The Impact of Advocacy for People who Use Social Care Services

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Scoping Review

NDTi
National Development Team for inclusion

The School for Social Care Research

The School for Social Care Research is a partnership between the London School of Economics and Political Science, King's College London and the Universities of Kent, Manchester and York, and is part of the National Institute for Health Research (NIHR).

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Impact of Advocacy for People who Use Social Care Services

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ABSTRACT

The role of advocacy in supporting people who use social care services has long been a focus of UK Government policy. However, there is a lack of understanding about the evidence of its impact in social care – with anecdotal evidence of recent disinvestment in advocacy taking place without consideration of its impact. Given this, the NIHR School for Social Care Research (SSCR) commissioned the National Development Team for Inclusion (NDTi) to carry out a scoping review to identify what evidence exists on the impact of advocacy, including cost effectiveness*.

While not following the full methdology of a Cochrane systematic review, this review nonetheless thoroughly reviewed the available literature – gathering and scoping evidence from the UK and Ireland from 1990. It sought to identify evidence on the impact of advocacy in social care and related fields and to help understand the benefits of investing in it against a range of different factors and outcomes (with particular interest in financial impact). Evidence covered different types of advocacy for all client groups likely to be in need of social care support. The review was desk-based and utilised online literature search engines, website searches, a targeted call for evidence and with key advocacy stakeholders being contacted directly to support evidence gathering. A total of 83 articles, reports and other documents were identified as being relevant and were reviewed and analysed.

The review found an overwhelming lack of published, robust evidence on the impact of advocacy, especially regarding its cost-effectiveness, but also with regard to both quantitative and qualitative data that evidences the impact of advocacy. These findings were significantly informed by shortcomings in the robustness and quality of existing published evidence. The three main problems with published materials were: a reliance on individual stories and anecdotes without analysing common themes, a reliance on people's views rather than empirical evidence, and no consistent basis for assessing the evidence of advocacy's impact. These shortcomings significantly arose from a lack of rigorous, routine and consistent collection of local data on outcomes by both providers and commissioners of advocacy.

Evidence from cost-benefit analysis of the financial impact of advocacy is very limited and focused on specific groups, especially parents with learning disabilities, where it reports that advocacy interventions return a net financial benefit. Other grey literature on cost benefit reports similar findings but did not publish detail of methodology.

There is a paucity of robust evidence on outcomes for individuals arising from advocacy interventions: evidence that highlights the outcomes that different types of advocacy

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* The review was conducted between April and July 2013 and references to evidence published up to March 2013. Further literature relating to this topic may have been published since.

achieve is unavailable; and evidence that describes the different types of outcomes that advocacy can achieve at an individual, service, or local/national level with regards to strategy or policy is limited.

Some qualitative evidence exists on the process of advocacy for particular people (such as disabled children and young people and those in the care system), but there are significant gaps in the literature on the evidenced effectiveness of advocacy, particularly (though not limited to) older people and people with mental health conditions or who lack capacity.

There is a similar lack of evidence on the impact that advocacy has on service delivery, design or local strategy. Literature describes positive impacts, such as on professionals' attitudes, but this typically relies on accounts from professionals or advocates. Beyond this, it is not possible to determine whether positive developments could only have happened because of the presence of advocacy organisations. Nationally, the literature reflects a stronger sense of policy initiatives impacting on advocacy, rather than vice versa.

The review concludes that this lack of robust evidence leaves advocacy in a potentially vulnerable position. During difficult financial times, with an increasing need to demonstrate effectiveness in public spending and a downward trend in the funding advocacy organisations receive, the need for better quality, more widely quantified information on the outcomes of advocacy has never been greater.

Having stated these limitations, it is important to clarify that this lack of evidence *should not be* interpreted as stating there is evidence that advocacy fails to have a positive impact, nor that it is not a cost-effective use of public resources. It could well be a highly effective, cost efficient way of investing public money. What this scoping review has identified is that there is a lack of robust research and evidence to enable conclusions to be drawn either way.

1. BACKGROUND AND FOCUS OF THIS REVIEW

The place of advocacy in supporting people who need or make use of social care services has been an increasing focus of UK Government policy over the last two decades.

However, in commissioning this research, the NIHR School for Social Care Research (SSCR)[1] has acknowledged there is a lack of understanding about the evidence base around the impact of advocacy in social care and an absence of an authoritative source that seeks to bring this information together in one, understandable place. At the same time, there seems to be a lack of shared understanding about what advocacy is and is not, with limited understanding about the different role and functions of varying types of advocacy – such as self-advocacy and professional advocacy. There is also growing anecdotal evidence that, in these difficult financial times, there is a move towards disinvestment in advocacy without consideration of its impact.

Against this background, SSCR commissioned the National Development Team for Inclusion (NDTi) to undertake a scoping review to gather and report on the evidence available on the impact of advocacy, to help understand the benefits of investing in it, against a range of different factors and outcomes. The review focused on evidence available on the impact of different types of advocacy to help inform decisions about what type to invest in and for which purpose. Economic and financial impacts were of particular interest within the context of the current economic situation.

The key focus was to scope relevant evidence on the relationship between all or some of:

- The resources invested;
- The type and style of advocacy;
- Impact against a range of variables.

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[1] National Institute for Health Research School for Social Care Research – http://sscr.nihr.ac.uk/

2. METHOD

This paper was commissioned as a scoping review. A scoping review maps the potential size and scope of research literature to a particular area, drawing out the main sources and types of evidence available, relevant key concepts and where gaps in the evidence base may lie (Grant *et al.*, 2009; Arksey and O'Malley, 2005; Manthorpe and Martineau, 2010). Its purpose is to provide an overview of the available evidence and highlight areas that merit further research.

This scoping review was carried out with the aim of mapping the literature and evidence on the impact of advocacy for people who are, or may be, users of social care services (including self-funders, i.e. people paying for their own care) and, within this, to ask:

• What is the state of knowledge in terms of the impact and outcomes of different types of advocacy available to people who need social care support?

• What economic evidence is available on resources invested and resulting benefits?

• Where are the gaps in this evidence?

• What are the implications in terms of future research?

The review was concerned with the impact and outcomes of advocacy for adults of all ages who are eligible for publicly-funded social care services. It also encompassed evidence from advocacy for people who fund their own social care and from advocacy impact beyond social care where transferable learning and lessons for the social care sector could be seen.

The review was desk-based and utilised online literature search engines, web site searches and a targeted call for evidence to identify and gather evidence. Further detail, including search engines and terms used, websites searched and the wording of the call for information issued are shown in Appendix 1.

We developed a framework for the analysis of content and description of the evidence gathered. Each article, report, document, response to our call for information and set of notes from discussions with individuals was analysed against, and reported within, a thematic content analysis grid. This facilitated the collation and cross analysis of evidence emerging in the following areas:

• The source of the evidence and related observations (e.g. relevance to our research questions, sample size, date, objectivity);

• The type of advocacy (see Section 3 for a description and discussion of different types);

• Client or population group(s) to whom the evidence relates;

• Resources invested and cost/benefits seen;

• Evidence of impact in a range of areas, including: outcomes for people; policy and strategy (at local or national levels) and service design and delivery;

• Critical success factors identified in the effective delivery of advocacy support;

• Other relevant learning.

Key findings, patterns and themes emerging from the review of evidence were then identified and are described and discussed within this review in order to add to the existing evidence base as well as informing and shaping future research on the impact of advocacy.

The documents reviewed in this way are shown in the Evidence Map in Section 13.

This method of scoping the literature produced a coherent overview of the evidence and the gaps in knowledge. It was not, however, intended as a traditional systematic review in terms of its coverage nor approach to analysing the literature.

2.1 Scope/caveats

The brief for the review was to concentrate on evidence from the UK and Ireland from 1990 onwards. A few articles and other documents outside of these parameters were included if they were referenced within this search parameter and the content seemed to be particularly relevant in terms of presenting evidence on the outcomes and impact of advocacy. Inclusion of such wider documents, however, is by no means exhaustive.

Evidence covering advocacy for all client groups likely to be in need of social care support was included in this work, this resulted in a very broad range of information being reviewed. In addition, information on many different types of advocacy was retrieved. However, given the focus specifically on social care, some fields in which advocacy activity exists were beyond the scope of this review, including:

- Advocacy which is solely related to campaigning – sometimes referred to as 'cause advocacy';

- Advocacy related to physical (medical) or public health;

- Legal advocacy (involving representation by a legal professional).

Similarly, explicitly considering advocacy for specific groups of people with 'protected characteristics' (using the terminology of the Equalities Act 2010, e.g. gender/sex, lesbian, gay, bisexual and transgender, ethnicity/race) that was not in a social care context was beyond the scope of this review. Furthermore, this study does not consider other forms of support which may be thought to have the same objectives as advocacy, such as user involvement or "information" and "advice" (on which, see Section 3.1 – definitions of advocacy).

This review was time and resource limited. We, therefore, focused on gathering and reviewing evidence of the outcomes and impact of advocacy. This was mainly from published sources, although some information from unpublished, 'grey' sources was also included. Given the wide scope and the limited time available, it would have been impossible to gather and review all evidence available on the impact of advocacy, and we know that much more 'grey evidence', often related to individual providers and schemes, exists. Although we were unable to include all existing evidence in this project, we believe the findings of this scoping review provide a full picture of what is known about the impact and outcomes of advocacy for people who are supported in this way in the UK.

3. ADVOCACY: ITS DEFINITIONS AND PURPOSES

3.1 Definitions of advocacy

Prior to considering the evidence of the impact of advocacy, it is important to understand what is meant by "advocacy", its desired outcomes/impact and the type of measures that have been developed to determine effectiveness. This section provides an overview of these issues.

Action for Advocacy[2], which (at the time of this review[3]) was a sector representative body, defined the practice of advocacy as:

> Taking action to help people say what they want, secure their rights, represent their interests and obtain the services they need.
>
> (Action for Advocacy website, accessed November 2013).

A wide range of advocacy organisations typically describe independent advocacy as a partnership between a concerned member of the community (advocate) and a person who may be feeling vulnerable, isolated or disempowered. The advocate provides support, information and representation with the aim of empowering their advocacy partner and enabling them to express their needs and choices. If necessary, the advocate can represent their partner's wishes to another person or agency on their behalf (Office for Disability Issues (ODI), 2009a; Action for Advocacy, 2002, 2011; Disability Rights Commission (DRC), 2006).

The definitions of different types of advocacy given below are those most typically accepted by all relevant stakeholders with an interest in advocacy, including advocacy organisations. There continues to be a debate about the definition of different types of advocacy (CHANGE, 2010) as well as difficulties from all stakeholders (commissioners, providers, advocates and advocacy partners) about what advocacy is or does (Action for Advocacy, 2008; ODI, 2009a). In practice, the different types of advocacy can and do overlap, and organisations or projects may provide a combination of different advocacy types (Bauer *et al.*, 2013).

The following are the most commonly-defined types of advocacy:

Self-advocacy: Individuals represent and speak up for themselves, with support, either individually or collectively. This support can be in a paid or unpaid capacity (Lawton, 2007, 2009; DRC, 2006; Roberts *et al.*, 2012).

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[2] www.actionforadvocacy.org.uk

[3] Since this review was carried out, both Action for Advocacy and DAN, the Dementia Advocacy Network, have closed as a result of funding issues.

Peer advocacy: The advocate and the person have a common background, for example, they may have shared experience of service provision and be "experts by experience" (Monaghan, 2012). Peer advocacy can be conducted on an individual or collective basis and often develops spontaneously, for example in care homes or day centres (Scottish Independent Advocacy Alliance, 2008; DRC, 2006; Roberts *et al.*, 2012).

Volunteer advocacy (sometimes also called Citizen Advocacy): this involves volunteers (unpaid) who are recruited, trained and matched with an individual – generally only one client at a time. It involves a one-to-one relationship over an extended period and goes beyond befriending, as the volunteer represents the views of the person. The partnership is independent, supported, but not influenced by, the advocacy organisation (DRC, 2006; Roberts *et al.*, 2012).

Independent/professional advocacy: A partnership between a paid advocate and a person who accesses support. The advocate provides support, information and representation, with the aim of empowering their partner and enabling them to express their needs and choices. This type of advocacy can be undertaken on a short-term or long-term basis. Long-term advocacy work may be required due to changing needs over time and the complexity of issues, for example, with parents with learning disabilities involved in the child protection system (Townsley *et al.*, 2009; DRC, 2006; ODI, 2009a; Roberts *et al.*, 2012).

Non-instructed advocacy: Advocacy can be provided to those who are, for reasons of capacity, unable to personally instruct their advocate (Henderson, 2007; Colclough, 2012). This may be because of the person's limitations in grasping concepts, or because they are not able to make others understand their wishes due to significant communication barriers. Capacity to instruct or understand can be diminished for a number of reasons, for example, mental health problems, dementia, acquired brain injury, or learning disabilities. However, it should be noted that having one of these conditions does not automatically mean a person lacks capacity. An advocate will observe the partner and their situation, look for alternative means of communication with the partner using techniques such as The Watching Brief (Asist, date unknown; Henderson, 2007), gather information from significant others in the partner's life, if appropriate, and seek to ensure the partner's rights are upheld.

Some advocacy is statutory, i.e. some people have a legal right to an advocate in some defined circumstances. Statutory advocacy includes:

Independent Mental Capacity Advocacy (IMCA), which supports people who have been assessed to lack capacity to make specific decisions about medical treatment or moving accommodation, or in some circumstances where there are adult safeguarding concerns, and who have no family or friends to support them (Department of Health, 2013).

Independent Mental Health Advocacy (IMHA), which supports people detained under the Mental Health Act (MHA) (1983) or people who are the subject of Community Treatment Orders (defined in Sections 17A-G of the MHA) to understand and champion their rights and entitlements (Hakim and Pollard, 2011).

The Mental Health (Wales) Measure is unique to Wales, and extends the group of people who are entiteld to statutory advocacy under mental health legislation (Dunning, 2010).

Local authorities have a duty to provide advocacy services for looked-after children and children in need if they wish to make a complaint; advocacy aims to protect looked-after children and young people and safeguard them from abuse and poor practice.

It should be noted that legislative obligations (e.g. within the Mental Health (Care and Treatment) (Scotland) Act (2003) or Adults with Incapacity (Scotland) Act (2000)) to provide or direct people to advocacy are not voided simply because an individual cannot instruct an advocate for any of the above reasons. Non-instructed advocacy can be utilised in these circumstances. Obligations to provide or direct to advocacy are mandated differently in Scotland than in England and Wales (Scottish Independent Advocacy Alliance, 2009; Stewart *et al.*, 2013).

In Improving Health and Lives: Learning Disabilities Observatory (IHAL)'s survey involving 88 advocacy organisations in England (which focused on advocacy for people with learning disabilities) (Roberts *et al.*, 2012):

73% (56 organisations) said they provided professional or case-based advocacy;

62% (48 organisations) said that they provided self-advocacy;

55% (42 organisations) said they provided citizen advocacy;

32% (26 organisations) said that they provided peer advocacy.

This study reported that funded general advocacy groups were more likely to offer professional or case-based advocacy for people with learning disabilities. Furthermore, the authors noted that advocacy groups working just with people with learning disabilities were more likely to provide self-advocacy and group advocacy.

Two key sources of information have captured who advocacy providers offer support to: the Equality & Human Rights Commission (EHRC) (2010) survey of advocacy organisations, and Action for Advocacy's (2011) survey of advocacy providers. Both surveys noted that approximately one quarter of providers offer advocacy support to any individuals who needed such support, irrespective of personal characteristics, whilst the majority (approximately 75%) had the objective of providing support for one or more specific groups.

The following estimates of what proportion of advocacy providers offer their support to specific groups are based on data drawn from the EHRC (2010) (number of organisations

surveyed = 403) and from Action for Advocacy (2011) (number of organisations surveyed = 95):

55% provided advocacy for people with mental health conditions;

55% provided advocacy for people with learning disabilities;

47% provided advocacy for older people;

43% provided advocacy for people with dementia;

39% provided advocacy for people with physical or sensory impairments;

30% provided advocacy for people from a Black or Minority Ethnic (BME) background;

22% provided advocacy for Lesbian, Gay or Bisexual (LGB) people (advocacy for transgender people was considered separately);

27% provided advocacy for carers;

17% provided advocacy for children and young people.

There are a number of things that advocacy is not. For example, it is not (Salman, 2012):

- Information or advice – these are separate and distinct from advocacy (Improvement and Development Agency (I&DeA), 2009);

- About mediation, counselling, befriending, taking complaints or giving advice, although elements of these can be found to varying degrees across the different models;

- Support from staff – advocacy is independent from the delivery of direct services;

- Support from relatives.

3.2 Measuring the quality of advocacy

Many of the key features and characteristics of all forms of advocacy – including independence, promoting empowerment, providing people with a voice, challenging inequality, etc. – have been captured in various quality marks and advocacy qualifications.

The Advocacy Quality Performance Mark was developed by Action for Advocacy and supports minimum standards in advocacy provision, as well as aiming to drive up the quality and consistency of advocacy. This builds on the Advocacy Charter and ensuing Quality Standards for Advocacy Schemes and Code of Practice published by Action 4 Advocacy in 2002 and 2006 respectively. There are also some national or local advocacy standards that have been developed for specific groups, such as those supporting children, BME communities and people who use mental health services (Lawton, 2009; Equalities National Council, 2012).

A survey of Welsh advocacy schemes found that 56% used the advocacy standards developed by Action for Advocacy, whilst the other 44% used a variety of frameworks, including those developed by the Welsh Assembly Government (Dunning, 2010).

3.3 Policy context

Advocacy, its principles or what it seeks to achieve, has been cited or referred to in most relevant government policy and legislation over the last 25 years. Key documents in which advocacy or its principles appear include:

- Disabled Persons (Services, Consultation and Representation) Act (1986)

- NHS and Community Care Act (1990)

- Direct Payments Act (1996)

- Valuing People (2001) and Valuing People Now (2007)

- Fair Access to Care (2002)

- Every Child Matters (2004)

- Improving the Life Chances of Disabled People (2005)

- Mental Capacity Act (2005)

- Mental Health Act (2007)

- Our Health, Our Care, Our Say (2006)

- Independent Living Strategy (particularly section 8.2) (2008)

- No Health Without Mental Health (2011).

Other relevant regulation and minimum standards frameworks also make reference to advocacy, including:

- The National Institute for Health and Care Excellence (NICE) and Social Care Institute for Excellence (SCIE)'s Dementia Guidelines (2006)

- Department of Health's (DH) National Minimum Standards for independent healthcare providers

- Care Quality Commission's regulation framework (Salman, 2012).

With the continued drive towards the personalisation of care and support services – especially in social care, though also increasingly in health policy (through the introduction of Personal Health Budgets) and elsewhere (Gateshead Advocacy Information Network (GAIN), 2011a) – the importance of advocacy appears to have been reaffirmed.

Putting People First (DH, 2007) particularly highlighted the goal of universal information, advice and advocacy services for people in the context of personalisation in social care. As noted by many advocacy organisations (see Salman, 2012), the hallmarks of advocacy are presented in aims for social care in the White Paper, Caring for our Future (DH 2012). This was further reinforced by two key documents which shaped and informed the White Paper, namely the Law Commission (2011) review of adult social care and the Dilnot Review (2011), which both recognised and valued the important role advocacy has and should continue to play in the future adult social care system.

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Demand for advocacy services has grown recently; 62% of respondents to Action for Advocacy's survey reported that demand had increased for their services in the last 12 months, typically by between 10 to 40%. This increase was felt to reflect the changes in welfare benefits and health and social care services, as well as increasing debt and financial problems (Action for Advocacy, 2011).

Nevertheless, there is concern that advocacy is "largely absent" (Salman, 2012) or being "downgraded" (McWilliams and Miles, 2012) in both the Social Care White Paper and the Care Bill 2013 (at the time of writing this report) (Care and Support Alliance, 2013). In its report on the draft Care Bill[4], the pre-legislative scrutiny Joint Committee, chaired by the former Care Services Minister Paul Burstow MP, noted that ""Information", "advice" and "advocacy" are nowhere defined in the draft Bill" (para 97) and that the omission of advocacy from the relevant clauses seemed "curious" (para 94). The Joint Committee concluded: "The general duty to provide information and advice should be extended to include independent advocacy."

Advocacy also plays an essential role in preventing, detecting and responding to abuse. The importance of people's voices being heard, and advocacy's role in this, have been highlighted by reviews such as those relating to Winterbourne View private hospital (Flynn, 2012), the Confidential Inquiry into premature deaths of people with learning disabilities (Heslop *et al.*, 2013) and the Francis Inquiry into Mid-Staffordshire NHS Foundation Trust (Francis, 2013) as well as earlier cases (Commission for Social Care Inspection (CSCI) and Healthcare Commission, 2006).

3.4 Advocacy funding context

The Advocacy Consortium UK (2009) estimated there are over 1,000 independent advocacy organisations in the UK providing various forms of independent advocacy, using both paid staff and volunteers. However, there is patchy geographical provision (ODI, 2009).

Roberts *et al.* (2012) captured the range of advocacy organisations that exists and provides support for people with learning disabilities, albeit for a relatively small number of advocacy providers, which varied in response number each year (from 23 to 35). Data from 2009/10 to 2012/13 identified organisations with funding in the range £0 (i.e. unfunded) to £1.3m. The median funding for 2012/13 was £55,500, down from £64,375 and £85,000 in 2011/12 and 2010/11 respectively.

This income for advocacy organisations comes from a range of sources, including:

• Local authorities;

• NHS sources, including Primary Care Trusts (as were) and Foundation Trusts;

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[4] http://www.publications.parliament.uk/pa/jt201213/jtselect/jtcare/143/14302.htm

- Grant-giving bodies, such as the Big Lottery Fund and charitable foundations and trusts;

- Disability charities;

- Donations.

The EHRC (2010) reported that half of the organisations it surveyed spent between 75–100% of their total income on providing advocacy, with another 12% spending between 50–74% of their income on providing advocacy. One in five spent less than 25% of their income on providing advocacy.

Action for Advocacy's report, *Advocacy in a Cold Climate* (2011), aimed to capture the current financial context in which some advocacy organisations operate. In the 12 months preceding publication of the report, 45% of the advocacy organisations who responded to Action for Advocacy's survey (a total of 95) had experienced a reduction in their funding by an average of 36%. In the next 12 months, nearly 7 in 10 (68%) advocacy organisations expected their funding to be reduced.

Impacts of such funding cuts for advocacy providers included:

- Supporting fewer people – 74% of advocacy providers who responded to Action for Advocacy's survey said their funding was insufficient to cover current demand, and 63% said they expected to support fewer people in the future;

- Making advocates or associated staff redundant (39%);

- Reducing service hours or operating waiting lists (45%);

- Considering mergers or consortium formations (37%).

Some commissioners recognised funding as a problem for advocacy organisations: 17% of commissioners surveyed by EHRC (2010) noted a general lack of provision/funding as gaps in the provision of advocacy; and 31% thought a lack of funds was a barrier to commissioning advocacy for people with protected characteristics (as defined in the Equality Act 2010) in the future.

Roberts *et al.* (2012), based on a small sample, noted that trends in commissioning were moving away from funding advocacy specific to particular people (e.g. learning disability) or advocacy types (e.g. self-advocacy) within the total spend of advocacy commissioners. For example, spend on advocacy for people with learning disabilities or self-advocacy was 88% of total advocacy spend in 2009/10; this dropped to 63% in 2010/11 and 47% in 2011/12. Indications for 2012/13 suggest this proportion has fallen further to 37% in 2012/13.

4. EVIDENCE FOUND IN THE SCOPING REVIEW

This section considers the range and type of evidence on advocacy , and discusses the quality of evidence available.

4.1 Range and type of evidence available

The documents reviewed as part of this review are fully detailed in the Evidence Map in Section 13. Tables 1 and 2 provide a summary of the types of documents.

Table 1. Articles

Total number	Type of publication		Country of origin		Group of people supported by advocacy/type of advocacy	
24 (23 full articles and 1 abstract)	Peer reviewed journal	21	UK	19	People with learning disability	4
	Industry news magazine	3	USA/ Canada	4	People from Black and Ethnic Minority Groups	3
			Australia	1	Families with a disabled child	3
					People with mental health issues	6
					People with dementia	2
					Across different groups	3

Table 2. Reports and other documents

Total number	Type of report/document		Type of organisation involved		Group of people supported by advocacy/type of advocacy	
59 (all from the UK)	Research project report	18	Government Dept. or funded body	15	People with learning disability	8
	Other project report	3	Academic team	11	People from Black and Ethnic Minority Groups	2
	Report on advocacy provider/project	11	Research foundation	6	People with mental health issues	11
	Report on wider provision	6	Observatory	1	People with dementia	3
	Scoping (type) study	6	Advocacy provider	7	Children and young people	4
	Guidance/discussion document	8	Alliance/network	17	Disabled people	3
	Summary/highlights publication	3	Independent agency (inc.charity)	11	Across different groups	17
	Case studies	3	Royal College	1		
	Report on Government Bill	1				

Note: Figures for some of the columns in the tables add up to more than the others, as some documents covered people from different groups, e.g. older people with mental health issues, or involved more than one organisation, or appeared in different types of literature.

4.2 Discussion of the quality of evidence

As will be noted from the following sections, a large quantity of material was identified that was described as evidence about the impact of advocacy. However, there are significant shortcomings in the robustness and quality of that evidence. Indeed, it is widely reported within the literature itself that there is a general lack of evidence on the impacts, outcomes and cost-effectiveness of advocacy, a situation which seems to exist across the range of types of advocacy provided and different groups of people supported.

There are thus limited empirically-based conclusions that can be drawn from the published research and evidence and it is important to understand these limitations prior to reading the detail of claims made about the impact of advocacy in the sections that follow.

There are three main problems with the published materials:

1. A reliance on individual stories and anecdotes

There are many anecdotal and descriptive reports of individual advocacy interventions (e.g. reported in case study format). These can be very useful in illustrating the impact advocacy can have and are often seen as confirming its value (for example, GAIN, 2011b). However, there appear to be very few critical perspectives on advocacy and few system-wide accounts of its working (Manthorpe and Martineau, 2010). There appear to have been no studies to draw together evidence and learning from case studies to identify common themes and issues and, thus, the case studies each simply stand on their own. Furthermore, the limitations of case studies are sometimes noted by advocacy organisations themselves (McWilliams and Miles, 2012).

2. A reliance on people's views rather than empirical evidence

Much of the evidence reported is descriptive and relates to views on, and perceptions of, the impact and value of advocacy, rather than on purposefully measured outcomes or robust assessments or evaluations of services (Williams *et al.*, 2007). In addition, there is much discussion about the potential, rather than actual quantified impact and outcomes.

Several reports of small scale, pilot projects were gathered in the search for evidence for this review, both in the format of project reports and articles (e.g. Fazil *et al.*, 2004; Age Concern & Help the Aged 2009a, 2009b). These reports did tend to consider and discuss outcomes extensively. However, in such studies there was often a lack of 'quantification' of the impact and benefits seen and no real cost benefit analysis carried out for most of the projects of this kind. In several cases, where empirical evidence was asserted, this was not reported in the materials and this information was not made available to this scoping review.

3. The basis on which evidence of impact has been assessed

In 2005, the Social Care Workforce Research Unit and Values into Action carried out a project funded by the Department of Health on Local Authority Perceptions of Advocacy and People with Learning Disabilities (Manthorpe *et al.*, 2005). A survey carried out as part of the project found that the main way in which advocacy schemes seemed to be

monitored and evaluated by local authority commissioners was through reporting against service level agreements and documents such as annual reports produced by individual providers. There was a widespread reliance on data provided by schemes themselves and little further interrogation of this information.

Although several models for evaluating advocacy outcomes have been developed (see next paragraph for examples), these did not seem to be widely used. This resulted in a great lack of consistency in information recorded in different areas – a situation which was also found, for example, amongst providers of advocacy for older people in a project carried out as part of the Older People's Advocacy Alliance (OPAAL) Regional Development Programme (OPAAL, 2004).

In 2010, the Personal Social Services Research Unit (PSSRU) added to the evidence on outcomes measurement and developed a new tool that could be adapted for use across information, advice and advocacy provision more widely (Windle *et al.*, 2010). In addition, there are other evaluation frameworks – of differing robustness – that would enable advocacy organisations to make inroads to the lack of evidence on the outcomes of advocacy interventions (ODI, 2009b; SIAA, 2011; GAIN, 2012; Manthorpe *et al.*, 2005). However, these have generally not been used by, in particular, commissioners of advocacy. Indeed, in this scoping review, we have not found any information to suggest that the above situation has changed significantly since Windle *et al*. undertook their study nor that the situation is different for advocacy in other policy areas.

In addition to these three challenges, there are two further significant issues that this scoping review has identified, namely:

• The lack of longitudinal evidence, which contributes to difficulty in identifying whether outcomes are short- or long-term (Manthorpe and Martineau, 2010);

• The overall lack of research and evaluation of advocacy that has taken place – particularly when considered against the amounts of investment made and the political profile and priority given to advocacy: "There are many examples of individual advocacy schemes but their range is wide and evaluations rare" (Manthorpe and Martineau, 2009, p6);

Having stated these limitations, it is also important to clarify (particularly in these difficult economic times) that this lack of evidence *should not* be interpreted as stating there is evidence that advocacy *does not* have a positive impact, nor *that it is not* a cost effective use of public resources. What this scoping review is indicating – discussed in more detail in the Conclusions section – is that there is a lack of robust research and evidence to enable conclusions to be drawn either way.

5. COLLECTING DATA ON ADVOCACY

It is noted by GAIN (2012) that advocacy projects largely report outputs (e.g. time spent with clients, number of meetings) rather than outcomes (e.g. increased choice and control, improved health and wellbeing). Before considering, therefore, what evidence exists on the costs and benefits of advocacy, it is instructive to explore what type and range of information and evidence exist on the inputs and outputs that are used and collected by commissioners or funders of advocacy, since the presence or otherwise of these informs the ability to calculate costs and benefits.

We have found three key issues:

1. Advocacy organisations collect data on the characteristics of people who are supported, but not consistently or robustly

For example, Roberts *et al.* (2012) report that 93% of the advocacy organisations that participated in their survey collected certain types of data on the people they support, such as age, gender, ethnicity and disability, but only 28% collected information on all of these characteristics. The EHRC (2010) found that data on which users received advocacy support were often estimates and not based on actual data;

2. Practical, uniform methods for capturing information do not exist

Information about the work of advocacy organisations is collected in a variety of ways, including quarterly and annual reports, meetings, contract monitoring meetings, reports against service level agreements (SLAs) (Hakim and Pollard, 2011) and then other general means of communication (such as a website, newsletters, events, Partnerships Boards) (Roberts *et al.*, 2012 and Hussein *et al.*, 2006). There is no common method for capturing information relating to the provision of advocacy support. Similarly, some providers reported that inconsistent referral mechanisms for advocacy support mean that recording relevant data on the work of advocacy organisations is not always possible (Mencap, 2006) and that there remain basic practical issues, such as whether travel time should be included in advocacy intervention calculations (OPAAL, 2009a);

3. Commissioners are in a similar position to advocacy providers

Commissioner perspectives on how the impact of advocacy is measured were noted by Roberts *et al.* (2012). They reported that some commissioners had done little to monitor advocacy outcomes previously while others monitored advocacy by looking at reports from advocacy groups, outcomes for people with learning disabilities, and feedback from professionals and people with learning disabilities. Less than half (44%) of commissioners who responded to their survey reported that advocacy organisations were monitored through numbers or reports. Monitoring of advocacy organisations was often only associated with the renewal of contracts.

Having considered the extent to which advocacy providers and commissioners capture the inputs and outputs relating to advocacy support, we now turn to the evidence of its impact.

6. COST-BENEFIT/EFFECTIVENESS OF ADVOCACY

6.1 Evidence on advocacy's cost-benefit and cost-effectiveness

This scoping review was designed to have a particular interest in the relationship between levels of investment in advocacy and outcomes or outputs achieved. Sefton (2000) drew a distinction between:

- Cost-Benefit Analysis, which is described as the 'most complete form of economic evaluation', where the various costs and benefits of each alternative are identified and weighed against each other to provide a comparable benefit/cost ratio; and

- Cost-Effectiveness Analysis, which is more commonly used in the social welfare field as a form of economic evaluation whereby the overall cost of a scheme is weighed against outcomes, often the number of physical outcome units such as numbers of people being provided with an advocate, or service changes arising as a result of an intervention. Through this, differential impact of similar types of services can be calculated.

The scoping review therefore sought out evidence of either type of analysis.

In considering the impact of advocacy, advocacy providers maintain that local commissioners should recognise the benefits and cost savings provided by independent advocacy services and ensure that advocacy is a priority. At the same time, advocacy providers should ensure that the need for and benefits of their work are fully understood by a broad range of stakeholders. This will include developing systems for the effective monitoring and analysis of relevant data (Roberts *et al.*, 2012).

Nevertheless, this review has found that there remains little evidence on the cost-benefit or cost-effectiveness of advocacy. What evidence exists is often descriptive rather than based on robust assessment in evaluations. This echoes consistent findings across the literature over a period of time (I&DeA, 2009, quoted in ODI, 2009; Manthorpe and Martineau, 2010; Lawton, 2009).

Since the cost-benefit/effectiveness of advocacy is a particular focus for this scoping review, we describe in detail the relevant literature and evidence.

ODI (2009a) followed up a commitment in the Independent Living Strategy to investigate the effectiveness and cost-benefit of advocacy support for disabled people in situations where they are at particular risk of losing choice and control. They systematically identified, evaluated and synthesised existing evidence in four particular scenarios. Using a broad definition of advocacy (which included paid, professional advocacy, unpaid, citizen advocacy and peer advocacy, but not self-advocacy) they found:

- There is no published research evidence of costs or cost-benefits of advocacy at transition to adulthood;

- There is a small, but growing, research base assessing the impact of independent

advocacy for disabled parents, especially when their children are subject to safeguarding procedures. The research team identified 45 publications and 47 items of grey literature for data extraction and critical appraisal; of these, 27 items related to disabled parents of children subject to safeguarding proceedings;

- There is no research evidence of costs or cost-benefits in relation to advocacy services specifically for disabled people when entry into residential care homes is a possibility. There is only very basic data exploring the costs of a general advocacy service for older people based on average figures and extrapolations;

- There is no identifiable research exploring the related costs of independent advocacy services for disabled victims of crime. There are high costs involved with prison placements, but there is no research around the cost-benefits of schemes that work to divert disabled offenders from prison;

- Despite it not being an area of focus in their systematic review, the ODI research team noted that there are data regarding time spent on referrals to the Independent Mental Capacity Advocate service. However, this does not equate to a financial cost nor any financial benefits calculated;

- ODI also concluded that most evidence relating to the benefits that arise from advocacy emanate from the process of advocacy itself rather than the outcome that advocacy achieves (ODI, 2009a);

- Finally, ODI hypothesises what the potential benefits and savings might look like for the four situations they focused on. However, these are only described and not quantified (ODI, 2009b).

Bauer *et al.* (2013) provided one of the very few rigorous cost-benefit analyses focusing on the children of parents with learning disabilities who are subject to child safeguarding procedures. They calculate a mean average cost of an advocacy intervention in such cases to be £3,040 and a gross mean saving directly to children's social services of £3,760. This creates a net benefit arising from the advocacy intervention of £720 with an associated Return on Investment (ROI) ratio of 1.2. More generally, they calculate a net benefit from a public sector perspective after taking into account the costs and benefits of early interventions referred to by advocacy and for which there was sufficient economic evidence. In this case, the net benefit was £1,900 and the ROI ratio was 2.0. While noting that their findings must be seen as tentative in nature they conclude:

> Our findings indicate that investing in advocacy for parents with learning disabilities is likely to offset costs in the short term and bring a positive return on investment from a wider public sector perspective. Furthermore, our research findings suggest that there could be additional quality of life improvements to the parent due to reduced anxiety, stress and depression. In addition, there may be some productivity gains from a few parents who seek and find employment as a result of the advocacy intervention, possibly due to an increase in confidence and skills in communicating with professionals. Our findings suggest that both,

children subject to safeguarding procedures and those previously removed may benefit from the advocacy intervention provided to their parents.

Roseman *et al.* (2000) described an Australian trial of a model of personal advocacy for people with mental health conditions who were subject to involuntary hospitalisation. Advocacy was provided by one individual (a lawyer with extensive knowledge of public health policy) to an experimental group of 53 patients for the entire period of their involuntary treatment. The model was described as 'personal advocacy' based on patients' 'needs and best interests'. Outcomes for the experimental group were compared to outcomes for a control group of 52 people who were matched to the experimental group (in terms of their characteristics, diagnoses and levels of severity of illness) and received only 'routine rights advocacy', which tended to be focused around the time of admission. Outcomes for the experimental group included significantly higher levels of satisfaction with care, and attendance at aftercare. There was also a significantly lower risk of rehospitalisation amongst the group of people receiving the personal advocacy support that led to an estimated saving of AUS$150,000 over a seven-month period (costs of running the trial were not reported; therefore, it is unclear whether cost-benefit analysis was undertaken). The authors acknowledge that the trial involved a specific model of advocacy – undertaken by a highly qualified person – and that the model itself and characteristics of the person delivering the advocacy support may have had a significant impact on the results.

In a review of advocacy services for looked-after children provided by The Children's Society (Pona and Hounsell, 2012), a range of costs for delivering advocacy support for different issues and situations was calculated. It was estimated that the provision of this type of advocacy support cost £31 per hour on average and the total cost of a case varied substantially from an average of £320 for family contact to £3,830 for safeguarding issues. Extensive cost-benefit analysis was not carried out as part of this review, rather illustrative cases were presented where it was felt that it could be shown that advocacy would have resulted in savings by local authorities, including:

- Enabling a child to change social worker, which avoided a formal complaint being made to the local authority, authors estimated that this saved over £1,000 of public money;

- Supporting a young woman with a new baby, which avoided the baby being taken into care, where it was estimated that the money spent on advocacy avoided expenditure of around three times the amount that would have been spent on fostering;

- Supporting a young man to move to a new residential placement where he was happy, estimating that spend increased in the short term through advocacy support but more money was saved over the following year through reaching placement stability.

There is a variety of grey literature that provides information on the cost benefit and/or effectiveness of advocacy. However, many of these results need to be treated with caution.

For example, White (2012) undertook an "evaluative" analysis of Kirklees Advocacy Service and estimated the service had created benefits to its stakeholders of between £120,000–160,000, or a ROI of between 2.4 to 3.15. However, no method or detail is given for how these figures were calculated. Similarly, POhWER (date unknown) noted that a Social Return on Investment (SROI)[5] analysis of its service "results in a ratio of £1:£16.40" and that "for every £1 invested into the service £5–£20 of social value is created". Again, no method or detail is given for how these figures were calculated. Glasgow's older people's advocacy service reported that for every £1 invested in its service, the SROI was £8 (Cameron, 2013). This is reported to be currently undergoing a process of validation by the SROI Network, so more certainty might be attributed to this figure if it is validated.

Other forms of grey literature have provided indications of the potential savings advocacy can lead to, without formally or informally calculating the financial effectiveness of advocacy interventions or providing a method for how costs were arrived at. Salman (2012), for example, highlights two case studies. In one case it is noted that someone who had previously spent an average of eight weeks a year in a crisis centre at a weekly cost of £1,300, amongst other expenditure, was now managing their own care through a Personal Budget, for which no expenditure information was provided. A second case study noted that "exact savings are difficult to quantify" when it came to a service's advocacy intervention regarding child safeguarding, but observed that it costs "around £1,000 to complete a needs assessment and then £489 on average for foster care" and that calls to a duty desk cost "around £50 an hour" but that being an associate member of the organisation in quality "costs £60 per week". Another example confused input costs for SROI:

> We are doing a social return on investment exercise. We calculate the hours that people attend each month at the minimum wage. If a member has a specific role in the organisation (chair, treasurer etc), we calculate an hour's work at £12.50. When you add it up, it demonstrates that pound for pound, we give very good value. (Roberts *et al.*, 2012).

ODI concluded that "There is an urgent need for cost-effectiveness analysis" of advocacy (ODI, 2009a). As such, it developed a framework for future research to investigate the cost-effectiveness of independent advocacy, including proposals for control groups and suggestions as to what types of benefits could arise for advocacy in certain types of situations, such as during transition to adulthood (ODI, 2009b).

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5. The Charities Evaluation Service describes SROI as a method which values outcomes by using financial proxies, so that they can be added up and compared to investment made. This results in a ratio of total benefits (a sum of all the outcomes) to total investments. For example, an organisation that has a Social Return on Investment of 4:1 returns £4 of social value for every £1 spent on its activities (see http://www.ces-vol.org.uk/tools-and-resources/Evaluation-methods/SROI/index).

Other quality frameworks have been developed that could provide a platform from which advocacy organisations can build the case for their (cost) effectiveness. As well as Action for Advocacy's outcomes measures, the Scottish Independent Advocacy Alliance (SIAA) (2010) developed an evaluation framework for advocacy that provides tools for measuring the effectiveness of advocacy services against their principles and standards (Stewart *et al.*, 2013). A literature review carried out in by Manthorpe *et al.* (2005) identified a number of models of evaluation and discussed their issues, advantages and disadvantages. Models described include:

- Independent Advocacy: A Guide for Commissioners, Scottish Executive (2000)

- Resource Pack for Evaluators, ASA funded by Scottish Executive(2003)

- CAPE (developed for citizen advocacy in the late 1970's)

- CAIT (also for citizen advocacy)

- ANNETTE (which focuses mainly on outcomes), developed by Newcastle Council for Voluntary Service

- Citizen Advocacy Lincolnshire Links (CALL) used an adapted version of CAPE and combined it with a psychological personality inventory to evaluate their citizen advocacy service for young people, looking at both process and outcomes.

- A Dementia Self Service evaluation where questionnaires were sent to carers and professionals in touch with the advocacy service

- Evaluation carried out by RETHINK involving questionnaires, structured interviews with individuals and focus group interviews.

Nevertheless, our review of the available evidence strongly suggested that the need for cost-effectiveness analysis had not been met and found no evidence that any of the frameworks that could support such analysis had been used extensively by advocacy providers or commissioners alike.

6.2 Challenges to evidencing advocacy outcomes

A number of publications have asked why capturing and/or evidencing advocacy outcomes should be so difficult (see for example, Scottish Executive, 2000).

This scoping review has identified a number inter-related causal factors that research and reports have described:

1. Definition and boundaries

Obtaining evidence is hampered by the lack of agreement about definitions of advocacy and understanding about the role of advocacy (Stewart *et al.*, 2013). Similarly, it can be difficult to disentangle advocacy from other areas such as information and advice. In a project undertaken in 2010 (Measuring Outcomes of Information and Advice Services), Windle *et al.* (2010) developed a continuum of information and advice activity, which depicted advocacy at the longer term end of Information, Advice and Advocacy (IAA)

Services. It argued that outputs and outcomes for clients of IAA services are not linear, making evaluation more difficult.

Linked to this, advocacy is an enormously diverse area. Many schemes exist, supporting a range of people in different situations with different issues and working towards different aims and objectives. A disparate range of services has developed in different areas, often from small grass roots organisations or as bolt-ons to other services. This lack of coherence makes it very difficult to form a coherent picture and compare impact (Williams *et al.*, 2007)

2. Defining outcomes

As previously noted, a lack of agreement on identifying and defining outcomes hampers the gathering of evidence. It is difficult to measure the impact that advocacy has on outcomes for people who access support and their families, partly because there is such a wide range of schemes with differing aims and objectives with shifting and often multiple or unclear outcomes (McNutt, 2011, quoted in Stewart *et al.*, 2013; Rapaport *et al.*, 2005). The difficulty in defining desirable, quantitative outcomes makes evidence gathering difficult (Rappaport *et al.*, 2005; Hussein *et al.*, 2007) and the initial goals of the advocacy input may change during the process itself (OPAAL, 2009 quoted in ODI, 2009a).

In addition, the data collection capacity of small scale projects is limited (Bauer *et al.*, 2013).

Other identified challenges around outcome definition include:

- People who use advocacy services may have difficulty in clearly identifying or expressing goals and/or outcomes. Therefore, measurement cannot be solely reliant on the service user perspective (Action for Advocacy, 2009);

- Outcomes of specific types of advocacy, e.g. advocacy for people with dementia, are often tangible but not quantifiable, and outcome measures can often be more suited to bigger advocacy organisations since they are more aligned with service models used by commissioners (Brown *et al.*, 2013);

- Advocacy is often about moving towards a goal and developing the potential of people rather than the achievement of a final state or change; therefore, measurement cannot be solely based on achieving a desired concrete result (Action for Advocacy, 2009).

Finally, the absence of widely agreed benchmarks against which to measure performance, with advocacy schemes often being excluded from local authority reporting systems, leads to each local authority deciding itself how to report on this area with a commensurate lack of consistency (Rapaport *et al.*, 2005, 2006).

3. Methodological challenges

The nature of advocacy has been identified as presenting challenges to effective evaluation. For example, a major limitation has been suggested in terms of establishing causalities between advocacy and the outcomes that occurred because of a lack of a

comparison group (Bauer *et al.*, 2013; Action for Advocacy, 2009). Recognising this is only one form of evaluation (and that other formal evaluation methods exist) it is difficult to compare people supported through advocacy (or similar) interventions with an appropriate control group to measure different outcomes for those who have had a particular form of support compared to those who have not. This issue was explored in the evaluation of a community mentoring service for older people (Dickens *et al.*, 2011).

Bauer *et al.*, (2013) report that in other cases, information was drawn from a small number of case studies and often relied on data and outcomes reported by advocacy organisations themselves. Furthermore, they suggest that it needs to be acknowledged that only certain, quantifiable and 'monetisable' outcomes can be captured with economic evaluation methods; and economic findings should therefore be interpreted in the context of qualitative evidence which takes into account personal experiences and satisfaction with services.

These articulated challenges stand alongside an identified growing recognition among advocacy providers of the need to improve monitoring and evaluation of outcomes (Hussein *et al.*, 2007). In the Measuring Outcomes of Information and Advice Services project carried out by Windle *et al.* (2010), there was some evidence of a desire to move more towards recording outcomes amongst organisations providing information, advice and advocacy. Findings from interviews with 34 key informants, undertaken as part of the project, included recognition amongst some providers that, although capacity issues did play a part in limiting the development of measuring and reporting on outcomes, this could be used as an excuse by some and the situation could improve through changing cultures and including methods of measurement as part of ongoing work programmes.

The literature search identified some examples of advocacy providers reflecting this shift to recording outcomes (see, for example, GAIN (2012)). One further example was provided through the Call for Information for this present review (Help and Care charity, personal coomunication, 2013), in which service users identify 'position statements' appropriate to their situation at the beginning of the advocacy intervention and then revisit these statements at the end of intervention to see what impact advocacy has had on the service user's 'position'.

Although extensive grey literature was not made available to us as part of this scoping review, the information we did receive would indicate capturing people's outcomes arising from advocacy is a growing trend.

7. IMPACT OF ADVOCACY ON PEOPLE'S OUTCOMES

7.1 Process and advocacy outcomes

There are a considerable number of assertions about the difference that advocacy interventions make on outcomes for people, which we discuss in this section.

The differences that advocacy interventions make can be broken down into benefits that arise from the process of advocacy itself, i.e. process outcomes, as well as the outcome that that advocacy achieves (ODI, 2009a). In this section we describe outcomes identified in the literature under the most relevant headings. Inevitably, some of these impacts are also felt at service delivery and design level, so we have included examples where we feel the primary impact of advocacy is made under the relevant sections.

In reading the evidence described below, the discussion of Section 4.2 on shortcomings in the general robustness of the evidence should be kept in mind.

Process outcomes of advocacy included:

- Having an advocate meant people's voices were heard (Stewart *et al.*, 2013). This was the most common theme identified by advocacy organisations themselves in Roberts *et al.* (2012) with 60% of organisations citing this as a reason why advocacy exists. Similarly, this was the top response given by commissioners (69% of all responses). Overall, advocacy organisations and commissioners agreed that giving people with learning disabilities a voice was the most important reason for funding advocacy. Similarly, people valued being listened to by someone who understood their concerns (ODI, 2009a);

- Increased ability to access and use information (ODI, 2009a; OPAAL, 2009c), services (Roberts *et al.*, 2012) and applying for housing and benefits (Newbigging *et al.*, 2011; Wright, 2006);

- Increased ability to make informed decisions and be involved in decision making (55%) (Roberts *et al.*, 2012), including in situations of inpatient mental health treatment (Roseman et al, 2000). In another example, the benefits of advocacy in decision-making for disabled people around care home entry are identified as supporting greater choice and control and reducing the chances of inappropriate placement (Davies *et al.* 2009, referenced in Manthorpe & Martineau, 2010). Similarly, people report a greater ability to plan for themselves, to help others and to feel well when supported by an advocate (White, 2012);

- Increased knowledge of and ability to obtain rights and entitlements. Over a third (36%) of advocacy organisations reported that advocacy enabled people with learning disabilities, for example, to achieve equality and gain their rights. 36% of commissioners also agreed with this (Roberts *et al.*, 2012). OPAAL (2009c) reported that 31% of older people supported felt they had been empowered by their advocacy support;

- Better communication and relationships between individuals and professionals (ODI, 2009a; Older People's Commissioner for Wales, 2012) as well as independent reassurance was helpful, helping to alleviate fears, regardless of the outcomes (ODI, 2009a; Bauer *et al.*, 2013);

- Increased opportunities for participating in the community (Advocacy and Resource Exchange, 2004), supporting people to participate in democratic processes (Harnett, 2003) and take part as active citizens (Scourfield, 2007).

Outcomes achieved by advocacy reported include:

- Increased confidence;

- Increased choice and control;

- Increased independence;

- Increased feeling of safety and security: for example, OPAAL (2009c) notes advocacy support was given to older people in cases of various forms of abuse (including financial and physical abuse); in the view of advocacy schemes, abuse was reported as having been stopped in 46% of cases and prevented in 17%; of cases;

- Improved health and well being;

- Reduced mental distress;

- Empowerment and personal development. This was particularly reported in advocacy interventions for young disabled people at transition (i.e. increased confidence and self-esteem, raised expectations about what is possible, and a more positive self-identity as a disabled person) (ODI, 2009a; Oliver *et al.*, 2006);

- Reduced activities arising from safeguarding concerns about children's welfare;

- Increased access to early intervention (reduced use of more intensive services later on);

- Being part of a peer support group was reported to boost parents' morale (ODI, 2009a). More generally, self-advocacy, peer advocacy and citizen advocacy in particular are thought to offer great potential to promote networks and support individuals to build relationships by offering them a safe and stable environment (Stewart *et al.*, 2013).

Unsurprisingly, longer-term problems seemed to be more difficult to resolve through advocacy support. In an article reporting on action research evaluating an advocacy project supporting quality of life for Pakistani and Bangladeshi families with at least one child with severe disabilities, significant housing problems (such as supporting a move to a new home) appeared to be the most difficult to solve, while smaller issues such as arranging adaptations were more likely to be achieved (Fazil *et al.*, 2004). The project was a time-limited pilot which compounded this situation; however, this type of finding is also reported in an article which reported on advocacy for people from Black and Minority Ethnic (BME) groups in Glasgow, where access to services was found to improve through advocacy support, however people's basic situation often remained unchanged (Bowes and Sim, 2006).

7.2 Observations of the research – process outcomes

Overall, there is a paucity of evidence on the process benefits of advocacy (ODI, 2009a). Nevertheless, some areas of evidence relating to the process of advocacy are relatively well developed.

There is a good amount of qualitative evidence of parents with learning disabilities during their children's safeguarding procedures of the value of having an advocate (for example Tarleton, 2007; Mencap, 2007; ODI, 2009; Bauer *et al.*, 2013; CHANGE, 2010). Similarly, some reasonable process evidence exists regarding the process outcomes of advocacy for young disabled people at transition. The focus of three well-designed studies was on qualitative methods with young disabled people (Hoggarth *et al.*, 2004; Balcazar *et al.*, 2004; Grove and Giraud-Saunders, 2003), and identified the process outcomes noted above (ODI, 2009a).

For advocacy itself, we found only one methodologically sound study that explored whether independent advocacy had met service users' expectations (Murphy, 2001), which found that most respondents felt their expectations had been met. Other reports sometimes note satisfaction with the advocacy process, for example OPAAL (2009c) noted that advocacy partner goals were achieved in 36% of cases, partially achieved in 36% of cases and not achieved in 13% of cases, and that 44% of older people reported being fully satisfied with advocacy support received.

There are a considerable number of anecdotes and case studies that demonstrate the impact that advocacy has had for specific individuals (GAIN, 2012; Cameron, 2012). However, it is generally unclear if these are typical examples of the impact of advocacy.

7.3 Observations on the research – advocacy outcomes

The evidence base for outcome benefits is sparse (Lawton, 2009). A major focus has been on outcomes of advocacy for parents with learning disabilities (ODI, 2009a), but evidence is much less well developed in other areas. For example, there are no studies that explore the benefits of independent advocacy when entry to residential care is a possibility (ODI, 2009a, Manthorpe and Martineau, 2010).

Below, we briefly consider what the literature has to say about evidence of advocacy impact for particular groups beyond those where there has been greater focus (such as people with learning disabilities).

1. Disabled children and young people and those in the care system

This review has uncovered a reasonable amount of qualitative evidence related to the outcomes of advocacy for children and young people, including disabled children and young people and those in the care system, described as 'looked after'.

The National Children's Bureau (Harnett, 2003) compiled a *Highlights* paper that summarised and referenced evidence related to the benefits of peer advocacy for children and young people. The first national study of children's advocacy in England, prepared for the DH and Department for Education and Skills (DfES) (Oliver *et al.*, 2006), involved

extensive research including: a literature review; a telephone survey of 75 services; and, an in-depth investigation of 10 services that included semi-structured interviews with 48 children and young people, 18 advocates, 40 health and social care professionals and 13 parents and carers.

Two Children's Society research projects (Franklin and Knight, 2011; Pona and Hounsell; 2012) have also added to the evidence base in this area – one involved a survey of Children's services in England, the other an in-depth study of advocacy programs run by the Children's Society itself. Furthermore, advocacy outcomes for young disabled people at transition were covered by six research studies with a methodology that was considered robust against a framework developed by the ODI (2009a; see Annex 3 of the report). However, the particular advocacy outcomes identified seem limited in range and did not cover all the outcomes that might be expected from advocacy for young disabled people at transition (including, for example, the impact of advocacy on access to healthcare and social care or its impact on personal relationships).

2. Older people

This review uncovered a large amount of literature related to advocacy services for older people; however, much of this highlights the lack of robust evaluation and assessments of costs benefits and quantified impacts and outcomes (Manthorpe and Martineau, 2010).

Although advocacy schemes for older people have grown significantly over the past two decades (from 12 in the early 1990s to 136 in England alone in 2006), there is a widespread view that provision is varied and there is much unmet need (OPAAL, 2009). A scoping study of advocacy services for older people in Wales by Dunning (2010) also painted this picture of variable provision and lack of capacity in a sector, which is also 'under researched'.

3. Mental health and people who lack capacity

Evidence on advocacy related to people who lack capacity to make decisions is growing, through the development of the IMCA and IMHA services (DH, 2013). The Mental Capacity Advocacy Project (Age Concern and Help the Aged, 2009a, 2009b) has built up the research base within this area, although this primarily described anecdotal outcomes for people supported through this project and volunteers who were involved in delivering the service.

Regarding choice, there has been some analysis of referrals to IMCA services which showed that IMCAs believed they were able to discern the views of the person in 1,417 of the 3,047 cases involving a decision about moving accommodation, and that the decision made reflected the individual's choice in 1,071 of these cases (DH, 2008; Redley *et al.*, 2009). This is cited as evidence that advocacy enables the views of individuals to be heard (ODI, 2009a). However, data in the DH's five-year review of IMCA services is available for less than half of all accommodation-based decisions. The only conclusion about the extent to which IMCA involvement had had an impact on the accommodation outcome for people supported was that the IMCA "may have an impact on the type of accommodation [and] on the choice of accommodation" (DH, 2013).

4. Victims of crime

There is no robust evidence on the benefits of independent advocacy for disabled victims of crime (ODI, 2009a). NACRO's (2007) report argued that increased use of independent advocates trained in criminal justice issues is an effective support mechanism and can help ensure the needs of disabled offenders are met and they are able to access suitable services. However, there appears to be a paucity of evaluations of such advocacy services (ODI, 2009).

7.4 Capturing outcomes

GAIN (2012) has developed a tool for measuring outcomes for people achieved through independent advocacy. The Advocacy Outcomes Scale Tool helps to evidence the difference that advocacy support makes to individuals across 5 areas (drawn from Putting People First (DH, 2009)). As well as reporting on process measures (such as number of clients accessing advocacy, common referral routes and what the key presenting issues are), the tool also demonstrates outcomes and progress made by individuals during their advocacy journey. For example, across 160 service users who have accessed their advocacy service, GAIN visually depicts the average increase in outcomes achieved (see Figure 1).

Figure 1: Outcome gains through GAIN's advocacy service
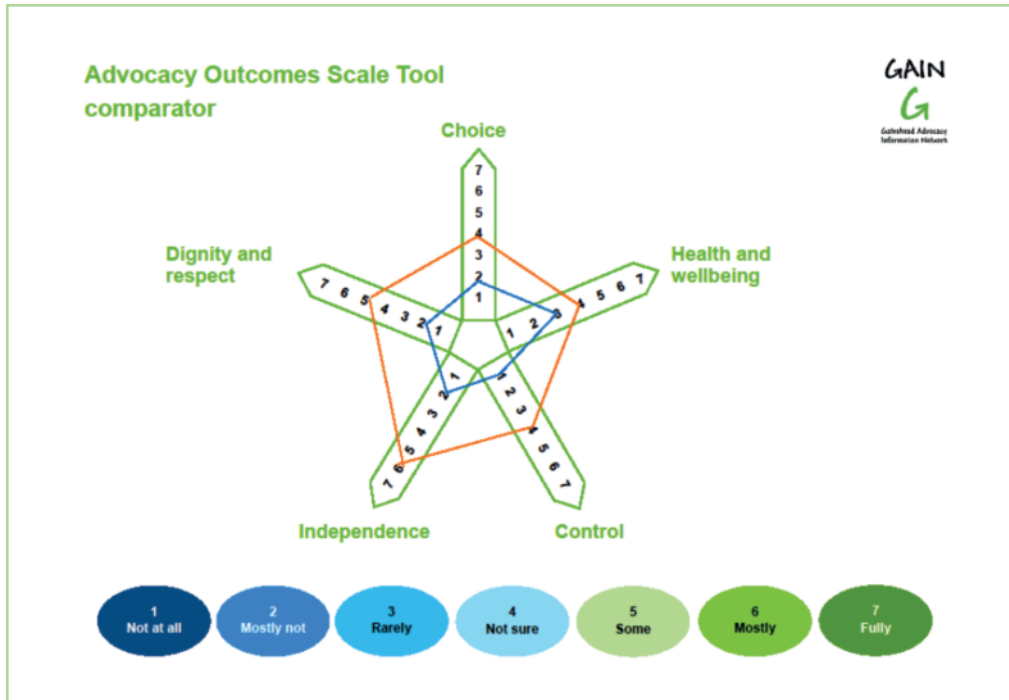
Note: blue line is before, orange line is after

This reaffirms the point that it is possible to capture advocacy outcomes and that some organisations are seeking to do so (see Section 6.2). Overall, however, reliable, robust evidence on the effectiveness of advocacy remains limited and its impact on individual outcomes remains largely unclear (Manthorpe and Martineau, 2010; GAIN, 2012).

8. EVIDENCE OF ADVOCACY IMPACT ON SERVICE DESIGN AND DELIVERY

Having considered evidence of the impact of advocacy on cost-effectiveness and outcomes for individuals, we now consider the evidence for impact at service design and delivery levels.

There is one key finding in the evidence on the impact of advocacy on service delivery: the ability of advocacy to change professionals' attitudes. This finding is repeated in several areas of the literature, for example:

> Advocacy was considered to have the ability to change professionals' attitudes and lead to a better way of working together. For example, an increase in the awareness that social workers had about the barriers faced by parents with learning disabilities was thought to lead to changes in the way children's social services approached parents. It was felt that with the advocate's involvement sometimes more time was given to considering different options and evaluating the pros and cons of different decisions (Bauer *et al.*, 2013).

Advocates essentially modelled good practice in working with people with different needs, including people with learning disabilities (Mencap, 2006) or dementia (Brown *et al.*, 2013). Differences in professionals can be summarised as:

- More positive behaviour by professionals towards disabled people;

- Better knowledge and understanding from professionals of the barriers disabled people face;

- Better communication and interaction by professionals with disabled people;

- Increased coordinated working between different public sector teams;

- Better awareness of and adherence to guidelines for working with disabled people (White (2012), Mencap (2006), ODI (2009a)).

Indeed, some professionals are reported as viewing the involvement of an independent advocate as a way of getting a better outcome for their service user than they might have been able to secure by themselves, especially when the advocacy organisation providing the service was known and trusted (OPAAL, 2009b).

Other benefits arising from advocacy interventions for service delivery are reported to include:

- Raised awareness of the support needs of particular client groups (Mencap, 2006) and more informed providers who are better able to meet people's needs (Older People's Commissioner for Wales, 2012). For example, a NCB *Highlight* on Peer Advocacy for Children and Young People (Harnett, 2003) described evidence that peer groups set up to support children and young people (e.g. for those who are asylum seekers or

looked after in the care system), through enabling the voices of these groups to be heard, have had an impact on service design and delivery and on the development of social services practice;

- Increasing service quality and influencing change in the "established ways of doing things" (White, 2012). For example, the first national study of children's advocacy in England (reported by Oliver et al. 2006) found that where local authorities used casework advocacy as a form of internal audit, this was felt to have encouraged the development of a range of new policy initiatives and also to have contributed towards cultural change and the development of more 'child-centred' services;

- Improving joint working and the sharing of good practice between providers (McWilliams and Miles, 2012). The existence of national and local networks may also help to strengthen this (Rapaport *et al.*, 2006). An example of this was given through the OCD (Obsessive Compulsive Disorder) Action project (2010) where the organisation's Advocacy Manager was also the North West representative on the National Coalition of Advocacy Schemes and was reported to have the shared best practice from the development of the scheme with other advocacy providers through this forum;

- Supporting local authorities to meet their duties, and so ensuring greater legal compliance, as well as creating a more open culture where safety, respect and dignity can flourish (Older People's Commissioner for Wales, 2012).

However, the research underpinning this is far from robust: it typically relies on accounts based on opinions from care professionals or advocates in reporting these outcomes and so must be treated with caution.

At a service level, concerns are also expressed in parts of the literature that advocacy may support service users to stay within the confines of services, which maintain existing attitudinal and institutional views on what is appropriate for certain groups of people, without challenging these structures themselves (Keywood, 2003), although evidence to support this assertion is not given.

9. IMPACT OF ADVOCACY ON POLICY OR STRATEGY AT AN ORGANISATIONAL, LOCAL OR NATIONAL LEVEL

Where advocacy has had an impact at a policy or strategic level, this scoping review has found that such impact has most typically been at a local level, particularly with regard to social care services.

Roberts *et al.* (2012) reported that 85% of advocacy organisations had undertaken advocacy or other work, such as challenging or complaining about service and taking part in consultations, to improve social care services for people with learning disabilities. Commissioners themselves felt that the provision of advocacy made a positive difference to social care services. For example, 97% of commissioners who responded felt that advocacy helped people with learning disabilities be better represented in policy and service developments. Similarly, 83% of commissioners who responded said advocacy services also worked to improve health services for people with learning disabilities, for example in informing developments such as health passports and routine health screening.

Beyond social care, Roberts *et al.* (2012) found commissioners often observed that advocacy had made a positive difference in their areas, including the raising of safety and hate crime by people with learning disabilities as an issue. As a result, some service developments – such as a Safe Place Scheme and partnerships with the local police – had arisen. This same study also noted that advocacy was reported to have influenced use of mainstream services, such as local leisure centres and public perceptions of people with learning disabilities.

It is not possible to determine from the literature, however, if these developments happened because of the presence and actions of advocacy organisations.

It is also argued that the existence of an effective and well-known advocacy service can benefit the wider community (even if they currently have no need for the service) (Jones, 2004 quoted in ODI, 2009a). Such benefits can also include establishing trained and supported individuals who understand their local area and can challenge existing systems and barriers (Scottish Independent Advocacy Alliance (2008). However, evidence to support these assertions is not generally available within the literature.

We found very little evidence reported on the impact of advocacy on policy at a national level. One exception is the result of a Mental Capacity and Advocacy Project run by Age Concern & Help the Aged (now Age UK) (2009a, 2009b). Practice lessons arising from this project about advocacy for people who may lack capacity to make decisions were included in the DH's National Dementia Strategy (2009). Similarly, specific measures regarding advocacy in Wales are likely to have arisen from work done by advocacy organisations working with the Welsh Assembly Government (Dunning, 2010).

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More generally, the literature reflects a stronger sense of policy initiatives impacting on advocacy rather than advocacy impacting on policy – at least for some groups of people. This was illustrated by Manthorpe *et al.* (2005), where in a survey of local authorities commissioning advocacy services for people with learning disabilities, 'policy initiatives' were given most frequently by respondents from local authorities (73.1%) as a reason for financially supporting advocacy schemes. Statutory imperatives for advocacy in certain situations, such as for looked-after children or through IMCA and IMHA services, stand in contrast with the lack of dedicated advocacy strategies for older people (OPAAL, 2009; Dunning, 2010).

9.1 Observations from the literature on statutory and non-statutory advocacy

The theme of differences between statutory / non-statutory advocacy was one that was repeated throughout the literature.

Concerns were highlighted by Roberts *et al.*, (2012) that some commissioners may conflate statutory and non-statutory advocacy. There were also fears that the introduction of statutory advocacy could lead to a two-tier system of advocacy support with people subject to compulsory measures under mental health legislation being more likely than others to access advocacy (Atkinson *et al.*, 2008; Stewart *et al.*, 2013). A number of advocacy organisations have collectively called for more people to be legally entitled to advocacy by extending the statutory right to advocacy if people are involved in safeguarding procedures or where it is required to participate fully in planning care and support (Salman, 2012).

This scoping review could not identify any evidence or analysis to determine whether having a statutory right to access advocacy supports, or otherwise, leads to beneficial advocacy outcomes.

10. EVIDENCE OF IMPACT OF DIFFERENT TYPES OF ADVOCACY

One of the key objectives of this review was to scope relevant evidence on the relationship between the type and style of advocacy and its impact against a range of variables. However, evidence on the impact of different types of advocacy is very limited.

This is heavily influenced by the inconsistent and patchy nature of advocacy provision and the fact that options to choose between different forms of advocacy support is very rare, making direct comparisons for people in similar situations difficult to carry out. We found some information from articles and reports on specific projects or initiatives involving a particular form of advocacy or support and some further information based on personal views rather than firm evidence of outcomes.

Key findings relating to specific types of advocacy are reported below.

10.1 Peer advocacy

Peer advocacy has been reported as being impactful for specific groups, including children and young people and people and their families with mental health issues. Several documents have supported this. The National Children's Bureau *Highlight* (Harnett, 2003) described peer advocacy for children and young people and claimed that it may help to encourage participation of children and young people in different areas. The first national US survey of Family Advocacy, Support and Education Organisations (Hogwood *et al.* 2008), which serve families of children and adolescents with mental health problems, identified peer-to-peer support as one of the most important roles for families in mental health services. Davidson *et al.* (2012), writing about the growth of peer staff working in the mental health sector in the US, described evidence showing that peer support that involves the person offering support sharing their own experiences of mental illness and recovery may have many positive impacts.

10.2 Advocacy for people from Black and Minority Ethnic (BME) communities

Several documents were reviewed that focused on advocacy for people from BME communities, which can also involve bilingual advocacy. Advocates in these circumstances were considered to have improved communication and helped people to express their views and wishes and receive better outcomes through breaking down language barriers. Similarly, advocates in this situation are felt to help people to reduce reliance on family members who would otherwise be required to translate for them. Finally, advocates working with people from BME communities may contribute towards developing greater cultural understanding amongst professionals and other people who offer support. This is subject to the advocate being well matched to the client, in terms of knowledge and understanding of the client's community and culture (El Ansari *et al.* 2009).

10.3 Self advocacy

Self advocacy can highlight issues within families for people with learning disabilities, related to views on adulthood, independence and 'letting go' (Mitchell, 1997). From the project on Local Authority Perceptions of Advocacy and People with Learning Disabilities (Manthorpe *et al.*, 2005, and further analysed in Rapaport *et al.* 2006), results of interviews with stakeholders showed that self-advocacy was on the whole regarded very positively and clearly seemed to be appreciated by people with learning disabilities involved in this form of advocacy.

10.4 Other forms of advocacy

The Manthorpe *et al.* study also reported that stakeholders were viewing shorter term, representational advocacy in positive terms, helped by the fact that it is often easier to show changes made to lives through this type of support. Longer term advocacy, such as volunteer advocacy, was felt to be much more difficult to measure, as this tends to be far more reliant on the relationship built between the advocate and the person supported.

One final point is worth highlighting, given the number of times it is mentioned: the importance of the independence of advocacy organisations from public services. This is an important principle of advocacy (Action for Advocacy, 2002); however, there is no evidence that considers the extent to which independence supports, or otherwise, beneficial advocacy outcomes.

10.5 Observations from the literature on the type of advocacy providers

Some mention was made in the literature on the theme of the type of advocacy provider, e.g. user-led organisations, disabled people's organisations, professional advocacy organisations, and whether this made a difference to the impact that advocacy has. Unfortunately, it was beyond the scope of this review to look at this issue in detail. However, reflecting similar observations about the impact of statutory or non-statutory organisation on advocacy outcomes (see Section 9.1), we did not find any readily available evidence or analysis on this question[6].

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[6] Interested readers may wish to look at the conclusions of the Support, Advocacy and Brokerage "demonstration" project (ODI, 2011).

11. CONCLUSIONS

There is an overwhelming lack of published, robust evidence on the impact of advocacy, especially regarding the cost-effectiveness of advocacy but also with regard to both quantitative and qualitative data that evidences the impact of advocacy and how it works.

Evidence is not available that highlights the outcomes different types of advocacy achieve. Similarly, there is very little evidence that describes the different types of outcomes that advocacy can achieve at an individual, service or local/national level with regards to strategy or policy.

While there is a comparatively large amount of published material that states the positive impact of advocacy, there are three main problems with the quality of this evidence:

- There is a reliance on individual studies and anecdotes that capture advocacy interventions. Though useful illustrations of what advocacy can achieve, such evidence stands alone and does not draw a bigger picture of the effectiveness of advocacy;

- There is a reliance on descriptions and perceptions of the impact of advocacy, rather than empirical, independently verified evidence. In addition, there is much discussion about the potential, rather than actual, quantified impact and outcomes of advocacy;

- Where information does exist, much of it reports on inputs and outputs associated with advocacy processes rather than the outcomes advocacy achieves.

It is very likely that an even larger amount of information exists, especially grey literature related to different types of advocacy provided and the associated funding arrangements. However, based on what has been identified in this review, it is very likely to reflect the three problems identified above and is unlikely to be available in a consistent way to enable the effectiveness of advocacy to be easily identified.

It is likely this is the case because advocacy is a large, very diverse area which has often grown sporadically, in an unplanned and uncoordinated way over the last 30 years in the UK. It forms a complicated picture, involving many different types of provider organisation, different types of advocacy and a huge range of different people supported in different ways. It is also often difficult to separate out from different but related provision, such as information, advice, service user voice and befriending. Advocacy as a concept appears to remain misunderstood by many and target outcomes are often viewed differently from different perspectives. All this combines to make evaluation of the impact of advocacy very difficult. That said, it is not impossible, and ways to improve the evidence base need to be sought.

Some organisations and projects have attempted to undertake cost-benefit analysis to determine the financial impact of advocacy. Where this information exists, it has typically focused on specific groups, especially parents with learning disabilities whose children are subject to safeguarding procedures. Where the evidence is robust, which is in a very limited number of cases, it reports that advocacy interventions return a net financial

benefit. Other grey literature reports similar findings; however, these wider conclusions must be treated with caution, because there is not sufficient information to determine whether the methods for reaching these conclusions are robust or not.

Regarding outcomes for individuals arising from advocacy interventions, there is a paucity of robust evidence. Some reasonable qualitative evidence exists on the process of advocacy for particular people (such as disabled children and young people and those in the care system), but there are significant gaps in the literature on the evidenced effectiveness of advocacy, particularly (although not limited to) older people and people with mental health conditions or who lack capacity.

At the level of service delivery, a finding in the literature is that advocacy can change professionals' attitudes for the better. However, the research underpinning this conclusion is far from robust: it typically relies on accounts from professionals or advocates for reporting these outcomes and so must be treated with caution. At a policy or strategy level, it is not possible to determine whether positive developments – especially locally – could only have happened because of the presence of advocacy organisations. At a national level, the literature reflects a stronger sense of policy initiatives impacting on advocacy rather than vice versa.

A strong belief remains from many different perspectives that advocacy – where it is available – has very positive outcomes for people supported, and that it also plays a significant role in supporting key tenets of current social policy and practice, such as personalisation, promoting voice, choice and control and helping to uphold the rights of vulnerable people. However, this belief is currently overwhelmingly underpinned by evidence which is focused on individual stories, description or process.

The lack of evidence on the impact of advocacy (of many kinds and in many different situations) has been highlighted in a range of different studies over many years. Although some advocacy providers are now using any one of the various outcomes frameworks that are available to capture outcomes arising from their advocacy work, their approach is far from typical, and there is not yet a determined or coordinated effort to rectify the situation across the sector.

The lack of robust evidence regarding the impact of advocacy leaves advocacy in a potentially vulnerable position. During difficult financial times, with an increasing need to demonstrate effectiveness in public spending and a downward trend in the funding advocacy organisations receive, the need for better quality, more widely quantified information on the outcomes of advocacy has never been greater.

In this context, it is important once again to emphasise that while this scoping review has identified the shortcomings in evidence of impact summarised here, the review has equally found no evidence that advocacy does not have a positive impact. The issue and challenge are a lack of robust evidence either way and thus the current need to rely on evidence that is mainly based on individual case study, anecdote and personal opinion.

12. RECOMMENDATIONS FOR FUTURE STUDY

In the course of carrying out this review, we have identified a number of gaps in the research and key areas for further study, including through drawing on gaps identified by previous research into this topic.

The main areas for potential future research are captured below.

■ A comprehensive mapping of advocacy organisations, including (but not limited to) identifying:

- Trends in income levels;

- Client groups receiving advocacy;

- Gaps in the provision of advocacy, particularly:

    by the groups that advocacy is for, and

    by geographical area;

- Trends in demand;

- Types of advocacy provided and trends associated with this;

- Trends in the number of staff and volunteers.

■ Research on the impact of advocacy for particular groups of people who are likely to use social care services and where evidence appears particularly limited at present, including:

- Older people;

- The intersection of people with mental health conditions and at least one other protected characteristic (e.g. older women with depression and other disabilities);

- People with dementia;

- Research on the impact of advocacy beyond the scope of this review, particularly:

    people from BME backgrounds, and

    advocacy aimed at people who are not necessarily likely to use social services, such as Lesbian, Gay, Bisexual and Transgender individuals, victims of crime (including domestic abuse), women and advocacy in physical health settings;

■ A systematic search for literature and evidence from beyond the UK and Ireland from 1990 onwards.

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- ■ Research on the typical characteristics of advocacy provision and the extent to which these affect its impact. Such characteristics would include:

- • The independence – actual or perceived – of advocacy providers;

- • The extent to which the delivery of advocacy adheres to the identified principles of advocacy and how these affect its impact;

- • Statutory advocacy and non-statutory;

- • The types of advocacy;

- • The types of organisation providing advocacy.

- ■ There is also a very clear need for more cost-benefit analysis to fill the well-established gaps that have been noted extensively throughout the literature and reaffirmed by this scoping review. Following ODI's research framework (2009b), such work should collect and analyse information on costs, outcomes and cost-effectiveness of advocacy. It would do so through, for example, detailed service mapping, costs collection and capturing the experiences of people before and after advocacy input. Such research could also include examining the overall impact advocacy has in a particular area or community over time, possibly using a Social Return on Investment approach.

13. EVIDENCE MAP

The following map provides detailed information about the various forms of literature analysed to inform this scoping report.

Table 3. Evidence from the UK

People supported	Reference / Type of publication	Summary
Across different groups	Action for Advocacy (2011) Published document	The findings of this report are drawn from an on-line survey of advocacy schemes in England and Wales that was carried out by Action for Advocacy from March to May 2011. 300 advocacy organisations were invited to take part using an email bulletin and personal calls and emails to contacts within the organisations on Action for Advocacy's membership database. The on-line survey was supplemented by a workshop discussion about the draft findings at the Action for Advocacy annual conference on 26 May 2011. A total of 95 advocacy organisations responded to the survey. 65 organisations gave their name and contact details. 30 respondents chose to complete the survey anonymously.
Across different groups	Cameron J (2013) Article	Article in Scottish Independent Advocacy Alliance's seasonal magazine sharing the findings of an SROI analysis of an advocacy service based in Scotland. The findings were based on analyzing the Older People's service in Glasgow. Service recipients were interviewed using SIAA non-instructed advocacy guidelines, therefore talking to the significant people in client's lives to discuss the outcomes achieved on their behalf. Evidence from case notes and interviews with advocacy workers was also used. The study also interviewed referring agencies. A reference group was set up to identify advocacy outcomes and apply a financial value to them. The group consisted of a retired social work manager, a senior researcher with NHSGGC, two advocacy workers, the service's Operations Manager and Director.
Across different groups	Care and Support Alliance (2013) Report/published document	Briefing from the Care & Support Alliance noting its 3 main areas of concern with the Care Bill during its passage through the House of Lords

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Table 3. Evidence from the UK (continued)

People supported	Reference	Summary
	Type of publication	
Across different groups	Forbat and Atkinson (2005) Article	Article reporting on a review and critical appraisal of the theory and practice of advocacy. Draws on research evaluating a range of different types of advocacy services in Nottinghamshire provided by five organisations (Note: attempts were made to find a copy of the original report but this was not retrieved). Research involved mixed methods including: • review of in-house documents and advocacy literature. • visits to the 5 sites, where discussions with managers focused on recruitment, working relationships, the work environment, supervision/support and monitoring procedures. • interviews with 10 advocates and 5 partners • 132 questionnaires sent to managers, advocates/ volunteers (both past and present) and current partners. • systematic telephone/email consultation with a range of health and social care managers • 'drop in' observation and informal interview sessions with the public in hospital and GP waiting rooms Argues that meaningful evaluation of advocacy needs a dual focus on process (including relationship) and outcomes (practical results for people supported), therefore review of Nottinghamshire services looked at both process and outcomes for people involved. Advocacy seems to be effective where people lack a network of support. Effectiveness is often judged by accounts given about the value of advocacy partnerships which captures the process of advocacy, but often not the outcomes. As well as being valued, listened to and represented, the actual resulting changes in the person's life as a result are also important. Proponents of advocacy suggest it has a key part to play in two areas – promoting active citizenship and social inclusion. Findings specifically from the Nottinghamshire study: • Advocacy works – it does make a difference. • It is not there for everyone who needs it; there is considerable unmet need. • Advocates often work in a hostile environment (alongside or against health and social care staff). • Advocates need continuing support to be effective. The study found advocacy worked in different ways for different people, but was thought to be effective across the range of long-term (citizen advocacy) relationships and short-term work on specific issues (paid advocacy). Advocates gained job satisfaction/sense of achievement and reported successes, e.g. enabling people to make choices; supporting them in moving in and out of care and enabling them to express views at review meetings. People supported were predominantly positive about its impact on their lives.

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Table 3. Evidence from the UK (continued)

People supported	Reference / Type of publication	Summary
Across different groups	GAIN (2011a) Published Document	A series of 19 advocacy stories that were developed in autumn 2011 as part of GAIN's Department of Health funded 'A Stronger Voice' project. These stories aimed to capture advocacy case studies in relation to personalisation, and were used to inform the end of project report *The journey to self-directed support*.
Across different groups	GAIN (2011b) Report / Published Document	A document which brings together extracts from relevant literature, especially policy documents, on the role of advocacy in personalisation.
Across different groups	GAIN (2012) Published Document	Description of the development and results of a new outcomes measure framework for advocacy services covering all client groups in the North East. The outcomes framework was brought together as follows. GAIN undertook a short desktop research exercise to explore the literature relating to advocacy outcomes. GAIN then developed a draft monitoring and evaluation framework, primarily with Personalisation cases only, although this was later extended to include all advocacy cases. The tool was piloted with seven organisations. Outcome measures were related to Putting People First principles. Additional data was captured relating to advocacy outputs, including included information on client satisfaction with advocacy services, referral routes, time spent on cases and issues worked on. Frameworks were developed and refined for each individual service over a period of one year as the pilot continued to develop and take shape. The framework presented in this report is the final framework for Pathways Advocacy, a mental health advocacy service. Projects interested in looking at frameworks for other service user groups can find these on GAIN's website at www.gain.org.uk

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Table 3. Evidence from the UK (continued)

People supported	Reference / Type of publication	Summary
Across different groups	Hardwick (2013) / Article	This paper is informed by a service evaluation of an Advocacy Rights Hub from the perspective of representatives of stakeholder organisations (location unspecified). The evaluation comprised two phases: qualitative data from semi-structured interviews and an observation of a Reference Group meeting, and quantitative data from the Hub's monthly data collection. The initial phase assessed understanding and use of advocacy, and understanding and use of the Hub. The aim was to elicit how meaning was constructed by participants through semi-structured interviews. Additionally, each participant was asked if they had any case examples that they could recall that would exemplify observations made.
		Cluster sampling was employed to determine who participated. This involved inviting all members of the Hub Reference Group (n=20) to participate, all of whom were representative of a key stakeholder organisation. Eleven members put themselves forward. Six of these were 'issue-based advocates', one a 'peer advocate', one a 'citizen advocate', two commissioners of welfare services, and one a manager of a welfare organisation which did not offer advocacy. The researcher also observed a Reference Group meeting which discussed the strategy for publicising the Hub city wide and the emerging gaps in advocacy provision.
		Finally, in this phase of the evaluation, a semi-structured interview was held with both the Hub manager and the Hub statistician. The themes covered were the same as for the stakeholder's interviews. Data was then analysed using thematic analysis. The second phase was a quantitative analysis of monthly data sets collected by the Hub during 2010.
Across different groups	Henderson (2007) / Article	An article that aimed to stimulate debate about the relative merits of non-instructed advocacy.

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Table 3. Evidence from the UK (continued)

People supported	Reference / Type of publication	Summary
Across different groups	Office for Disability Issues, ODI (2009a) / Report	Commissioned by the ODI, a significant research study which investigated the nature of existing evidence and gaps therein regarding four particular periods in disabled people's lives where advocacy is needed.
		The researcher's primary search strategy was to conduct a systematic search of bibliographic databases. In addition to the systematic search of formal literature, the research team also searched for grey material, held in reports or unpublished form. Across all topic areas, the systematic search identified 45 publications to include for data extraction and critical appraisal. The search of the grey literature generated an additional 47 items. Other additional items were read for background and context (policy documents for example), even though these were not suitable for inclusion in the critical appraisal process.
		Once obtained, items were read in full and key data extracted and recorded using a tailored 'reading tool'. This included basic bibliographic details as well as more detailed standard information for each item of literature. Each publication was appraised for quality, using a scoring scale agreed with ODI. This process was useful in that it helped to prompt the research team to evaluate each piece of literature in a similar way, using a standard set of criteria. The combined scores from the scale gave the research team a basic means of estimating the relative 'quality' of the different studies reviewed, and of gauging the extent to which particular findings were based on a robust research methodology, where a report of this existed.
Across different groups	Office for Disability Issues (2009b) / Report	A report which sets out a proposed framework for future research to investigate the cost-effectiveness of independent advocacy for disabled people in four specific situations.
Across different groups	PohWER (date unknown) / Published document	Brief internal analysis document of the SROI for an advocacy service in Hertfordshire. The SROI analysis was supplemented by interviews and focus groups with 88 service users (10% representative sample of whole service user group), and a phone interview and questionnaire with commissioner (Hertfordshire County Council).
Across different groups	Salman (2012) / Published document	Series of case studies from advocacy providers detailing the difference their service makes.

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Table 3. Evidence from the UK (continued)

People supported	Reference / Type of publication	Summary
Across different groups	Scottish Independent Advocacy Alliance (2008) / Report/pPublished document	A guidance document produced by Scottish Independent Advocacy Alliance (SIAA), a membership organisation for independent advocacy organisations in Scotland, which develops and updates Principles and standards in Independent Advocacy organisations and groups (2002) produced by Advocacy 2000. The document states that "Independent advocacy can help to widen a person's horizons and enable them to become active members of society". It also describes advocacy as helping people to: express their own needs and make their own informed decisions; gain access to information; explore and understand their options. Advocates are described as: speaking on behalf of people who are unable to speak for themselves, or choose not to do so; and safeguarding people who are vulnerable or discriminated against or whom services find difficult to support.
Across different groups	Stewart and Macintyre (2013) / Published document	Document which draws on evidence in relation to advocacy in health and social care to which summarises what works in relation to advocacy provision.
Across different groups	Suffolk Advocacy Forum (2011) / Published document	The research, which underpins this briefing paper, was carried out by the Office of Research and Enterprise, University Campus Suffolk, in between May and August 2011. In stage 1 the views of a range of individuals, from groups which can be said to be disadvantaged and/or socially excluded – groups which struggle to have their voice heard, were collected. Interviews focused on their experiences and views regarding advocacy, access to advocacy and being heard. Outcomes provided a set of qualitative data which offered an insight into individual's lives and struggles for representation. Approximately 40 interviews were undertaken and 6 meetings with organisations were attended. Interviews focused on groups identified as experiencing significant gaps in advocacy provision. See appendix 1. The outcomes of the research were supplemented by a half day workshop which focused on extensions to existing advocacy provision to meet the needs of socially excluded groups or communities.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference / Type of publication	Summary
Across different groups	White (2012) / Published document	Brief internal analysis document of the SROI for an advocacy service in Kirklees.
		This report was completed by first identifying three key groups of stakeholders for the Kirklees Advocacy Service. They were:
		• Service users – including users of 1:1 support, peer network members and peer advocates (volunteers)
		• Commissioners – those who funded the service
		• Referrers – those who referred others to the service
		Each group were contacted with bespoke questionnaires sent to Commissioners and referrers and a mixture of focus group, 1:1 interviews and questionnaires offered to service users. Some 11 service users took part in interviews (12% of all service users), although the response from referrers and commissioners was much poorer (2 questionnaires returned from a total of 25 sent out).
Across different groups	Williams et al. (2009) / Report/published document	Social Care Programme Board, to scope current activity and thinking in relation to information, advice and advocacy (IAA) and the delivery of 'Putting people first' (2007).
		Involved a literature and website review; a survey of directors of adults social services (82 - 55% responded); engagement with a range of stakeholders (including service users)in 7 local authority areas including visits, focus groups and interviews; interviews with and visits to a small sample of national statutory and voluntary organisations
		Led through a steering group including commissioners, funders and representatives from the DH, DCLG, DWP and the ODI.
		Findings included:
		• It can be difficult to unpick IAA services, areas have a disparate range of services which are generally not strategically ordered or coherent, but have developed from different initiatives
		• Much evidence around IAA is descriptive and not based on robust assessments or evaluations, making it difficult to know on what basis initiatives are deemed 'best practice.
		• Effective IAA is widely felt to be vital for personalising services and support.

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Table 3. Evidence from the UK (continued)

People supported	Reference / Type of publication	Summary
Across different groups	Windle et al. (2010) Report /published document	Final project report on a two-phase project – first exploring, then testing an initial outcomes tool. Part of the Measuring Outcomes for Public Service Users (MOPSU) Project. Funded by the Treasury under 'Invest to Save' and led by the Office of National Statistics.
		An exploratory phase involved: a literature Review, enabling development of a model of IAA outcomes; consultation, 15 interviews with national IAA providers; fieldwork, in two sites: 19 interviews with staff, 10 with service users. The development phase followed the analysis of the exploratory phase and involved: cognitive testing of the tool with 26 users; an iterative process of adding new questions and making changes and piloting of the tool by 7 organisations, involving 79 participants. It was reported that:
		• Output, rather than outcome, data was recorded by organisations although there is a desire to move to this
		• Outcomes are sometimes measured by a specialist project
		• Resolution of the problem/issue/crisis and resultant reduction in anxiety is key for the client
		• Cases which involved identification and discussion of options tended to be more successful that those where more proactive help was needed
		• Peace of mind and control are two short term outcomes for clients.
		• From a staff perspective, key outcomes for users were empowerment and increased knowledge, enabling independent action. However it was felt that clients may not often share these desired outcomes.
		The model was developed to measure two types of outcome: increases in knowledge and empowerment; and problem resolution. It is argued that there needs to be a culture change within IAA service commissioners and providers towards a focus on evaluation of outcomes.

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Table 3. Evidence from the UK (continued)

People supported	Reference / Type of publication	Summary
BME communities	Bowes and Sims (2006) / Article	Report of findings of research which explored the understanding and expectations of advocacy services for BME groups in Glasgow. Undertaken by researchers from University of Stirling. Research involved interviews with 18 representatives from BME groups and 60 potential service users. Identification and discussion of themes emerging within this article.
		Independent advocacy was seen as having the potential to support people to have their own voices heard and communicate their needs (including to services). Also, perceived as a way of tackling more general injustice including race and gender discrimination. It is seen as supporting self assertion and the ability to control one's own life through the advocate interpreting, speaking up for and supporting the user. It should also challenge service providers to fulfil their tasks in ways which are appropriate to their clients.
BME communities	El Ansari et al. (2009) / Article	An article exploring development of bilingual advocacy in East London, considering the development of the bilingual advocacy services by an NHS University Hospital Trust, the local experience of these services and the factors that have influenced their development.
		Four authors employed the Delphi method to examine the advocate, service or client-related challenges that face advocacy services and the threats of these challenges to Trust based advocacy and their implications to the service, client and advocate.
		Includes reference to findings of previous literature. Describes impacts of bilingual advocacy including: improving BME clients' experiences by providing: a sensitive / responsive service; client service matching; client-centred care and improved choices leading to satisfaction. The improvement in client–provider communication decreases reliance on family members to interpret, while increasing information accuracy, adherence to care regimes and follow-up of appointments. May lead to improved use of resources and effectiveness of consultation time for practitioners and BME clients. Can play a role in developing 'active patients'. Vital for: transparent informed consent; identifying risks which only patients will know about and involving a more diverse group of people in clinical trials. Access to advocacy may be specifically required where people are at risk of marginalisation and where their needs may not be well understood, eg. People with long term conditions, learning disabilities, mental health problems, refugees, asylum seekers and older people.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference Type of publication	Summary
Families from Pakistani and Bangaldeshi communities with disabled children	Fazil et al. (2004) Article	Article reporting on action research which evaluated a small advocacy project (duration 9 months) designed to improve the quality of life for Pakistani and Bangladeshi families with at least one child with severe disabilities. 19 families were involved, supported by individual advocates assigned to families and support groups for parents. Advocates were able to maximize family income and put families in contact with service providers, e.g. respite and health services. Housing problems proved to be most difficult e.g. transfers to a different housing (may have been impacted by the short duration of the project). Greater success seen achieving household adaptations. The majority of parents reported being happy that they were part of the advocacy service and experienced loss when the service stopped. Also many felt more able to communicate and access services by having an advocate and that advocates helped to get things moving quicker with services. Three families felt able to deal with service providers on their own after the service stopped – but most did not. Families mainly viewed the service at the beginning as problem solving, at the end this had changed to be viewed more as befriending. Advocates can help professionals to realise the limitations of their own expertise and the blind spots which can cloud judgement (e.g. cultural/class/gender knowledge).
Disabled people from black and minority ethnic communities	Equalities National Council (2012) Report/published document	A manifesto which aims to ensure there is a better national voice for disabled people from BME communities, their families and carers.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference Type of publication	Summary
Disabled people from black and minority ethnic communities	Trotter (2012) Report	Research report which presents the findings of work dedicated to bring together the disability and race equality sectors and to strengthen the knowledge base of this intersection.
		The first part was producing a statistical profile of BME disabled people, primarily drawing on government datasets, e.g. the Family Resources Survey, Households Below Average Income Survey, Life Opportunities Survey and Labour Force Survey – the principal sources of national level data for disabled people. The aim was to sketch an indicative outline of the population rather than a detailed analysis. As such, researchers focused on a number of key indicators, including the prevalence, age profile, household and individual income levels, employment status, and the geography of disabled people in ethnic minority communities.
		A literature review of the existing research around disability in ethnic minority communities provided a framework within which to place the research.
		The third part of the methodology was holding focus groups with BME disabled people, in order to understand more fully their needs, experiences and preferences for service provision. In total, researchers spoke to nearly 60 people in London, Bradford and Preston, where they asked people about their experiences of formal and informal care, their understandings of disability and ethnicity, and what an ideal service would look like. These geographical locations were chosen because they have some of the largest BME populations in the UK.
		To understand BME disabled people's needs as broadly as possible, a purposive sampling approach was used. Four focus groups were held: young people, adult men, adult women, and parents/carers of disabled children who were users of Scope services. Researchers spoke to people with a range of impairments.
Children and young people	Harnett (2003) Report/published document	Highlight document describing the concept of Peer Advocacy and comparing this to the more established types of citizen and self advocacy, plus peer support and mentoring. Summarises key findings from research and other literature in this area. Reports that peer advocacy groups have been shown to be effective at enabling voices of young people to be heard in the development and delivery of local services. A perceived advantage of peer advocacy is that children and young people have the support of their peers in order to express and develop their own ideas and become empowered to find solutions to the problems at hand.
		Principal problem faced by advocacy services reported to be a shortage of suitable advocates.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference	Summary
	Type of publication	
Children	Oliver et al. (2006)	Report on the first national study of children's advocacy in England. Prepared for DH and DfES.
	Report/published document	Involved a literature review; telephone survey of 75 services; in-depth investigation of 10 services including semi-structured interviews with 48 children and young people, 18 advocates, 40 health and social care professionals and 13 parents and carers.
		A range of perceived practical and psychological benefits reported for children as a result of advocacy, including: enhanced self-esteem; improved care packages and the reversal of decisions perceived as contrary to young people's wishes or welfare. It was reported to be widely believed that advocacy empowered children and young people, even if they did not always get what they wanted.
		The majority of young people involved reported a high level of satisfaction with their experience of advocacy, identifying emotional and practical outcomes, such as feeling more confident and less stressed, and that their views were taken more seriously. Examples of very significant practical outcomes including retaining custody of a baby, achieving contact with family and friends, tracing siblings, remaining in a placement of their choice, and access to housing, counselling and welfare benefits.
		Professionals and parents identified outcomes including enhancing young people's involvement in reviews, increasing their self-confidence and communication skills, in overturning or improving care plans, and with increasing young people's opportunities for socialising with their peers.
		Issues of concern to young people engaging advocates included: child protection and bullying, including racial and sexual harassment; contact with family and friends; complaints against social workers, residential care staff and foster carers; housing; welfare and other benefits; education; legal problems, including immigration and child custody and health related issues.
		A majority of respondents in advocacy services could identify policy changes that were achieved as a result of advocacy interventions. However, some advocates were also frustrated by LA's resistance to learning from the lessons of individual advocacy, and applying them to children's services on a strategic level.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference / Type of publication	Summary
Children and young people in or leaving care	Pona and Hounsell (2012) / Report/published document	Report on a review of the 9 advocacy services run by The Children's Society across England, providing support to children living in or leaving care and children with Special Educational Needs and/or disabilities. Internally led review with input from independent professionals, including peer review. Involved visits to three programmes and telephone interviews with staff at three others. A representative sample (of 142) of cases reviewed from two of the programmes.
		A range of costs for providing advocacy support for different issues and situations was calculated, with a £31 per hour average cost and cases ranging from £320 for family contact to £3,830 for safeguarding issues. Cases were described where advocacy is estimated have saved local authority money.
		In 75% of cases, Children's Society advocates were reported to have effectively supported young people to communicate their wishes and feelings and achieve their desired solution to the issue. Other advocacy outcomes reported include helping children and young people in the looked after system to: play an active role in decision-making about their lives; get – and benefit more from – the services they need; share concerns with adults; stay safe; improve their self esteem; build resilience through and make a successful transition to adulthood and independence. Advocacy is also reported as supporting local authorities to meet their duties as corporate parents to children in care by improving both children's experience of the care system and their outcomes as well as delivering financial savings.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference / Type of publication	Summary
Disabled children and young people	Franklin and Knight (2011) / Report/published document	Report of research which aimed to contribute to the small body of literature by illustrating advocacy in practice for disabled children and young people, and exploring the processes and outcomes of advocacy.
		105/150 (70%) replies to the initial questionnaire, 75 said they had advocacy services for disabled children and young people, provided a contact name and these were then sent a detailed questionnaire, which was also circulated with the Children's Rights Officers and Advocates newsletter. 45 responses to the detailed questionnaire were received, from people representing 35 groups providing advocacy for disabled children and young people accross 60 Local Authority areas. 12 case studies written.
		Findings of the report include: indications of high levels of unmet need; low provision of advocacy services; lack of awareness of advocacy and its potential; little evidence that provision had grown in the last five years; lack of accessible information.
		Key findings of this study on the impact of advocacy for children and young people were that it can: enable them to express views and contribute to decisions; lead to improvements in their and their families', lives through improved services; lead to more appropriate placements in care, improved stability at home, reduction in pain and improved safeguarding; lead to improved confidence, self-esteem and independence amongst children and young people; lead to better communication with and increased trust in adults; lead to changes in professionals' attitudes and approaches towards a child.
		Lessons learnt from individual advocacy cases did not seem to be replicated to improve services more widely. Findings from previous literature described as demonstrating benefits of advocacy to children, including: improved transition to adult services; being represented in reviews and child protection meetings and ensuring that their needs are being met in foster and residential care.
		Also disabled young people reported positively about having an advocate, feeling nurtured, being taken seriously and having someone to talk to in confidence (Knight and Oliver, 2007).

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference Type of publication	Summary
Dementia	Brown et al. (2013) Report	A pilot study conducted across 5 areas using mixed methods, which explored the views and experiences of advocacy practitioners, managers and volunteers on the need for dementia advocacy and its benefits.
		Utilising a qualitative approach, the study was based on data collected from participants working in voluntary/ community organisations providing Dementia Advocacy. The study was conducted across five localities across England, including organisations based in urban and rural settings, in areas with diverse ethnic minority communities and areas identified as deprived and affluent.
		The methods used included, semi structured interviews, a focus group and observations based on shadowing advocates in their work environment and attendance at a range of Advocacy related events.
		A total of 17 interviews were carried out across the five localities, participants included:
		• Service Managers
		• Professional Advocates
		• Independent Mental Health Capacity Advocates
		• Volunteer Advocates
		• Independent Mental health Advocates
		• Representatives working in partner organisations. This included the following roles; social worker, vicar, resident care home manager, older people key worker.
		Alongside interviews and one focus group, the study is also informed by observations carried out in three of the five research sites. Observations were carried out by the researcher shadowing advocates in their role.
		Researchers sought to generate and formulate theory from empirical data using a grounded approach where data was analysed using a system of 'open coding', which involved sorting the data into analytical categories, which were compared and contrasted to generate themes.
Dementia	Colclough (2012) Published document	An overview of non-instructed advocacy.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference / Type of publication	Summary
Dementia	Dementia Advocacy Network and Advocacy Plus (2012) / Report/published document	Publication focused on 16 Stories (case studies) demonstrating the difference that advocacy can make for people with dementia, written with the aim of explaining the complexity and scope of work of advocates for people with dementia. Written from the perspective of the advocate. Stories illustrate the impact of advocacy in promoting personalisation of services, safeguarding vulnerable adults and achieving positive outcomes for people with dementia by improving their well-being and quality of life. Also helping people – and others in their lives – to recognise and achieve their rights.
Dementia and their carers	Valios (2010) / Article	Descriptive article about the development and piloting of dementia adviser services in various areas of the country. Includes examples of support offered and details/quotes from a person supported and a dementia adviser. Describes dementia advisers linking people up to resources and groups in their communities, which helps to alleviate social isolation.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference	Summary
	Type of publication	
Groups protected under equality legislation	EHRC (2010)	A research report which assesses the extent to which existing advocacy provision is available to people with protected characteristics.
	Report	The first phase of the research gathered information on the provision, quality and accessibility of advocacy services for members of protected groups through surveys of providers and commissioners of services in England, Scotland and Wales. A database of 1,500 advocacy providers was compiled from databases held by Action for Advocacy, the Older People's Advocacy Alliance and Action Resource Exchange. In total, 403 advocacy providers took part in the survey, around 27% of the providers on the database, though not all details on the database proved to be up to date. Two hundred commissioners of advocacy services also took part. These were identified through existing contacts, website searches and snowballing. Of 178 who were initially contacted, 57 agreed to take part in interviews. A further 143 interviews came from referrals from either provider or commissioner interviewees. Both survey samples included large numbers of organisations which provided or commissioned advocacy services for people in the protected groups. Nevertheless, the surveys were not based on random samples of advocacy providers and commissioners, and cannot be considered to be representative of all providers or commissioners across England, Wales and Scotland.
		The second phase of the project consisted of case studies. These aimed to add detail to the survey findings, and to increase understanding of the availability of advocacy for members of the protected groups in relation to social care services. The evidence collected in Phase 1 provided information about interesting or promising practice in relation to the provision or commissioning of advocacy for the protected groups. From this, a shortlist was drawn up of potential case studies. Scoping interviews were undertaken with individuals from the selected organisations in order to obtain further detail about their work. On the evidence collected from the scoping interviews, 13 case studies were selected as examples of good practice. For each of the case studies, between two and 10 semi-structured interviews were conducted with members of the advocacy organisation (including organisational leaders, paid and volunteer advocates) and commissioners. Where possible, researchers also interviewed service users or their carers.
		The 403 advocacy providers that took part in the survey ranged from large providers with well-established advocacy services, to smaller organisations starting to develop their services. Of them, 309 worked in England, 54 in Scotland and 58 in Wales: some provided services in two or more countries. Of the 200 commissioners that responded to the survey, 129 funded advocacy services in England, 47 in Scotland and 24 in Wales. The majority (157) worked for local authorities, of which 83 per cent were located within adult social care teams. A total of 76 respondents worked for a health organisation, including those who held joint appointments with local authorities.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference / Type of publication	Summary
Lack capacity to make decisions	Department of Health (2013) / Report/published document	5th annual report of the IMCA Service and overview of the first five years (2007–2012), England only. Presents an analysis of quantitative and qualitative information recorded on the national database by IMCA providers. Referrals to the service have increased year on year over the five years to just under 12,000 in 2011/2. Impacts reported include IMCAs (through providing 'life story' and other information) about the person's needs and wishes can have an impact on the personalisation of that person's support e.g. the type and choice of accommodation, how well a particular care home will represent the person's best interests and on the support the person receives whether in their own home or in a care home.
Lack capacity to make decisions supported by an IMHA	Newbigging et al. (2012a) / Report	A report reflecting the development and introduction of a quality framework for IMHA services. When reviewing IMHA services in 2010, the researchers asked nearly 300 stakeholders what they thought made a good quality IMHA service. This included over a 100 people detained under the Mental Health Act, most of whom had used IMHA services but the researchers were also able to understand why people did not use IMHA services from talking to people who had not used them Researchers also interviewed IMHAs, managers of IMHA services, mental health professionals, including mental health nurses, psychiatrists, psychologists, social workers and occupational therapists, people with responsibility for commissioning IMHA services and people involved in the administration of the Mental Health Act, particularly Approved Mental Health Professionals and also hospital panel members and a solicitor. They also reviewed the literature on mental health advocacy services, particularly research but also standards and other quality indicators that have been developed, and undertook shadow visits with IMHA services to get an in-depth understanding of what is was like to work as an IMHA. All of this data was combined to develop a framework for the quality indicators and to establish the detail of the indicators.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference Type of publication	Summary
Lack capacity to make decisions supported by an IMCA	Redley et al. (2009) Article	Quantitative and qualitative data from an evaluation of the pilot IMCA service.
		The aim of the evaluation was to ascertain whether an IMCA service could protect the interests of adults who lack capacity and are without family or friends, and are faced with a potentially life-changing decision. In addition, researchers sought to identify and understand any practical difficulties that IMCAs might face following the introduction of the statutory service. To achieve these aims, the evaluation team working closely with each advocacy organisation, collected quantitative data describing the number and types of referrals to the pilot IMCA service, and qualitative interview data capturing key stakeholders' experiences and perceptions of IMCA casework.
		The quantitative data were collected by asking each participating advocacy organisation to complete a 22-item checklist describing each individual referred for an IMCA and associated casework. The items on the checklist were discussed and piloted with representatives from each of the seven organisations, and the persons responsible for its completion were given face-to-face guidance in its use.
		The qualitative data were gathered by a series of interviews with: (1) each manager of an IMCA provider organisation, on two occasions: just after the pilot service was set up and, again, shortly before the MCA came into force (14 interviews); (2) one IMCA caseworker from each advocacy provider organisation, again, just after the start of the pilot service and then shortly before the MCA came into force (14 interviews); (3) the person(s) in each advocacy provider organisation with responsibility for ensuring that local health and social care services were aware of the pilot IMCA service (8 interviews); (4) the decision-makers in health and social care who, having worked with an IMCA, made a substitute decision on behalf of an adult lacking decision making capacity (16 interviews); health care practitioners who had not worked with an IMCA but who had some knowledge of both the MCA and the impending statutory IMCA service (35 interviews).
		The analysis of the interview data began with identifying key issues around IMCA practice (e.g. the assessment of a client's capacity and whether family members might be appropriate to consult) and how these were described and characterised. These descriptions became the basis for hypothetical models of IMCA practice. The models were tested and refined in subsequent interviews and at the monthly network meetings, and then used to provide nodes for data coding.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference / Type of publication	Summary
Lack capacity to make decisions supported by an IMCA	Townsley and Laing (2011) / Report/published document	This research by Norah Fry Research Centre, University of Bristol and funded by SCIE looked at the difference Independent Mental Capacity Advocates (IMCAs) can make when instructed to support and represent individuals. Focusing on the impact of IMCA involvement during casework related to: change of accommodation decisions; serious medical treatment decisions; deprivation of liberty safeguards cases; care reviews and safeguarding of vulnerable adults cases. Involved a sample of IMCAs (describing the extent and nature of the difference their input had made to casework) from 11 advocacy providers through an online survey and semi-structured telephone interviews. Data relates to 151 different cases between 1 April 2009 and 31 March 2010. IMCAs felt that they were having an impact in the following ways: • Increasing clients' involvement in the decision-making process • Supporting clients' communication, ensuring their views and wishes were known • Identifying new relevant information that would not otherwise have been known • Providing practical, emotional and social support to enable clients to understand, and become more involved, in decisions – helping to identify some clients' decision making capacity • Increasing knowledge and helping to improve practice of other professionals. • Making a difference to the outcomes of decisions • Achieving additional direct outcomes for the client • Positive changes for other clients being supported in the same settings.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference Type of publication	Summary
Learning Disability	Goodley and Armstrong (2001) Report/published document	Research with four groups representing characteristics of different types of group making up the self advocacy movement. Researchers spent time with both groups and individual members. Research involved narrative enquiry, including: recording and writing up detailed stories of 17 people; accessing 'accessible narratives' – lifelines of a further 30 people and Circles of Importance of 16 people; group interviews with each of the 4 groups; interviews with 4 supporters of the groups. Findings related to impact of self advocacy included: • groups can offer a stable, safe context for the development of meaningful opportunities and experiences which are self-created in contrast to community care settings designed by others • peer support being a key aspect of groups – members helping each other out at difficult times • groups could support a move away from 'constant surveillance' (in service settings) to a place of 'hopeful privacy' • groups can demonstrate that people with learning difficulties are capable of working for themselves without the interventions of 'more capable' others. • people often cited their abilities: challenging demeaning notions of handicap and disabilities in relation to learning difficulties • self-advocacy in professional-client contexts and cultures has potentially positive implications for user empowerment.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference Type of publication	Summary
Learning Disabilities	Hussein et al. (2006) Article	Findings of a survey of Local Authority (LA) Commissioners plus expert seminar with stakeholders. Primary aim to investigate how LA's perceive outcomes of advocacy schemes and the criteria they use to evaluate them. From the Outcomes in Advocacy for People with Learning Disabilities project carried out by the Social Care Workforce Research Unit (Kings College London) and Values into Action. Surveys (design informed by a literature review) were sent to all 189 LA's in the UK. 54 returns, with details of 97 schemes were received. Advocacy schemes are widespread throughout UK, most (60%) are financially supported by LAs, usually involving a service level agreement (SLA). Reasons LA's gave for providing support: policy initiatives (73%); changes in service provision (33%) and hospital closure programmes (27%). Results of this survey showed the majority of schemes were not evaluated in any depth and many LA's don't systematically collect or scrutinize outcomes of advocacy services they fund but rely on sources of information from schemes themselves using SLA's / contracts to commission, monitor and review. Monitoring and review processes are not well developed. Respondents to the questionnaire felt that advocacy schemes for people with learning disabilities had a range of outcomes, including: empowering service users; improving service user status and credibility; meeting policy aims; promoting independent living; providing independent representation; identify needs /causes for concern; improve service quality; improving family/carer understanding and attitudes; assisting with decision-making in complex cases; improving inter-agency working; improving service monitoring and fulfilling legal requirements. During the stakeholder discussion, the following emerged: the importance of advocacy as a way of improving service users' experiences and implementing policy and the belief that it makes a positive difference to lives. Independence from services was seen as being important, enabling reflection of people with learning disabilities' (and sometimes carers') wishes (different to a best interests approach). The need for greater levels of evaluation was recognised.
Learning Disabilities	Lawton (2007) Published Document	A discussion paper which shares ideas about self-advocacy for people with learning disabilities. SCIE started with a literature review. 21 self-advocates and supporters came to a workshop in September 2005. After the workshop, a small group of people and their supporters met several times to work on ideas for this paper. People took away some of the information to work on and SCIE worked on other sections. A copy of the paper was produced and sent out to everyone who was at the workshop. In another workshop the researchers talked about what should be in the paper and then published it through SCIE.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference / Type of publication	Summary
Learning Disabilities	Manthorpe et al. (2005) / Report/published document	Final project report on the Outcomes in Advocacy for People with Learning Disabilities project which included a Literature Review, Local Authority Survey, Stakeholder Interviews and Consultation Seminar carried out by the Social Care Workforce Research Unit (King's College London) and Values into Action. Described in three articles in this table, Hussein et al (2006), Rapaport et al (2005) and Rapaport et al (2006).
Learning Disabilities	Mitchell (1997) / Article	Article describing a small scale, qualitative, in-depth study underway at the time of writing the article, related to experience of self advocacy from perspective of both self advocates and families. Involved three co-researchers with learning disabilities. Discussions were held with six groups of people with learning disabilities. Discussion focused on issues within families, and for disabled people in living with families.
Learning disabilities	Rapaport et al. (2006) / Article	Article reporting results of 27 semi structured interviews with a purposive sample of people from statutory and voluntary agencies providing advocacy and other services, government departments, and nongovernmental organisations across the UK. From the Outcomes in Advocacy for People with Learning Disabilities project carried out by the Social Care Workforce Research Unit (King's College London) and Values into Action. A mixed picture of the effectiveness of advocacy services emerged. They were believed to be working better where national and local forums were having an impact. Self-advocacy was generally viewed very positively, particularly amongst service users, and felt to help people to have a voice, make choices and develop their skills. It was felt to be easier to demonstrate outcomes of representational advocacy and citizen advocacy was felt to be most difficult to measure due to the central importance of the quality of the partnership and a need for evaluation of the relationship and the difference this makes to lives. Some Local Authorities were reported as commissioning advocacy intentionally to ensure robustness of the services they provided for people with learning disabilities and appeared open to criticisms which might arise. There was general agreement (despite limited evidence from evaluation) that advocacy services played an important role in helping people with learning disabilities to attain their rights and influence service improvements, leading many to argue that more advocacy is needed, often to fill in gaps. There was acknowledgement that this area is always likely to be under resourced. Two apparent reasons were reported for under-evaluation. It was felt that advocacy services tend to be excluded from existing systems designed to measure performance (with local authorities left to their own devices). Secondly, there are disagreements around the most effective ways of evaluating advocacy services, whether the focus should be on quantitative or qualitative measures and how to capture relationship and enabling factors.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference Type of publication	Summary
Learning Disabilities	Rapaport et al. (2005) Article	Article reporting on review of the literature on models of evaluation of advocacy schemes for people with learning disabilities. From the Outcomes in Advocacy for People with Learning Disabilities project carried out by the Social Care Workforce Research Unit (King's College London) and Values into Action. Discusses main models of evaluation, their issues, advantages and disadvantages. Models described include: • Independent Advocacy: A Guide for Commissioners, Scottish Executive (2000) • Resource Pack for Evaluators, ASA funded by Scottish Executive(2003) • CAPE (developed for Citizen Advocacy in the late 1970s) • CAIT (also for citizen advocacy) • ANNETTE (focuses mainly on outcomes), developed by Newcastle Council for Voluntary Service • Citizen Advocacy Lincolnshire Links (CALL) use of an adapted version of CAPE, combining it with a psychological personality inventory to evaluate their citizen advocacy service for young people. • Dementia Self Service evaluation where questionnaires were sent to carers and professionals in touch with the advocacy service • Evaluation carried out by RETHINK involving questionnaires, structured interviews with individuals and focus group interviews. The article concludes that whilst fears exist about the potential for evaluation to infringe advocacy schemes' autonomy, funders need to undertake it for public accountability. Evaluation is complicated by the diversity of schemes and their differing aims and objectives. There are no widely agreed benchmarks to measure performance. The article argues that evaluation models are not easily accessible and decisions about evaluation are not being taken in full light of the existing evidence base.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference / Type of publication	Summary
Learning disabilities	Roberts et al. (2012) Report/published document	The project started through a consultation of advocacy commissioners, advocacy organisations and advocacy networks to find out what they thought about specific questions about the nature of advocacy services and how funding changes might affect these services. Comments and suggestions were also invited concerning the advocacy project in general.
		For this project the researchers carried out two separate surveys, one for advocacy organisations and one for commissioners. Both surveys were made available online and in paper format on request.
		The surveys were carried out between December 2011 and January 2012. A total of 88 advocacy organisations responded to the questionnaire, mostly by using a link to a Surveymonkey questionnaire, with 53 completing the entire survey. 78 commissioners of advocacy services responded (all local authorities), predominately using the Surveymonkey link. 39 commissioners reached the end point of the survey. Advocacy organisations and commissioners completing the survey came from all regions of England.
		In addition to the advocacy organisation and commissioner surveys, the third aspect of the advocacy project involved in-depth work with three advocacy organisations to find out more about what they are doing to promote better health. Three organisations were selected from respondents to the advocacy organisation questionnaire who had indicated they were willing to be contacted, and were visited in February 2012.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference / Type of publication	Summary
Learning Disabilities and high support needs	Lawton (2009) Report	A review commissioned by SCIE to identify and consolidate available evidence of progress and innovation in advocacy practice in relation to people with learning disabilities and high support needs. It was not a full, systematic review but looked at what had already been written on the subject and followed up questions from Position Paper 6 (Lawton, 2007). Searches for relevant research papers were made using key words generated by Position Paper 6, Social Care Online, ASSIA, research journals in the field of learning disabilities and social sciences and key websites.
		The practice survey aimed to find out about advocacy practice in existing services. The project advisory group agreed the practice survey questions. Each site was asked for contextual information about their structure, funding, referrals and evaluation, and to report on methods used by advocates to capture the views, experiences or preferences of people with high support needs. The range of questions was decided following the research review, which had given indications of gaps in evidence. It was intended that the practice sites would provide additional information and evidence that could supplement the identified research and fill in some of the gaps. Practice sites reported on their own work and shared examples that they felt demonstrated good practice. Sites needed to demonstrate innovative methods and good practice in working with adults with high support needs in a mix of urban, rural and semi-rural locations, and had to indicate that they would provide examples of the experiences of black and minority ethnic groups and young people in transition from school to adult services. Five were chosen to cover the range of approaches to support advocacy identified by the research review and project advisory group. These approaches identified were:
		• Multimedia advocacy
		• Storytelling
		• Group work
		• Self-advocacy
		• Representational advocacy
		• Non-instructed or non-directed advocacy
		• Peer advocacy
		Site leads were required to complete the work within a relatively short time, and given the pressures on many smaller advocacy organisations, the requirements of the practice survey may have resulted in an element of self-selection. Leads from successful sites attended a project advisory group meeting to talk through their proposals and to discuss timescales, reporting and expectations.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference / Type of publication	Summary
Parents with Learning Disabilities	Bauer A et al. (2013) Report	A research study using a range of methods which explores some of the economic consequences of advocacy interventions for parents with learning disabilities.
		The economic analysis was carried out using simple decision modelling which combined information from different data sets and sources. Information was elicited from workshops with people working in the advocacy field, from an anonymous survey to a selected number of advocacy projects and from reviews of published evidence.
		Two workshops were held in February and June 2012 at the London School of Economics and Political Science (LSE) with representatives of advocacy projects and umbrella organisations. The aim was to agree the scope of the research, generate information relevant for assessing outcomes and costs, and to discuss how projects could extract further relevant data and information from their data systems. Information gathered at the workshops also informed the design of the survey questionnaire.
		The survey of individuals from advocacy projects was designed to gather quantifiable information from projects to: (1) Roughly estimate the costs of running an advocacy project for parents with learning disability including the costs per parent and intervention; (2) Assess the outcomes that parents and their children achieved during the course of the advocacy intervention; (3) Evaluate the resources used by parents and their children during the course of the advocacy intervention.
		The research team also reviewed the literature for evidence about the costs associated with safeguarding activities, care proceedings and children in care. They also searched for evidence on the economic consequences linked to outcomes of advocacy as reported in the survey responses. As well as looked in the literature for evidence about the cost-effectiveness of the interventions to which advocates had referred parents.
		Using data collected from the different sources, the research team calculated 8 types of costs: (1) Cost of a mean hour of advocacy work; (2) Costs for each case from the costs per hour of advocacy multiplied by the number and length of sessions (measured in hours), plus expenses; (3) Financial benefits or cost savings of prevented child safeguarding activities for each case; (4) Mean net benefit across the cases; (5) Costs savings (if any) related to the early intervention that parents were referred or signposted to by the advocate; (6) Mean net benefit of advocacy across the cases; (7) Economic value of reduced quality of life impairments experienced by parents; and (8) Economic value of productivity gains due to employment changes.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference Type of publication	Summary
Parents with Learning Disabilities	CHANGE (2010) Report	A document commissioned by the Office of the National Director for Learning Disabilities into national best practice in independent advocacy for parents with learning disabilities. The report interviewed people with learning disabilities as users of independent advocacy. In addition, an introductory letter and a questionnaire were sent mostly to advocacy organisations, based on a questionnaire used by the Norah Fry Research Centre in their research 'Finding the right support? The questionnaire was sent by email and by post to advocacy organisations who work with parents with learning disabilities as well as to advocacy organisations who for example do not work with parents with learning disabilities and do work with issues as mental health. The questionnaire was sent to approximately 268 Organisations, and 42 responses were received – a response rate of 15.67 %. Four visits to advocacy organisations were also carried out. Finally, replies received to another questionnaire sent by CHANGE, in the context of a different but related project, were considered for answering the research questions of this research.
Mental health conditions	Hakim and Pollard (2011) Published document	A paper on IMHA services in England which assesse the extent to which PCTs have been successful in commissioning IMHA services and providers have been successful in delivering them. Mind sent Freedom of Information (FOI) requests to all 152 PCTs in England. The request focused on the six areas of work pertaining to IMHA service commissioning: • Documents and communications relating to the assessment of local needs undertaken prior to inviting tenders for IMHA contracts (or prior to awarding the contract without tender), including the title of the individual responsible for commissioning and reference to the specific needs of black and minority ethnic communities within the assessment. • Service specification and invitation to tender for the IMHA contract (or service agreement if no tender was undertaken). • Documents and communications pertaining to the number of providers that applied for the IMHA contract. • Documents and communications relating to whether the National Advocacy Qualification and the Quality Performance Mark were required as part of the IMHA contract. • Documents and communications pertaining to how the quality of the service is being monitored. • Monitoring of the uptake of the service, including monitoring of the ethnicity of those making use of the service. Alongside this request, services providing IMHA were also asked to respond to a survey, with the intention to compare PCT's commissioning obligations with service provider's experience of IMHA delivery. Around 10% of IMHA service providers responded to the survey, yielding 35 survey responses. For each, researchers also selected their PCT FOI response. Researchers also selected an additional 15 PCT FOI responses on the basis of the depth/ scope of information submitted by the PCT. The number of responses from FOI, and survey responses far exceeded the researcher's expectations.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference Type of publication	Summary
Mental health conditions and their carers	Keywood K (2003) Article	An article which explores the potential of mental health and mental incapacity law reforms on carers.
Mental health conditions	Mental Health Advocacy Scheme (2012) Published document	Annual review of a mental health advocacy scheme operating in Wales.
Mental health conditions	Royal College of Psychiatrists (2012) Report/published document	Guidance document written to provide information to college members on what advocacy is and why it is needed. Argues that independent advocacy can ensure that an individual's rights are upheld (especially where they may face discrimination and marginalisation) and they receive the care and treatment that they are entitled to. Also that advocacy can improve the quality of relationships between professionals and people with mental health problems (helping to even out the power balance).

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference Type of publication	Summary
Detained under the 1983 Mental Health Act and qualify for IMHA services	Newbigging et al. (2012b) Report	A report which reviewed the extent to which IMHA services in England are providing accessible, effective and appropriate support for the diversity of qualifying users, and to understand the factors that affect quality.
		Nearly 300 people in total took part in this study with 75 participating in focus groups, and 214 people participating across eight case study sites. Mental health professionals interviewed included a range of disciplines, nurses, psychiatrists, professionals involved in the administration of the MH Act (mainly Approved Mental Health Practitioners and MH Act Administrators) and a small number of occupational therapists and psychologists. They were working in a range of settings: secure services, acute inpatient wards, rehabilitation and recovery services, and community settings.
		90 qualifying patients were interviewed in the case study sites and this included 29 people who had not used IMHA services to enable researchers to explore the reasons why not. The sample was made up of 47 men and 43 women.
		The majority of service users (91%) interviewed completed a questionnaire about themselves and this showed that:
		• 12% were under the age of 21 and 6% over the age of 65 with the majority aged 21–65.
		• 30% of the sample were from a BME community, including Black Caribbean, Black African, Mixed heritage, South Asian and White Irish.
		• 88% identified English as their first spoken language with a range of other languages being spoken including Punjabi, Somali, Thai, French and Patois.
		• 8% of the sample completing the questionnaire identified their sexual orientation as gay or bisexual
		• Nearly two thirds (65%) of the sample identified having a disability with over a third (35%) identifying this as a mental health condition ranging from loss of confidence to bipolar disorder to psychosis and schizophrenia. A learning disability or Autistic spectrum disorder was identified by 13%.
		• Over half (58%) had more than five years contact with mental health services compared with 9% with less than a year of contact. Half had been sectioned three times or more compared with a quarter (26%) who had been sectioned once.
		One of the hallmarks of this research was reported to have been the partnership with mental health service users, meaning that the researchers had a range of skills and experiences to draw on in gathering and interpreting the data. The study was undertaken in partnership with Equalities National Council, Aawaz and Manchester African Caribbean Mental Health Services, who were involved in the Project Advisory Group or the Service User Reference Group. The Advisory Group provided guidance to the project and involved mental health service users. The Reference Group was established for the project and helped develop the questions and commented on the findings and what they could mean.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference Type of publication	Summary
OCD	OCD Action (2010) Report/published document	A report (produced by the organisation delivering the service) on OCD Action's 'Life Changing Advocacy Service', delivered over the preceding year (from Summer 2009) and described as being the only specialist OCD Advocacy service in the UK.
		Information obtained from feedback forms sent to all clients before and after working with the service and OCD Action's Advocacy Manager's reviews of cases. Reports on outcomes for 120 people supported directly and describes wider support for 1500 people helped through advocacy information leaflets, seminars and OCD Action website.
		83% of clients said the service had achieved their desired outcomes. Clients reported: (1) improvements in their knowledge of information/services/their rights; (2) improvements in their levels of anxiety and feeling in control/able to solve problems and cope; better relationships with health professionals; improvements in their confidence and their OCD symptoms. Outcomes have been recorded in the four main areas of support.
		Care and Treatment (68 cases) • Improved access to care and treatment 53% • Increased knowledge of treatment rights and options 96%
		Work (30 cases) • Job position now more secure 30% • Improved knowledge of rights at work 100% • Increased confidence in asserting rights under equality law 100%
		Education (4 cases) • Improved support from University / College 100% • Reasonable adjustments made to accommodate client 75% • Increased confidence in asserting rights under equality law 100%
		Housing (11 cases) • Tenancy more secure 55% • Greater support from housing services 82% • Increased knowledge of housing rights 100%
		As a result of interventions by the Advocacy Service 3 educational institutions, 2 healthcare providers and 3 housing authorities have reviewed their policies and procedures. Also, lessons learnt and recommendations shared more widely eg. on OCD centres briefing other healthcare providers, general awareness raising amongst staff such as housing officers and on implications for policies and procedures of large institutions.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference Type of publication	Summary
Older people	Dickens et al. (2011) Article	Article reporting on the effectiveness of a community-based mentoring service (Devon Community Mentoring Model) for improving mental health, social engagement and physical health for socially isolated older people. Carried out by researchers from the University of Exeter. A controlled trial compared a sample of mentoring service clients (intervention group) with matched control group recruited through general practice. 195 participants from each group were matched on mental wellbeing and social activity scores. Assessments conducted at baseline and 6 month follow-up. Results provided no significant evidence that the community mentoring approach has a positive impact on social isolation for older people.
Older people	Dunning (2010) Report/published document	A scoping study Carried out by Older People and Ageing Research and Development Network at Swansea University funded by Older People's Commissioner for Wales. Involved a mix of research methods, including: a desk top literature search and secondary data analysis of academic research publications and other documents; a web-based search of Welsh Assembly Government and local health and other care organisations' policies and procedures, evidence of operation and outcomes; electronic surveys undertaken with older people's strategy co-ordinators and officers in national and local government, health and voluntary organisations; and telephone and face to face interviews with stakeholders in national and local government, health and voluntary organisations. Identifies services in place, current context and what the best opportunities are for the Commission to make real progress in the provision of advocacy services for older people in Wales. Examines gaps and weaknesses as well as strengths and good practice examples.
Older people	Horton (2009) Report/published document	JRF Solutions Paper, discussing lessons for policy and practice. Refers to work supported by JRF by the Quality of Life Partnership in Newcastle to develop a more strategic approach to Information, Advice and Advocacy (IAA). A variety of processes were used to gather the views of older people, including through the Newcastle Elder's Council (older people's forum) and those designed to target more isolated groups such as housebound older people and elders from Black and Minority Ethnic communities. Examples include facilitated events, informal drop-in sessions and general outreach work when staff and volunteers visit older people to talk about issues important to them. During this project, older people were found to place a higher value on IAA than other groups, providing strong evidence of the need for IAA services amongst older people. It was reported that access to good, high quality information can help older people to stay independent and in control.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference Type of publication	Summary
Older people	Manthorpe and Martineau (2010) Article	Article reporting a critical synthesis of the findings of a scoping review of literature on advocacy and entering a care home in England. Commissioned to inform work on the development of independent advocacy services being considered as part of the Independent Living Review by the Office for Disability Issues (ODI). Article including findings outlined in the project report listed below.
Older people	Manthorpe and Martineau (2009) Report/published document	Report of a scoping study of literature on advocacy and entering a care home in England. Commissioned to inform work on the development of independent advocacy services being considered as part of the Independent Living Review by the Office for Disability Issues (ODI). 64 studies and reports identified. A list of current projects and individuals with interests in this field was generated and those undertaking work were contacted and asked for any material in press or recently published. Overall finding – great lack of evidence, with no work found looking specifically at entry into care homes. No clear evidence was found for cost effectiveness of advocacy on a larger scale. Anecdotal reports often seen as confirming the value of advocacy. Very few critical perspectives on advocacy and few system-wide accounts of its working. No longitudinal studies were identified, making it difficult to know if outcomes were short or long term. Few depictions of advocacy recognise the limits of their approach although there are valuable descriptive accounts and case studies. The benefits of advocacy in decision-making for disabled people around care home entry are surmised as providing greater choice and control, diminishing the chances of inappropriate placement and saving (state) money. Advocacy felt to be particularly important to older people when considering entry to a care home as it helps people to: understand their options; make their voices heard; enjoy the same rights as everyone else and get value for money. Access to advocacy reported to be patchy and inadequate (by CSCI in 2008) despite its (perceived) crucial role in prevention of and early intervention in instances of abuse and neglect.
Older people	McWilliams Miles (2012) Report/published document	A summary of the first three years of the Making it Personal programme, which ran from 2009–2012.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference Type of publication	Summary
Older people	Mulvihill (2011) Article	An article arguing the case for more mentoring and befriending projects to be set up to support older people with various levels of needs. Case study examples of projects in action provided, followed by a discussion of some of the ways befriending can be used to support older people. The author argues that the many benefits of mentoring and befriending include reducing social isolation and help with form filling. (Abstract only available).
Older people	Older People's Commissioner for Wales (2012) Report	A set of recommendations from the Older People's Commissioner for Wales regarding advocacy for older people in Wales. The recommendations are based on various stages of work. The first stage of the work was commissioning Advocacy for Older People in Wales – an initial scoping study undertaken by Andrew Dunning of Swansea University. The findings of this research were further confirmed by Advocacy Counts undertaken by Age Cymru. Further research was commissioned on Advocacy and Care Homes, which specifically investigated the provision of independent advocacy for older people who live in care homes. The final stage of this work was to undertake a formal review of advocacy in care homes across Wales. It was reported that the voices of older people and of others who engaged were reflected in the report. Information collected via research and written correspondence with a selection of care homes throughout Wales, all Local Authorities and Local Health Boards, as well as through focus groups with Inspectors and advocacy providers, is also drawn upon.
Older people	OPAAL (2004) Report/published document	Report relating to regional meetings with providers of advocacy services for older people and discussions held around 4 topic areas. Meetings took place in 18 different English towns and cities, involved 51 independent advocacy providers, 29 Age Concern organisations and 21 older people. Part of the OPAAL National Development Project (Robinson, 2006). Topic areas were: guidance and good practice examples of quality frameworks; evidence basis for advocacy, and different methods employed by schemes to collect and collate statistical evidence; the case for independent advocacy for older people as a right and examples of older people's involvement in promotion of independent advocacy; funding – sources and the problems of sustainability. Methods of recording of advocacy inputs and outcomes varied and there was a lack of consistent application between different schemes. All the Age Concern schemes seemed to record similar information, but there was no central system of recording to present a national picture. Some schemes record unmet need and enquiries which cannot be followed up, which were used to strengthen the case for additional funding. A number also recorded time spent on cases, also used for funding applications. Service user satisfaction forms were sent out by most advocacy schemes and some operated a client telephone survey. Several schemes felt that service users were not happy to report negative outcomes.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference Type of publication	Summary
Older people	OPAAL (2009a) Published document	Summary of the work and results of a small advocacy service for adults in Devon in 2008.
Older people	OPAAL (2009b) Published document	Qualitative research on an advocacy service for older people. Collecting information, experiences and opinions took place in a variety of ways.
		• Face-to-face discussions with individual users of the service, in their own homes;
		• Meeting with a group of 20 volunteer advocates;
		• Face-to-face meetings with the service manager and service coordinator;
		• E-mail exchanges with volunteers, followed up by completing a questionnaire;
		• E-mail and telephone exchanges with Direct Payments advisors employed by the ILA;
		• Sending an e-mail questionnaire to a number of other Direct Payments advisors;
		• E-mail and telephone contacts with field social workers employed by the county council;
		• Face-to-face meetings with selected other current (and one former) member of staff of the adult services department;
		• Review of AfI documentation;
		• Review of ILA and West Sussex County Council websites;
		• Review of national policy guidance and allied research.
		The work began with a scoping meeting early in September 09, and the fieldwork was concluded at the beginning of November 09. Telephone and face-to-face interviews were conducted using topic guides that set out to uncover peoples' views on a range of issues associated with the organisation and performance of the service and their different perspectives, based on a variety of relationships:
		• Users of the service;
		• Volunteer advocates providing the service;
		• Social workers and care managers who had engaged advocates or been required to engage with them; and
		• Staff of the ILA and the county council.

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Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference Type of publication	Summary
Older people	OPAAL (2009c) Published document	Project report of OPAAL's National Development Project, 3 year DH funded project. Includes main findings of a part of the project – a consultation involving 35 older people who used advocacy services (for detail see Wright, 2006).
Older people	Robinson J (2006) Published document	interviews and focus group discussions. A semi-structured questionnaire approach was used, with questions based upon the key considerations regarding the experience, impact and development of advocacy with older people outlined in the introduction of this report. There were three main phases of the consultation process:
		1. At the beginning of the project meetings were arranged with some key people involved in advocacy and this assisted in 'checking out' the OPAAL project plan and approach. These discussions proved to be extremely helpful in preparing for the interviews and have added to the feedback by older people about the value of advocacy.
		2. One to one interviews and discussions with older people who had used advocacy services, regarding their experience of advocacy and their interest in the future development of advocacy.
		3. A final focus group meeting of older people convened to discuss their interest in the future development of advocacy and the potential of an advocacy users network.
		A total of 35 older people were engaged within the consultation process. They were drawn from Greater London, North Tyneside and Edinburgh. The profile of the participants was as follows: age – late 50s to 80+ years of age; gender – 18 female, 17 male; ethnicity – UK white x 22, African Caribbean x 8, Asian x 1, African x 1, Sri Lankan x 1, Irish x 2; disability – included people who had physical disabilities and some who were wheelchair users.
		Findings of the consultation included:
		• Older people were unfamiliar with the concept of advocacy to begin with
		• Advocates' style and approach played a key part
		• Advocacy was felt to be needed to: be protected from abuse; combat discrimination; obtain or change services; secure and exercise rights, be involved in decision making and be heard
		• People felt supported by advocacy and emphasised how significant it had been to them
		• Two kinds of successful outcomes were discussed – one with tangible results e.g. obtaining a service and the other related to greater levels of confidence, self-esteem and feeling better equipped to cope

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference Type of publication	Summary
Older people lacking mental capacity to make decisions	Age Concern and Help the Aged (2009a) Report/published document	Final report (prepared by MCAP reference group members at Age Concern and Help the Aged) describing a 3 year (2006-2009) DH-funded project to develop Volunteer Advocacy in 4 pilot sites, involving some non-instructed advocacy. Involves staff reflecting on success, impact and influence of the project in meeting the project outcomes below: • To ensure that providers and commissioners of advocacy services (including local Age Concerns, Independent Mental Capacity Advocacy (IMCA) services, and generic advocacy services) learn the lessons of good practice from the MCAP; • To increase communication with key campaigners and policy-makers about the issues faced by older people who lack mental capacity. Details qualitative examples and evidence of work related to the above aims to support authors' assertions that above outcomes had been achieved, including contribution to the development of the National Dementia Strategy, DH, 2009).
Older people lacking mental capacity to make decisions	Age Concern and Help the Aged (2009b, 2009c, 2009d, 2009e) Report/published document	Report prepared by the Independent evaluator of the three-year (2006–2009) DH-funded project to develop Volunteer Advocacy in four pilot sites, involving some non-instructed advocacy. 123 people were supported by 68 volunteer advocates. Quantitative and quantitative information was gathered and used to build up a picture against each of the project outcomes below: • To enable older people who lack mental capacity to access a high-quality advocacy service; • To enable volunteers involved in the delivery of advocacy to be knowledgeable, skilled, confident and to have a positive experience of providing advocacy to older people who lack mental capacity. Involved analysis of data gathered through the course of the project, case studies, feedback from perspectives of people delivering the project (staff and volunteers), older people supported and staff referring people to the project. Outcomes reported include: • Volunteer advocates being able to have a significant impact on the lives of some people supported; • Some success in reducing isolation; • Help given to clients to identify and communicate their own wishes and views about key life decisions; • Help to represent clients' views to and ensure they are considered by professionals and other decision makers; • Development of the knowledge and skills of volunteers seen as important outcomes in their own right.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference Type of publication	Summary
Older people living in residential settings	Scourfield (2007) Article	Article discussing issues of active citizenship, democratic engagement and empowerment, how these areas often elude older people in the '4th Age' and how more effort should be made to involve people in residential settings in these areas. Much discussion around the lack of advocacy provision for older people in care homes, including references to: • an Office of Fair Trading report (Office of Fair Trading, 2005) which described the provision of advocacy services as variable, particularly for older people in care homes; • a study undertaken (Wright, 2005) which involved a trawl of Age Concern England's advocacy services database which identified that 29 local schemes were providing services for people in care homes and also revealed that some care homes appeared to be denying residents access to such schemes by restricting information on them; • OPAAL's coordinator describing the amount of advocacy available to care home residents as 'woefully inadequate'
Older people with mental health conditions	Bailey and Brown (2009) Report	A report which presents findings from a study exploring the advocacy needs of people aged over 65 years with mental health needs. The research team was requested by the research commissioners to use a survey methodology through the distribution of questionnaires to key stakeholders within Sandwell. Questionnaires were administered with three sets of key stakeholders: (1) People aged 65 and over with mental health needs, (2) Carers of people aged 65 and over with a mental health needs, (3) Providers of services to people aged 65 and over with mental health needs. Participants identified through a number of Sandwell residential, day care and extra care services. Access to service users was undertaken with guidance from service providers. In total nine organisations, providing a variety of care to older people, were contacted. Carers were accessed through a variety of settings. This included the distribution of questionnaires through a number of Voluntary Sector Agencies offering support to Carers of older people with mental health problems. In relation to Voluntary Sector Agencies, carers of people aged 65 and over with mental health needs were identified through agencies' databases and questionnaires were distributed by post to carers of people with mental health problems. Service providers were also recruited through Sandwell-based services. In each organisation managers were approached and asked if they could distribute questionnaires to staff and also complete a questionnaire themselves. In total 640 questionnaires were distributed or administered to respondent groups: 85 questionnaires to service users, 155 questionnaires to service providers and 400 questionnaires to carers. In total 147 questionnaires were completed – 52 by users (of which 36 were completed with the support of a member of staff), 49 by providers and 46 by carers.

Impact of Advocacy for People who Use Social Care Services

Table 3. Evidence from the UK (continued)

People supported	Reference / Type of publication	Summary
Older people with mental health conditions	Brown and Standen (2011) Article	Findings from a small study of Sandwell Advocacy, exploring the needs of people aged 65 and over with mental health conditions and to determine the current level of demand or need for advocacy amongst this group. For method, see Bailey and Brown (2009) above.
Older people with high support needs	Blood (2010) Report/published document	JRF Roundup analysing and reporting key messages related to quality of life for older people with high support needs. Taken from 11 reviews from the first part of the Better Life Programme and other JRF work.
Older people with high support needs	Katz et al. (2011) Report/published document	A report (part of JRF's 'A Better Life' programme) examining what older people with high support needs want and value in their lives and ways of determining what helps and hinders them in achieving these things. Involved a literature review, production of an evidence framework which was then tested out through conversations with 26 people with high support needs and identification of key themes which emerged.
		Information, self determination and involvement in decision making were identified as key themes. The report argues that there is scope for developing a stronger collective voice for older people with high support needs.
People who fund their own care and support (mostly older people)	Hudson and Henwood (2009) Report/published document	A report of research commissioned from independent consultants by ADASS, SCIE and JRF, reviews a range of literature on people who fund their own support and their access to information and advice. Also online questionnaire sent to 27 organisations, 16 replies received and 8 in depth interviews carried out.
		The report concentrates on information and advice, with some mention of advocacy. Findings include : evidence about self funders and IAA is scant, dated and focused on people already in care homes; there are shortcomings in provision of IAA for self funders with variable access to and provision of information, although there is some evidence of improvement in recent years; there is limited access to needs assessment and little ongoing support (following signposting).

Impact of Advocacy for People who Use Social Care Services

Table 4. Evidence from the overseas

People supported	Reference Type of publication	Summary
Parents of young people with learning disabilities	Duquette et al. (2011) Article (Canada)	Article reporting on a qualitative study to examine educational advocacy experiences of parents of adolescents and young adults with a learning disability, through 4 dimensions of advocacy. Involved 17 mothers completing questionnaires, 13 of whom also took part in depth interviews. Participants reported rewards for their advocacy efforts, with all but one of the young adults having graduated from high school and had enrolled in postsecondary education or were employed. They unanimously agreed that parents must advocate for their children in order to obtain accommodations and resources for their children.
Mental health conditions	Olley and Ogloff (1995) Article (USA)	Article on individuals being held in mental health care facilities and legislation to protect their rights. A number of patients' rights advocacy programs, strengths, weaknesses, and general success factors are identified. Recommendations made for development, implementation, and modification of advocacy programs. (Abstract only available)
Families of children and adolescents with mental health	Hoagwood et al. (2008) Article (USA)	Article on the first national survey of Family Advocacy, Support and Education Organisations (FASEOs) which set out to describe grassroots, locally based support agencies that serve families of children and adolescents with mental health needs. 226 directors of FASEO's involved in the survey. Findings reported include participants' views of most important roles of families in this area.

Impact of Advocacy for People who Use Social Care Services

Table 4. Evidence from the overseas (continued)

People supported	Reference Type of publication	Summary
Mental health conditions subject to involuntary hospitalisation	Rosenman et al. (2000) Article (Australia)	Article describing a trial of a model of personal advocacy (based on patients' needs and best interests) for involuntarily hospitalised patients. One (the experimental) group of (53) patients received the support of a personal advocate (a trained lawyer, with knowledge in health policy) throughout hospitalisation. Their experiences and outcomes were compared to a control group (of 52 patients) who received routine rights advocacy. Groups were consecutively (not simultaneously) selected and had similar demographic characteristics, diagnoses and levels of severity of illness. Overseen by a board independent of the hospital.
		Involved patients completing satisfaction surveys just after admission and after discharge. Hospital staff completed Health of the Nation Outcome Scales (HoNOS) with patients and reported on aftercare, compliance and medication (including perceived impact that the advocacy had on this area for patients). Service records were examined and statistical analysis undertaken.
		At the start of hospitalisation, satisfaction with care was similar in both groups. Over time, satisfaction with care improved significantly in the experimental group while it declined in the control group. Aftercare attendance was significantly better in the experimental group and their risk of involuntary rehospitalisation was less than half that of control patients. In 7 months following discharge, the control group spent more than 250 days in the hospital, costing approx $150k (Aus). The experimental group's 'community tenure' was also found to be significantly increased. Clinical staff reported that the experimental advocacy facilitated management of patients. Staff were positive towards advocacy, despite initial hostility.
		Better attendance (amongst the experimental group) at aftercare was felt to be directly related to better experience of hospital treatment (due to receiving information about and involvement in treatment decisions and the companionship of the advocate at a difficult and frightening time). Better aftercare attendance was in turn felt to be pivotal in reducing rehospitalisation.

Impact of Advocacy for People who Use Social Care Services

Table 4. Evidence from the overseas (continued)

People supported	Reference Type of publication	Summary
Mental health conditions and peer staff who support them	Davidson et al. (2012) Article (USA)	Article reporting findings of a review of evidence on peer support for people with mental illness. Describes different stages of research in this area. Details recent experience and outcomes of two trials where peer staff have been employed to carry out roles which encompass advocacy. This includes advocacy to facilitate person centred planning and community connections. Benefits were reported by participants (those being supported) as being: • responsive, more holistic care and support, inclusive of non-treatment issues; • an increased sense of control, hope and ability to bring about changes in their lives; • increased engagement in managing illness; • higher satisfaction with family life, positive feelings about themselves and their lives, social support, and sense of community belonging. One study found that participants' level of psychotic symptoms decreased, but the amount of distress they experienced due to these symptoms increased. Statistically significant findings in another study for reduced number of hospitalisations and days spent in hospital amongst people supported by peer staff in this way. Also, decreases seen in substance use, depression and increases in hope, self-care, and sense of well-being.

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The call for evidence also produced a range of individual case studies provided by a number of different organisations. In total, we received 24 individual case studies, which especially helped to illustrate the impact of advocacy on outcomes for people (see Section 7).

The call for evidence also led to telephone conversations with five advocacy stakeholders that helped inform this work. These conversations were with:

- Action for Advocacy

- OPAAL

- Equalities National Council

- Voiceability

- Help & Care.

We also received useful input from members of OPAAL at their AGM meeting, held in London on 25 September.

We are grateful to everyone who shared information to inform this work.

APPENDIX: SEARCH FOR EVIDENCE

This Appendix outlines our methodology for the search for evidence.

A1. Literature Search

As part of this project, a literature search was undertaken to identify and review published evidence on the impact of advocacy.

Search strategy and results

Geographical scope: the search focused on literature from the UK and Ireland. A few articles and other documents outside of these parameters were included if the content seemed to be particularly relevant in terms of presenting evidence on the outcomes and impact of advocacy. Inclusion of such documents, however, is by no means exhaustive.

Retrospective timespan: documents from 1990 to present

Sources: we used a university online search engine OneSearch, which accesses numerous research indexes, databases and online libraries, including:

- Academic Search Complete
- American Psychological Association (APA)
- Arts & Sciences (JSTOR)
- Bentham Science
- CINAHL (Cumulative Index to Nursing and Allied Health)
- Credo Reference eBooks
- Daily Mirror Archive
- Directory of Open Access Journals (DOAJ)
- ERIC (U.S. Dept. of Education)
- Informa - Taylor & Francis (CrossRef)
- International Bibliography of the Social Sciences
- MEDLINE (EBSCO)
- MyiLibrary ebooks
- Nexis
- Oxford Journals (Oxford University Press)
- Oxford Reference Online
- PsycArticles
- PsycINFO
- PubMed Central
- SAGE Journals
- Sage Publications

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- ScienceDirect (Elsevier journals)
- SpringerLink
- Taylor & Francis Online - Journals
- Times Digital Archive
- Web of Science
- Wiley Online Library

Two initial searches were performed on Onesearch using the search terms agreed with SSCR and detailed below. The first was carried out searching SUBJECT, which generated a list of 242 items. The second search was carried out using ANY, with narrower search terms involving phrases related to impact and outcomes of advocacy. 242 and 97 items respectively were listed for these searches – these are gross numbers, duplicates were not identified. Actual search terms used are shown are shown in the Table below.

Search terms used	Numbers of documents returned
If SUBJECT (field) contains: advocacy OR "service user movement" OR "service user voice" AND impac* OR evidenc* OR evaluat* OR outcom* OR result* OR "return on investment" OR "value for money" OR "cost benefit" OR "cost effectiveness" AND "service user" OR "older people" OR elderly OR disab* OR "learning disab*" OR "learning difficult*" OR "mental health" OR capacity OR children OR "young people" OR care* OR famil* OR social	242
If ANY (field) contains: "impac* of advocacy" OR "advocacy impac*" OR "advocacy outcom*" OR "outcom*of advocacy"	97

Each of the lists was scanned, initially by title. Items which were considered clearly outside of the scope of this review (from the title) were disregarded by the researcher. Where items may have been relevant, abstracts were read (where available). Where abstracts suggested that the item may be relevant to the scope of this study, copies of the full

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document were obtained and read. Items were judged to be outside the scope of this review if they were:

- From outside the UK and Ireland, EXCEPT if the subject looked to be very relevant – ie. describing specific impacts / outcomes of advocacy for people with social support needs

- Concerned with political/lobbying/business/legal advocacy

- On subjects such as international development

- Related only to physical (medical) or public health issues

- Concerned with non advocacy professionals' (such as nurses or social workers') advocacy roles

Exclusions were not used in the search strategy as we were cautious of excluding items which may otherwise be relevant – for example if we had excluded heath or medicine we may have excluded some items on mental health or where both health and social support were involved.

Following the initial two searches detailed above, numerous other searches were carried out (by the same researcher) on OneSearch, involving phrases including those shown below. Results from these searches were scanned by the researcher with a view to identifying additional relevant material which may not have been returned in the initial searches. Numbers returned during these searches were not recorded as many of the items returned had already been returned in the initial two searches.

Searches were carried out using the ANY field option. Phrases searched included:

"impact of independent advocacy"

"impact of service user(s) advocacy"

"outcome(s) of independent advocacy"

"outcome(s) of service user(s) advocacy"

"evaluation of advocacy" / "advocacy evaluation"

"evaluation of service user advocacy"

"evaluation of independent advocacy"

"advocacy review" / "review of advocacy"

"review of independent advocacy"

"review of service user(s) advocacy"

"return on investment of advocacy"

"return on investment of service user(s) advocacy"

"return on investment of independent advocacy"

"(cost) benefit(s) of advocacy"

"(cost) benefit(s) of independent advocacy"

"(cost) benefit(s) of service user(s) advocacy"

"return on investment of advocacy"

"return on investment of independent advocacy"

"return on investment of service user(s) advocacy"

"value for money of advocacy"

"value for money of independent advocacy"

"value for money of service user(s)advocacy"

"effectiveness of advocacy"

"effectiveness of service user(s) advocacy"

"effectiveness of independent advocacy"

We also searched for materials in the SCIE online library using the same search terms above. 101 items were returned from this search and the same process was followed as outlined above to scan the lists, read abstracts and obtain full copies where documents were within the scope of this review and had not already been retrieved via OneSearch.

A2. Online search

A number of websites were also searched for relevant information and evidence on the impact of Advocacy, including websites of the following organisations:

- The Centre for Policy on Ageing – www.cpa.org.uk

- Action for Advocacy – www.actionforadvocacy.org.uk

- SCIE – www.scie.org.uk

- OPAAL – www.opaal.org.uk

- Advocacy Consortium UK – www.acuk.org.uk (Note: website now closed)

- Advocacy Resource Exchange – http://www.advocacyresource.org.uk/ (Note: organisation and website now closed)

- Think Local Act Personal – www.thinklocalactpersonal.org.uk

- Voluntary Organisations Disability Group (VODG) – www.vodg.org.uk

A search for information on the impact of advocacy was also carried out on Google Scholar.

A3. Call for Information

A call for information was also issued as part of this project. The call was publicised on the NDTi website (www.ndti.org.uk) and supporting publicity for the call was also issued on social media sites. In addition, an email was sent to a list of 53 key stakeholders whose contact details were obtained from the NDTi database and through advocacy network organisations and other contacts. Several organisations contacted circulated the email to their own members and networks of contacts. Organisations and individuals contacted directly included:

• Advocacy providers

• Advocacy and other network organisations

• Associations, such as ADASS, ECCA and ARC

• Individuals and groups who have undertaken research and commentated on advocacy

• Other organisations and contacts involved in promoting the voice, choice and control of people who need support

A copy of the email sent is shown on the next page. This was sent on 19 March 2013, with a reminder email sent on 28 March 2013 to any contacts who did not respond.

A total of 37 responses were received from the call for information.

Results

A total of 83 articles, reports and other documents were gathered, reviewed and extracts added to the thematic content grid from the website search and call for information.

CALL FOR INFORMATION

THE IMPACT OF ADVOCACY FOR PEOPLE WHO NEED SUPPORT

Dear (Contact Name)

The NDTi (www.ndti.org.uk) have been engaged by the School of Social Care Research (SSCR) to gather and review evidence of the impact of advocacy for people who need support.

We believe that this work will help local authorities plan, buy and deliver more effective advocacy services. It will also provide vital evidence for organisations delivering advocacy services on existing and potential impact.

As part of this work we are asking for information and evidence from a range of organisations and groups who either provide advocacy services or are involved in planning or commissioning them for the following groups of people who need support: adults (of all ages) and children; disabled people; people with mental health problems or learning disabilities; and self funders.

We are interested in different types of advocacy including: Self Advocacy; Peer Advocacy; Professional Advocacy; Representational (or Citizen) Advocacy and Family Advocacy. We are also looking for evidence of impact in different areas such as: outcomes for people supported; service delivery and design; financial outcomes and impact on policy / strategy.

For more detail on this project, please see the following page on the NDTi website (http://www.ndti.org.uk/what-we-do/voice-choice-and-control/the-impact-of-advocacy-for-people-who-need-support/).

How you can help / get involved

Do you have information or evidence which you could share with us about the impact of advocacy services, or are you aware of other organisations/groups who may have this? If so we would be delighted to hear from you.

If you have or know of any information on the impact of advocacy services which you would be able to share with us or tell us about, we would be delighted to hear from you. Please contact Alison Macadam at NDTi on 01202 421 480 or alison.macadam@ndti.org.uk. We would be very grateful if you could send any information to Alison by Friday the 26th of April.

If you would like to register an interest in this review, and/or receive updates and learning materials as they are produced, please click here.

Many thanks in anticipation of your help.

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