sense of the effects that local partnership boards [Scottish equivalent] are having on advocacy services? [If yes, describe – or ask if predicted]

6. What do you think will be the effects of the proposed Mental Capacity legislation [or actual – if in Scotland] on advocacy services?

7. What do you think will be the effects of the proposed English mental health legislation on advocacy services? – [English respondents only]

8. Where do you think advocacy services will be in the next 5 – 10 years?

9. What would you like to see changed?
Learning Disability Advocacy: Local authority perceptions of its effectiveness

Consultation Meeting

Friday 15th April 2005
King’s College London

List of participants:

Jean Collins, Chief Executive, Values into Action (Co-Chair)
Mark Brookes, Values into Action (Co-Chair)
David Ellis, Principal Advisor on Learning Disabilities, Social Care Institute for Excellence (SCIE)
Janet Badger, Advocacy Grant Scheme Manager, BILD (British Institute of Learning Disabilities)
Lindon Philander, Care Manager - Learning Disability Homes, Leonard Cheshire
Rick Henderson, Action for Advocacy
Tricia Nicoll, Valuing People Support Team, Department of Health
Chris Mitchell, Deputy Chief Executive, ARC (Association for Real Change)
Karen Mellanby, Action for Advocacy
Sue Hogarth, North Somerset People First
Mark Smith, North Somerset People First
Pattie Ducie, Social Worker, Substance Misuse Team, East Kent NHS & Social Care Partnership Trust
Susanne Oldlin, Pembrokeshire Advocacy Service
Shereen Hussein, Research Fellow, Social Care Workforce Research Unit, KCL
Joan Rapaport, Research Associate, Social Care Workforce Research Unit, KCL
Jill Manthorpe, Co-Director, Social Care Workforce Research Unit, KCL
Advocacy and People with Learning Disabilities: Local Authority Perceptions of the Scope of its Activity, Extent and Effectiveness

Project outputs (as at August 2005)

