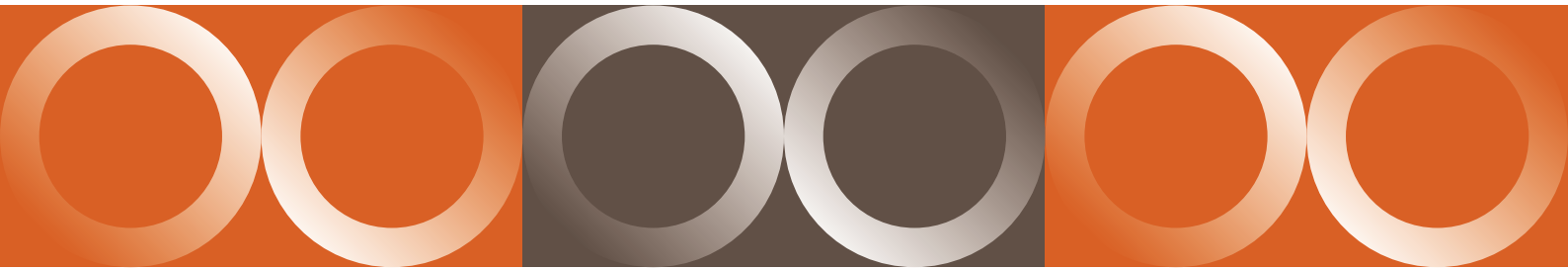




Office for Disability Issues

HM Government



A framework for research on costs and benefits of independent advocacy

Report for the Office for Disability Issues

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University of
BRISTOL

The Government's vision is that by 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life, and will be respected and included as equal members of society.

The Office for Disability Issues is here to help deliver that vision. We work to make equality a reality for disabled people by:

- promoting joined-up government to improve the way policy is made and services are delivered
- involving disabled people and their expertise in what we do and encouraging others to do the same
- being a source of evidence and expertise on disability for the rest of Government
- promoting human rights and ensuring effective disability equality legislation
- communicating what is happening across Government on disability.



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Executive summary





Executive summary

Introduction and remit of this paper

Independent advocacy involves¹ 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. Disabled people, their organisations and many leading voluntary organisations welcome the use of advocacy and believe it is crucial to achieving the Government's vision of more choice and control for all disabled people.

This paper sets out a proposed framework for future research to investigate the cost-effectiveness of independent advocacy (IA) for disabled people in each of the following four situations:

- during transition to adulthood
- when the children of disabled parents are subject to safeguarding procedures
- when entry to residential care is a possibility
- when disabled people are victims or alleged perpetrators of anti-social behaviour.

¹ The following definition is adapted from www.ageconcerncheshire.org.uk

The paper forms the second part of a scoping study commissioned by the Office for Disability Issues. The first part of the study was a systematic review of the evidence relating to the need, costs and benefits of IA for disabled people in each of the four situations listed above (Townsend et al 2009). This phase of the study is to determine how evidence could be collected to fill the information gaps identified, specifically in terms of costs, outcomes and cost-effectiveness of IA in these contexts.

The research approach proposed in this paper

The proposed research will use a comparison group method, to compare groups of people who use IA services with groups of people who do not use IA services. This will provide detailed information about the costs, benefits and impact of IA for disabled people in each of the above situations, and an assessment of the overall cost-effectiveness of IA across and within each setting. However, the lack of evidence highlighted by the systematic review (Townsend et al 2009) means that the suggested research will, of necessity, be exploratory, but will nonetheless generate good data of a kind not previously available.

The approach proposes six stages to the work:

1. setting up a sampling frame
2. identification of sites and participants
3. site mapping and service unit costs estimation
4. baseline data and costs collection
5. follow-up data and costs collection
6. cost-effectiveness analysis and economic modelling.



Stages 1 and 2 will enable the research team to identify 12 sites providing good quality IA to disabled people (three for each of the four situations) and thereby to recruit 60-120 participants across all 12 sites using these services (Group A). All of these sites would need to have waiting lists to support the sampling of 60-120 participants using non-IA services (Group B). A second comparison group (Group C) comprising a matched sample of 60-120 participants will be drawn from sites where there is no IA activity.

Detailed service mapping (involving visits to each IA site) will enable the research team to collect detailed data on the context of provision and service costs (Stage 3) and provide estimates of service unit costs.

Stages 4 and 5 will use a range of standardised measures to examine the experiences of disabled people from Group A who are receiving IA at two points of their engagement with the IA service (Stage 4 – start of intervention, Stage 5 – later point/end of intervention) to assess the impact in terms of outcomes relating to choice and control, and stated goals attained. The inclusion of Group B participants, who are on IA waiting lists, will allow the research team to compare the experiences of disabled people who are not using IA services, but who wish to and may have similar situations and goals to those in Group A. The inclusion of Group C participants will allow the research team to compare the experiences of disabled people in each of the four situations who live in areas where there is no formal IA activity at all. Costs of IA and non-IA service use will also be collected at these two stages.

Data from Stages 4 and 5 will enable detailed assessment and comparative analysis to be conducted, leading to a cost-effectiveness analysis, economic modelling and the calculation of an incremental cost-effectiveness ratio (Stage 6). This will allow us to determine the relative benefits and costs of IA for service users and local service providers. The economic modelling approach will provide information about the extent to which the results are transferable from the study settings and participants used in the research outlined here to other settings and groups of disabled people in general. The model will also highlight where there may be high levels of uncertainty about the transferability or scalability of the results.

What the proposed research will achieve

The research approach proposed here is intended to contribute to our knowledge about the costs and impact of IA services for disabled people in different situations and to examine the cost-effectiveness of these services by considering a number of different variables or controlling characteristics. In particular, we suggest that this research will be able to provide new data relating to the following potential benefits and savings:

- When entry to residential care is a possibility – The potential benefits and savings of an effective IA service for this group include improved outcomes in terms of whether goals set by the disabled person have been attained, the level of choice and control experienced by the individual when entry to residential care is a possibility, reductions in the number of people who are inappropriately placed in residential care with associated savings in the costs of residential placements, improved support services for people who do not move into residential care, improved health for service users and associated reductions in the use of health and social care services.
- During transition to adulthood – The potential benefits and savings of an effective IA service for this group include improved outcomes in terms of whether goals set by the disabled person have been attained, the level of choice and control experienced by the individual during their transition to adulthood, access to appropriate employment opportunities and accommodation with potential savings in the costs of supporting unemployed or inadequately housed people, improved support services for people during transition to prevent major problems or crises and reduced need for services to address these problems.
- When the children of disabled parents are subject to safeguarding procedures – The potential benefits and savings of an effective IA service for this group include improved outcomes in terms of whether goals set by the disabled person have been attained, appropriate placement and support of the child either with the parents or in formal care settings, and the level of choice and control experienced by the individual during and following the safeguarding process. There may be potential savings if the



number of situations where children are unnecessarily placed in care reduces. There may also be savings if the provision of IA services helps to prevent safeguarding issues in the future, by helping parents to access appropriate support when needed.

- When disabled people are victims or alleged perpetrators of anti-social behaviour – The potential benefits and savings of an effective IA service for this group include improved outcomes in terms of whether goals set by the disabled person have been attained, the level of choice and control experienced by the individual during and following judicial processes associated with the anti-social behaviour. There may be potential savings, if appropriate early support reduces the need and use of intensive justice system resources to deal with the allegations or prevents future instances of anti-social behaviour.

01

Background and overview of proposed approach



01

Background and overview of proposed approach

1.1 Introduction and remit of paper

Independent advocacy involves² 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. Disabled people, their organisations and many leading voluntary organisations welcome the use of advocacy and believe it is crucial to achieving the Government's vision of more choice and control for all disabled people.

The Government's Independent Living review identified evidence of the need for independent advocacy (IA) for disabled people in certain situations. The cross-government Independent Living Strategy (ODI 2008) therefore made a commitment to a scoping study 'to assist the development of research to assess the need for, and the costs and benefits of providing, independent advocacy' to those disabled people at particular risk of losing choice and control, namely those in the four situations outlined below.

The scoping study had two stages. The initial systematic evidence review (Townsend et al 2009) considered the evidence available (and the gaps in that evidence) in relation to independent advocacy (IA) for disabled people in the following specific situations:

- during transition to adulthood
- when the children of disabled parents are subject to safeguarding procedures

² The following definition is adapted from www.ageconcerncheshire.org.uk

- when entry to residential care is a possibility
- when disabled people are victims or alleged perpetrators of anti-social behaviour.

The evidence review found that core strategic elements of independent advocacy include:

- separation of independent advocacy from other forms of direct service provision
- independent governance
- independent funding arrangements (ie services are not directly funded by public bodies, but via other indirect means, such as pooled budgets³).

In reality, however, there is still confusion about what IA is and how this provision is interpreted by services, advocates and those they advocate with and for (advocacy partners). This includes acknowledging that funding arrangements for advocacy services are often far from being truly independent in the manner described above. IA is funded in a variety of ways, often via a range of funding streams including the public sector and voluntary/charitable sector. Funding is often short-term and insecure, meaning that many services only survive for a short time.

The review found that there is limited research evidence relating to the need for independent advocacy by disabled people in each of the four situations given above, or in relation to the benefits of IA and its costs in these situations. The second phase of the study was therefore commissioned to consider how a research framework might be designed to fill some of the gaps in the existing evidence base, particularly in terms of the costs and benefits of IA.

³ A pooled budget is a discrete fund to pay for an agreed set of services, whereby several public agencies enter into a partnership arrangement to pool separate financial contributions. The partners have to sign formal written agreements stating the functions to be covered by the pooled budget, the agreed aims and outcomes of pooling financial resources, the funds to be contributed by each partner, and which partner will act as host partner. Host partners are responsible for accounts and auditing. (Adapted from a definition given by makingendsmeet.idea.gov.uk)

1.2 Overview of paper

This paper responds to the brief for the second phase of the scoping study, outlining options for filling the gaps in the evidence available on the costs and benefits of independent advocacy, refined following discussions with advisers from the Office for Disability Issues (ODI) as this phase of the study has developed.

The research approach described in the following sections aims to assess the costs and impact of IA for disabled people in each of the four situations, and to consider the cost-effectiveness of IA across and within each setting. The approach proposes six stages to the work:

1. setting up a sampling frame
2. identification of sites and participants
3. site mapping and service unit costs estimation
4. baseline (T1) data and costs collection
5. follow-up (T2) data and costs collection
6. cost-effectiveness analysis and economic modelling.

Stages 1 and 2 will enable the research team to identify 12 sites providing good quality IA to disabled people (three for each of the four situations). Five to 10 people will be recruited in each site giving a total of 60-120 participants using these services (Group A). All of these sites would need to have waiting lists to support the sampling of a further 60-120 participants using non-IA services (Group B). A second comparison group (Group C) comprising a matched sample of 60-120 participants will be drawn from sites where there is no IA activity.

Detailed service mapping (involving visits to each IA site) will enable the research team to collect detailed data on the context of provision and service costs (Stage 3) and thereby provide estimates of service unit costs.

Stages 4 and 5 will use a range of standardised measures to examine the experiences of disabled people from Group A at two points of their engagement with the IA service (Stage 4 – start of intervention and Stage 5 - later point/end of intervention) to assess impact in terms of outcomes relating to choice and control, and whether people have achieved their stated goals. The inclusion of Group B participants will allow the research team to compare the experiences of disabled people who are not using IA services, but who wish to and hence have similar situations and goals to those in Group A. The inclusion of Group C participants will allow the research team to compare the experiences of disabled people from each of the four situations who live in areas where there is no IA activity at all. The costs of IA and non-IA service use (at T1 and T2) will also be collected at these two stages.

Data from Stages 4 and 5 will enable detailed assessment and comparative analysis to be conducted leading to a cost-effectiveness analysis, economic modelling and the calculation of an incremental cost-effectiveness ratio (Stage 6).

The research approach proposed here is intended to contribute to our knowledge about the costs and impact of IA services for disabled people in different situations and to examine the cost-effectiveness of these services by considering a number of different variables or controlling characteristics. Co-production with disabled people in defining outcomes and effective consultation, complemented by an expert panel and advisory group of relevant stakeholders, should ensure that the views of disabled people are at the centre of the debate about how IA can best support individuals' desires for choice, control and aspirations for independent living.

1.3 Aim and research questions to be addressed

The aim of the research approach proposed in this paper is as follows:

To evaluate the cost-effectiveness of IA for disabled people in each of the following four situations:

- during transition to adulthood
- when the children of disabled parents are subject to safeguarding procedures
- when entry to residential care is a possibility
- when disabled people are victims or alleged perpetrators of anti-social behaviour.

The following broad research questions need to be addressed to meet this aim:

- What are the core components and service unit costs of the 12 services identified as providing (good quality) IA to disabled people in each of the four situations?
- What is the nature/extent and costs of support services (including IA) received by people in Group A?
- What is the nature/extent and costs of support services received by people in Group B?
- What is the nature/extent and costs of support services received by people in Group C?
- What are the outcomes for Groups A, B and C in terms of goals attained and their perceptions of choice and control?
- What is the cost-effectiveness of providing IA in each of the four situations?

- What are the additional costs of IA and where do they accrue?
- What are the savings (if any) resulting from IA and where do they accrue?

The evaluation should also consider downstream costs and benefits beyond service use, for example whether IA may have any direct or indirect impact on the employment opportunities and rates of employment for disabled people in each of the four situations. However, it will be difficult to collect this downstream data. This means that evaluation of certain downstream impacts will need to be considered in the modelling stage (Stage 6) of the research.

1.4 Effective independent advocacy: potential benefits and savings

Recent primary research by the Improvement and Development Agency (2009) indicates that much of the evidence relating to information, advice and advocacy services is descriptive in nature rather than based on robust assessments or evaluations. It is therefore difficult to know on what basis certain initiatives are deemed as 'best practice' in terms of their effectiveness. This is confirmed by our evidence review for the Office for Disability Issues (Townsend et al 2009), which found very limited research available to date on the outcomes and effectiveness of independent advocacy. Nonetheless, some voluntary organisations have established 'standards' for effective advocacy and these include the following components which could be construed as potential benefits of IA:

- listening to the advocacy partner's views and feelings
- helping them to speak up in situations where their voice might not be heard
- advocating for their human and legal rights and reminding other professionals of the centrality of these
- giving information and advice about the different choices which are available and discussing any worries relating to different options

- supporting the advocacy partner to make the choice which is right for them
- helping to sort out problems and issues and making formal complaints to services and other bodies.⁴

It is not possible, as yet, to suggest a link between the above components of 'good practice' and any resulting outcomes in terms of potential benefits and savings of IA. Indeed, that is the purpose of the approach described within this paper. However, we can **hypothesise** about what potential benefits and savings **might** look like for each of the four situations, as follows:

- **During transition to adulthood** – The potential benefits and savings of an effective IA service for this group include:
 - improved outcomes in terms of whether goals set by the disabled person have been attained
 - the level of choice and control experienced by the individual during their transition to adulthood
 - access to appropriate employment opportunities and accommodation with potential savings in the costs of supporting unemployed or inadequately housed people
 - improved support services for people during transition to prevent major problems or crises and reduce the need for services to address those problems.
- **When the children of disabled parents are subject to safeguarding procedures** – The potential benefits and savings of an effective IA service for this group include:
 - improved outcomes in terms of whether goals set by the disabled person have been attained
 - appropriate placement and support of the child either with the parents or in formal care settings
 - and the level of choice and control experienced by the individual during and following the safeguarding process.

⁴ Adapted from Voice for the Child in Care

There may be potential savings, if the number of situations where children are unnecessarily placed in care reduces. There may also be savings if the provision of IA services helps to prevent safeguarding issues in the future, by helping parents to access appropriate support when needed.

- **When entry to residential care is a possibility** – The potential benefits and savings of an effective IA service for this group include:
 - improved outcomes in terms of whether goals set by the disabled person have been attained
 - the level of choice and control experienced by the individual when entry to residential care is a possibility
 - reductions in the number of people who are inappropriately placed in residential care with associated savings in the costs of residential placements
 - improved support services for people who do not move into residential care
 - improved health for service users and associated reductions in the use of health and social care services.
- **When disabled people are victims or alleged perpetrators of anti-social behaviour** – The potential benefits and savings of an effective IA service for this group include:
 - improved outcomes in terms whether goals set by the disabled person have been attained
 - the level of choice and control experienced by the individual during and following judicial processes associated with the anti-social behaviour.

There may be potential savings, if appropriate early support reduces the need and use of intensive justice system resources to deal with the allegations or prevents future instances of anti-social behaviour.

1.5 Overview of proposed research approach

The approach to the cost-effectiveness study described in this paper has six stages. We present an overview of the approach here, but full details of each stage are given in Chapter 2.

To ensure co-production, this approach needs to be underpinned by effective consultation with disabled people (as recipients of IA services and beyond). An advisory group of relevant stakeholders, researchers in this field, relevant policy makers and representatives of leading national bodies active in the field of IA is also proposed. An expert panel (members of which may already be part of the advisory group) will also be established to generate and comment on a series of vignettes that describe what might happen to a disabled person in a range of different scenarios relating to the four situations under review, both with and without access to IA.

Stage 1: Setting up a sampling frame

The objective of this stage is to identify a set of IA services meeting established and/or nationally agreed criteria for good practice⁵ from which to sample for Stage 2. These services are likely to comprise both specialist IA services (ie specifically set up to meet the advocacy needs of disabled people in one of the four situations⁶) and more generic services, covering the advocacy needs of disabled (and non-disabled) people, including some disabled people in the situations under review. Participants recruited from these services will comprise the IA intervention group.

A comparison group is required to assess effectiveness and cost-effectiveness. The comparison group would need to comprise people with similar characteristics and needs to those in the IA intervention group, but who are not (yet) receiving IA services.

⁵ For example, services which have been awarded Action4Advocacy's Quality Performance Mark (QPM).

⁶ For example, an IA service set up to support disabled parents throughout the child protection process and on through any court proceedings.

This comparison group could be sampled from IA waiting lists of disabled people in each of the four situations. The advantages of this approach are:

- Differences due to setting are minimised (for example, local population socio-demographic and economic characteristics, organisation, availability and access to health and social care services, urban/rural mix).
- Eligible participants for the comparison group are relatively easy to identify by services/the research team.

However, there are some disadvantages:

- The characteristics and needs of people who receive an IA service and those on the waiting list may differ in ways that are significant (for example, services may prioritise cases based on the perceived urgency of individuals' cases, rather than on a first come, first served basis).
- People on the waiting list may move on to receive IA services within the follow-up period.
- There may be a lack of available IA services that both operate waiting lists and meet the criteria for good practice outlined above.

An alternative approach would be to sample participants for the comparison group from localities where no IA service is available. The advantage of this approach is:

- A larger pool of participants who can be matched to IA intervention participants in terms of socio-demographic and economic characteristics, need for IA and urgency of service need.

The disadvantages here include:

- Differences due to setting are not easily controlled for (for example, local population socio-demographic and economic characteristics, organisation, availability and access to health and social care services, urban/rural mix).

- Access to, and identification of, people eligible for the control group by services/the research team is likely to be problematic.
- The participants for the control group may receive alternative services as substitutes for IA.

A third option, put forward in this paper, is to use a mixed approach that combines the advantages of using waiting lists with participant samples from settings where no IA services are available. Using this approach, participants receiving IA services (Group A) can be compared to those with similar characteristics who are waiting for IA (Group B) and those with similar characteristics who do not have access to IA (Group C). More detail on this is given in Chapter 2.

Stage 2: Identification of sites and participants

The first objective of this stage is to select a purposeful sample of sites for the research and to negotiate access with appropriate professionals/relevant user groups within those sites. Three sites providing IA to disabled people in each of the four situations are proposed (so 12 overall), in order to cover a range of geographical areas while providing access to a large enough sample of potential participants to make statistical analysis meaningful. More on the selection of IA services covering a range of characteristics is given in Chapter 2.

The second objective is to work with sites to set up a sampling frame for identifying disabled people to participate in Stage 4. This is likely to include all current recipients (meeting certain situation-related criteria) of the IA service and a matched sample of all those (meeting the same criteria) currently waiting to be assigned or referred to the service. A purposeful sample would then be selected to represent those receiving an IA service (Group A) and those in a similar situation but still awaiting an IA service (Group B).

The number of participants per group is likely to be in the range of 5-10 per site, depending on local contextual factors, giving a total of 60 to 120 in each group⁷. It will be important to ensure that the participants in Groups A and B are similar in terms of their situation and the stage they are at. This could be assessed in terms of the number and type of other non-IA services used to date and the duration of the problem or issue that IA is needed to address.

The third objective is to identify one or two settings that do not have IA services and work with local services to identify a sample of disabled people who are experiencing one of the four situations where they might be at risk of losing choice and control:

- young disabled people at transition to adulthood
- disabled parents whose children are the subject of safeguarding procedures
- disabled people at risk of entering residential care
- disabled people involved in the criminal justice system as victims or offenders.

From these, a sample of 60-120 participants for the comparison group (Group C) will be identified who have similar socio-demographic and socio-economic characteristics to the sample of participants receiving IA (Group A).

Stage 3: Site mapping and service costs collection

The objective of this stage is to visit each IA service and map its core components in terms of service planning and delivery. This would involve collecting data about a number of key service-related variables set out in Chapter 2.

⁷ Estimate based on best judgement of the minimum sample size necessary for statistical calculations and what is feasible within the budget and numbers of people dealt with by each service.

At this point, details of funding and expenditure for each of the 12 IA services would need to be collected. This would include:

- the amount of money the service receives to deliver the service
- the source(s) of this funding
- the amount of money that is spent to deliver the service.

These data would be used to determine the resources (eg staff time and facilities) used to provide the IA intervention and the unit costs of these resources.

Stage 3 will not be applied to settings identified for those in Group C who are not receiving advocacy.

Stage 4: Baseline T1 scenario data and costs collection

The first objective of Stage 4 is to collect baseline scenario data from participants from Group A, Group B and Group C, to map their current situations at that time point (T1). This would include:

- Group A – a description of their current situation and the issues they are hoping IA will help to address, details of the IA received or about to start, details of other (non-IA) services received, their desired goal or outcome for the later date when further data will be collected (T2).
- Group B – a description of their current situation and the issues they are hoping IA will help to address, details of non-IA services received or about to start, their projected goal/outcome for T2.
- From Group C – a description of their current situation, details of non-IA services received or about to start, their desired goal/outcome for T2.

It is important to note that desired goals/outcomes at T2 will have to be comparable between people who are receiving IA and those who are not, therefore, the measure to collect this data will need to be flexible in this respect and standardised across people in all three groups.

The second objective is to collect cost data associated with the mapped scenarios of participants in each group at T1. These costs will include IA and non-IA services received by each participant. It is important to assess all service use in this phase, since there is no evidence about what changes to wider service use will occur as a result of the disabled person having access to IA.

Stage 5: Follow up T2 data and costs collection

The objective of this stage is to collect data from Group A, B and C participants relating to the extent to which the hoped for goals/ outcomes specified at T1 have been attained.

For Group A, data will be needed relating to the process and outcomes of the IA intervention and the perceived benefits (or not) of this. Data will also need to be collected in relation to the process and outcome benefits (if any) of any non-IA services received alongside the IA intervention in relation to the goal specified at T1.

For Group B and C participants who do not receive any IA services, data will need to be collected in relation to the perceived process and outcome benefits (if any) of the non-IA services received in relation to the goal specified at T1. In addition, for any Group B participants who subsequently come off the waiting list and begin to receive IA, data will be needed relating to the process and outcomes of the IA intervention and the perceived benefits (or not) of this.

An additional objective of this stage is to collect further cost data from all participants at a second point in time (T2). For some participants, this may simply be a case of updating existing data already collected.

Stage 6: Cost-effectiveness analysis and economic modelling

By this point of the study, a range of costs and outcomes has been identified relating to the impact of IA on choice and control and individual goal attainment for disabled people in each of the four situations (see section 2.4.1). Economic modelling is then needed to assess the potential effectiveness and cost-effectiveness of the 12 IA services in terms of their impact on disabled people involved

in the study. An expert panel will be established to generate, and comment on, a series of vignettes describing what might happen to a disabled person in a range of different scenarios (relating to the four situations), both with and without access to IA. The vignettes represent a series of hypothetical case studies and will include descriptions of the characteristics of a hypothetical disabled person, the pathway taken in terms of range of services used, outcomes of the process, future employment and so on. The structure of the model will be informed by the data collected in Stages 3 to 5, the vignettes and the expert panel. The economic model will synthesise the data collected in Stages 3 to 5, with data from the vignettes, expert panel and relevant published literature/databases to generate estimates of services used, costs of services and effectiveness or benefits of IA. Any assumptions made must be transparent, informed by existing evidence and validated with the expert panel or other agreed stakeholders.

02

Proposed methodology



02

Proposed methodology

2.1 Stage 1: Developing a sampling frame

The objective of this stage is to establish a set of IA services meeting established and/or nationally⁸ agreed criteria for good practice⁹ from which to sample for Stage 2. These services are likely to comprise specialist IA services, specifically set up to meet the advocacy needs of disabled people in one of the four situations¹⁰ and more generic services covering the advocacy needs of disabled (and non-disabled) people, including some disabled people in these situations. For the purposes of setting up comparison Group B (for the cost-effectiveness analysis), all of these services will need to have waiting lists comprising disabled people from at least one of the four situations.

It is important that the sampling frame is sufficiently diverse and accurate in the details it offers in relation to the IA services. A potentially useful approach might be to negotiate access to Action4Advocacy's national database of independent advocacy services and to sample from those who have been awarded the A4A Quality Performance Mark (QPM). See Annex 1 for more details of this and how it is awarded. In short, it covers the following criteria for a quality IA service:

1. independence
2. clarity of purpose
3. confidentiality
4. equality, accessibility and diversity

⁸ We are assuming the study would cover England and Wales only.

⁹ For example, services which have been awarded Action4Advocacy's Quality Performance Mark (QPM).

¹⁰ For example, an IA service set up to support disabled parents throughout the child protection process and on through any court proceedings.

5. empowerment and putting people first
6. supporting advocates
7. accountability and complaints.

We would envisage that a sampling frame of at least 30 IA services would allow for sufficient variation in terms of a range of service characteristics (see section 2.2) to allow potential IA services to be identified for inclusion in the study. Using secondary data from the A4A database and additional data from the QPM evaluation reports (where these are available) the research team should aim to:

- identify the different IA service models operating in England and Wales
- develop key criteria to pinpoint services for inclusion in Stage 2 of the study.

At this stage, the research team will also need to identify and gain access to sites where IA services are not provided. We suggest identifying one or two sites that, as far as possible, share similar characteristics to those selected for the IA service sampling frame. The research team may want to discuss potential sites with national organisations active in the advocacy field (such as Action4Advocacy, or Older People's Advocacy Alliance), who may be able to help pinpoint areas where little or no advocacy activity is available.

2.2 Stage 2: Identification of sites and participants

We advocate selecting a purposive sample of 12 IA services (three per situation) from the sampling frame developed in Stage 1 to achieve a sample of services that reflect the range of characteristics included in the following criteria:

- length of time in existence
- size of service and number of potential clients on waiting list
- universal service, or specialist service for disabled people only
- generic service, or situation/impairment specific

- socio-demographic characteristics (social deprivation, ethnicity, rural/urban area)
- how the service is funded
- other relevant features of the local context (for example, availability of local adult social care services, quality of adult social care services).

Following agreement of the service managers to participate in the study, a key contact person at each site will be identified to work with the research team (by personal visit, phone and email) to develop a sampling frame for identifying disabled people associated with their IA service to participate in Stage 3.

This sampling frame is likely to include all new users of the service over a pre-specified time period, such as six to nine months (meeting certain impairment-related criteria) of the IA service, and all those (meeting the same criteria) currently waiting to be assigned or referred to the service.

Ideally, some sort of introductory pack should be produced to introduce the project to potential participants. This might include: a short leaflet about the project, consent materials, a video/DVD introducing the research and the concepts involved. (What is IA? What is a research interview? What is consent? Details of the research process including the T1 and T2 timeframe and the need to collect data twice). The consent form should include questions to assess/confirm the particular language/communication needs of the disabled person (for example British Sign Language, Makaton, English not first language, etc) and the appropriateness of a formal, face-to-face interview.

Close work with the key contact person at each site will help ensure that copies of the introductory packs are forwarded to all potential participants. A sample can then be identified from those people who respond positively to the introductory pack and return a signed consent form indicating their potential willingness to take part in the project. This would represent those receiving an IA service (Group

A) and those in a similar situation but still awaiting an IA service (Group B). It will be important to ensure that the participants in Groups A and B are similar in terms of their situation and the stage they are at. This could be assessed in terms of the number and type of other non-IA services used to date and the duration of the problem or issue that IA is needed to address.

The participants in Group B will be treated according to the normal practice of the IA service in question. In particular, they will not be kept on the waiting list any longer than necessary or denied access to IA as a consequence of participating in the research. We do, however, recommend that participants, who move from the waiting list to receive IA, or leave the service, are followed up as planned. This will provide valuable insight into the costs and benefits incurred from the time that a need for IA is identified to the completion of IA received. The length of this sample recruitment period will depend on the resources available for the research and the need to ensure that disabled people with a range of characteristics are included.

A sample of participants in the one to two sites where there are no IA services will be identified using a similar approach for comparison Group C. These participants will need to be matched in terms of their situation and on socio-demographic and socio-economic characteristics with those in Group A.

The systematic review has demonstrated that there is insufficient evidence at this stage to estimate sample sizes and power calculations for this study. However, enough people from each situation and IA service will be required to explore the impact of service characteristics and those of the disabled person. The sample size will need to be sufficiently large to ensure there are at least two to three people who demonstrate a given characteristic in each of the IA services and to allow for attrition over the time period covered by the study. This might indicate a sample in the range of 60–120 participants for each of Group A, B and C: say 250 overall.

2.3 Stage 3: Site mapping and service unit costs estimation

2.3.1 Site mapping

Site visits to each of the 12 selected services will need to be conducted to map their core components in terms of service planning and delivery. Information and guidance should be sent to the sites about data protection issues and to help them prepare for the visit detailing the format and content of the planned research activities. This will include a questionnaire to collect some of the more basic service details in advance.

Structured face-to-face interviews, an electronic questionnaire and telephone interviews with service managers (and other appropriate staff such as finance administrators) are needed to collect data about the following service variables:

- aims and objectives of service
- impetus for service: local need, rationale
- the range of disabled people who use the service and whether the IA service is targeted at disabled people in specific situations or is more generic
- the number of disabled people (and non-disabled people) supported each year/at the time of the study
- the number of disabled people (and non-disabled people) currently on the waiting list for the IA service and average time on the waiting list
- the criteria for deciding who receives IA
- the number and types of staff (including whole time equivalents)
- source(s) of funding (for what and over what period)
- budgets and costs
- management arrangements, including decision-making and accountability

- arrangements for training, support and supervision of advocates
- communication, consultation and partnership arrangements
- monitoring and evaluation of service.

The interviews will also be used to obtain or identify detailed financial budgets and other information about the resources and costs involved in delivering IA.

Additional interviews will be needed with the service manager, one or more advocates and other appropriate personnel to determine the core activities involved in providing IA to disabled people in each of the four situations. Each activity will be described in terms of who is involved in providing it, how frequently it is provided and the number of people using that service component. In this way, the aim will be to arrive at an agreed, comprehensive description of the activities of each IA service. Wherever possible, the research team should use or adapt existing measurement tools such as ANNETTE (ANN 2004) and the Scottish Executive's Advocacy Safeguards Agency's Resource Pack for Evaluators¹¹ for designing measures at this stage. Any new measures designed for the study should be pilot tested and validated.

2.3.2 Estimation of IA service unit costs

The next task will be to cost these activities from first principles, by obtaining details of expenditure, staffing and location for each service (Beecham 2000, Netten and Beecham 1993) and estimating unit costs for interventions provided by IA services as follows:

1. Identify the hourly cost for the different staff working in the IA services.
2. Identify the ratio of indirect to direct contact time so that a 'weighted cost' per contact hour can be estimated.
3. Estimate the number of staff involved in each intervention and duration of involvement.

¹¹ See Annex 2 for more details.

4. With the assistance of the relevant agency finance departments, compute an hourly service setting cost per person (on-site overheads) to add to the hourly cost of service.
5. Validate the estimates of unit costs and annual service use against total annual expenditure and budgets.

This approach will enable the research team to examine the range of costs for similar interventions provided by the 12 sites, as well as the total costs per service user (see 2.4.3).

2.4 Stage 4: Baseline T1 data and costs collection

2.4.1 Purpose and assumptions about methods for Stage 4

We suggest collecting three levels of data at two time points (T1 and T2) to assess the impact of IA on disabled people's choice and control and goal attainment. The purpose of Stage 4 is to collect individualised baseline data (at T1) from each participant from Groups A, B and C relating to three levels of data:

- Choice and control – baseline perceptions of choice and control in relation to their current situation/issues to be addressed.
- Goal attainment – a baseline relating to goal attainment (in terms of projected goals for T2).
- Costs – IA and non-IA service use and costs of this.

These levels of data collection are outlined in more detail in 2.4.2.

Defining outcomes – choice and control

Having carefully considered the evidence available, we believe an individualised approach (but using standardised measures) to defining outcomes and outcome measures is the only feasible way forward for research with disabled people in this service setting. Researchers and commentators in the field of IA have highlighted that tensions regarding the most effective and meaningful ways of

evaluating advocacy services may help to explain why advocacy schemes have remained so under-evaluated (Rapaport et al 2006).

The evidence review (Townesley et al 2009) indicated that there is no clear agreement on, or definition of, the outcomes of IA that are important to disabled people or, indeed, the commissioners/providers of IA and associated services. However, discussions with ODI have identified improved choice and control as the primary desired outcome of IA for the purpose of this study and the overall goal of the Government's Independent Living Strategy for disabled people¹². A range of 'generic' outcomes and benefits, which can be subsumed under this primary outcome, are listed below, and are derived from the evidence review¹³ (Townesley et al 2009):

- concerns and issues of disabled person addressed (including pre-set goals attained)
- more participation in decision making, case conferences, planning meetings and policy making
- better quality participation in decision making and improved communication between disabled people and professionals
- increased knowledge of professionals and services and knowledge and understanding of systems and resources
- improved awareness of rights and access to services/support and/or access to better quality services/support
- increased understanding of processes
- feeling listened to and voice heard
- understanding of rights

¹² The Independent Living Strategy was co-produced with disabled people and the outcomes identified therein are, therefore, not simply outcomes that the Government wants, but also what disabled people have said they want.

¹³ Most of the outcomes listed below are derived from interviews with IA providers and consumers/clients or observations from evaluations undertaken. These evaluations and interviews were not explicitly designed to systematically or comprehensively identify the full range of outcomes relevant and important to IA clients and providers.

- increase in independence, life skills, insights and skills for self advocacy
- improved social well-being and psychological health
- improved self-confidence and self-esteem.

Defining outcomes – goal attainment

Use of IA is usually predicated on the assumption that some sort of goal is to be achieved by the joint endeavours of the advocate and the person they are supporting. Some examples of these goals and some more specific outcomes that might be achieved by IA in each of the four situations are given below:

- **During transition to adulthood:**
 - Goal attained in terms of desired destination post-transition? This would include goals for further education, training, employment and/or other independent living aspirations, such as maintaining and/or developing relationships/family formation.
 - Impact on other services, for example, decreased unemployment, good practice guidance followed by professionals from other services? ie DfES SEN Code of Practice (DfES 2001).
- **When the children of disabled parents are subject to safeguarding procedures:**
 - Goal attained in terms of appropriate placement/custody outcome in best interests of child?
 - Is good practice guidance being followed by professionals? ie Framework for the Assessment of Children in Need and their Families (DH 2000), Good Practice Guidance on Working with Parents with a Learning Disability (DH/DfES 2007).
- **When entry to residential care is a possibility:**
 - Goal attained in terms of desired destination?
 - Good practice followed?

- **When disabled people are victims or alleged perpetrators of anti-social behaviour:**

- Goal attained in terms of anti-social behaviour abated?
- Justice obtained and human rights upheld?
- Good practice followed?

Outcome measures for choice and control

The outcomes of independent advocacy are clearly difficult to measure and evaluate, not least because of the diversity of IA services in practice (making the definition of standard objectives problematic) and the varying perspectives of different stakeholders on what constitutes a successful outcome (Chase et al 2006, Rapaport et al 2005).¹⁴ Hussein et al are clear that the 'cornerstone of evaluating advocacy should be the inclusion of the views of disabled people using the service' (Hussein et al 2006), which resonates with the Government's commitment to co-production and the Goal Attainment Scaling methodology proposed below.

Some social care research has identified outcome measures that could be relevant to an effective evaluation of IA¹⁵. These include:

- Personal Social Services outcomes (Netten et al 2006, Burge et al 2006)
- IBSEN domains (Glendinning et al 2008)
- Scottish Executive's Advocacy Safeguards Agency's Resource Pack for Evaluators (Scottish Executive 2000)
- existing government measures outlined in Annex 3
- Office of National Statistics' (ONS) Omnibus Survey Q24.

¹⁴ See Rapaport et al 2006 for a helpful review of tools currently available to evaluate IA services, including the advantages and disadvantages of each.

¹⁵ Annex 4 for more detail and discussion of these.

We are also aware of current work being undertaken by colleagues at the Norah Fry Research Centre for the ODI to evaluate the Support, Advocacy and Brokerage pilots, where a measure of choice and control has been developed to gauge disabled people's perceptions and feelings in relation to this issue. This work is based on tools developed by Scope¹⁶ and ODI¹⁷ to evaluate experiences of independent living which are also of potential use and interest.

None of these in their current form, however, is directly transferable as a means of measuring outcomes relating to choice and control for disabled people in the context of IA, since they have been designed for use in different research contexts. However, we would expect that a new measure could be constructed using a combination of these existing measures, with some adjustments to the wording of the questions and scaling.

Outcome measures for goal attainment

We have been unable to identify any existing outcome measures which could usefully be applied to assessing the impact of IA in relation to goal attainment in each of the four situations. A set of appropriate measures will need to be developed, drawing on insights from existing research tools, relevant literature and input from the advisory group. However, it is highly likely that the outcomes that might be expected from each of the four situations would relate to the goals that participants will be setting for themselves and their advocate at the start of the IA intervention. For example, we might expect that:

- A disabled young person at transition would be likely to set goals relating to their desired destination post-transition, and the extent of individual choice and control that might be expected as part of this decision-making process.
- A disabled parent, whose children are subject to safeguarding procedures, would be likely to set a goal relating to appropriate placement/custody outcome, and their expectations regarding their choice and control of this outcome.

¹⁶ Scope (2008) Independence Quiz – See Annex 4.

¹⁷ ODI (undated) Your experiences of independent living (questionnaire) – See Annex 5.

- A disabled person considering a residential care placement would be likely to set a goal that reflects the type of destination and amount of choice and control desired in choosing this destination.
- A disabled person involved in the criminal justice system would be likely to select a goal relating to their desire to see justice obtained and their human rights upheld, in a context of choice and control throughout the process.

If situation-specific outcomes are likely to relate to individual goals set at the start of the IA intervention, the most appropriate tool for measuring outcomes will be one that relates to individualised goal attainment, as, for example, the measure outlined below.

It is also important to note that members of Groups B and C will not have received IA, therefore, any measure used at this stage will also need to collect data about their non-IA related goals/outcomes. This suggests that the measure to collect this data will need to be flexible and suitable for standardisation across people in all three groups.

Goal Attainment Scaling – an outcome measure relating to individualised goal attainment

We have identified a measure which could be directly relevant to measuring disabled people's goal attainment and, where relevant, the impact of IA on this. Goal Attainment Scaling (GAS) evaluates the effectiveness of a service or an intervention by measuring the extent to which individualised goals are met over a specified timeframe. It involves the service recipient (in this case the disabled person) identifying and agreeing the most important and feasible goals of the intervention with the service provider (in this case the independent advocate or advocacy provider). GAS has been used in a variety of service contexts and there is evidence that it is a good measure of change and has acceptable reliability and validity, comparable to other rating scales (Cardillo 1994).

A positive feature of GAS (given ODI's commitment to 'co-production') is the participation of the service user in determining the outcomes to be measured. This ensures that the goals identified are meaningful to the individual and will have a positive impact on their life, if they are met.

The goals need to be realistic, achievable and set around areas that could reasonably be expected to be influenced by the intervention of an independent advocacy service in the time frame agreed. Each goal should describe an important condition that is both meaningful to the individual and related to a specific outcome. This is a responsibility shared with the advocate or advocacy manager involved in co-setting the goals. In the context of this evaluation, it is important the researcher and participant work together to establish the goals to be measured in each of the three groups.

GAS is individualised, in that what is measured (the goal area or projected outcome) will not be the same for each person. Effectively, when using GAS each service user receives his or her own outcome measure. However, GAS has been standardised by the use of a summary formula that calculates the extent to which goals have been met overall.

Within GAS the current performance level for each goal is described, this provides the baseline measure (0). Improvements and declines in outcomes are also specified. These descriptions need to be as detailed as possible, and able to be measured as objectively as possible. The outcome levels are defined as follows:

- +2 – an outcome that would be ‘much better’ than the baseline status
- +1 – an outcome that would be ‘somewhat better’ than the baseline status
- 0 – the baseline status (a description of the current identified problematic situation)
- -1 – an outcome that would be ‘somewhat worse’ than the baseline status
- -2 – an outcome that would be ‘much worse’ than the baseline status.

One of the important benefits of GAS is its facilitation of collaborative goal setting between advocacy provider or advocate (or in the context of this study, the researcher) and disabled person. This

encourages both realistic, and possibly challenging, expectations of the service. Previous research using GAS has shown that it can be a suitable evaluation tool for a small service, as it is highly responsive to change and therefore does not demand a large sample size for significant outcomes to be recorded (Rockwood et al 1993).

There is a vast amount of literature (spanning more than 30 years) relating to the use of GAS, its benefits and its limitations, that anyone considering the tool in the context of this proposed approach would do well to investigate further. A brief overview of some key texts indicates that there are a number of limitations that would need to be addressed by would-be GAS facilitators, such as:

- the importance of a uniform approach to delivering GAS, including training and updating of those administering it (Mackay and Lundie 1998)
- potential problems with the choice of statistical approach to analyse numerical data (Mackay and Lundie 1998)
- the time needed to discuss, set and agree the wording of goals that are steps towards a realistic outcome for the service user (Turner-Stokes 2009)
- the fact that accessible materials and extra time will be needed to explain and work through the process with people with learning disabilities or other cognitive impairments (Bouwens et al 2009)
- the need for accurate outcome prediction, that may include a need for specialist knowledge of what is possible given the local context and the characteristics of the service user (Turner-Stokes 2009)
- the difficulties of setting a priority order for goals, if more than one is chosen (Mackay and Lundie 1998)
- the possibility that a person's goals may change between T1 and T2 with the resulting impact that this has on the data collected from that person (Newton 2002).

2.4.2 Baseline T1 data collection from Group A, B and C participants

The first objective of Stage 4 is to collect baseline scenario data from study participants from Groups A, B and C in each site to map their current situations at that time point (T1). This would include:

- **Group A participants in each of the four situations:**
 - a description of their current situation and the issues they are hoping IA will help to address – current measure of choice and control
 - details of their use of the IA service – measure of IA service use
 - details of use of other (non-IA) services and whether their use is related to the need for IA – measure of non-IA service use¹⁸
 - their desired goal/outcome for a later date when a researcher will return to collect further data (T2) – measure of goal attainment.
- **Group B participants in each of the four situations:**
 - a description of their current situation and the issues they are hoping IA will help to address – measure of choice and control
 - details of use of other (non-IA) services and whether their use is related to the need for IA – measure of non-IA service use
 - their desired goal for T2 – measure of goal attainment.
- **Group C participants in each of the four situations:**
 - a description of their current situation – measure of choice and control
 - details of use of other (non-IA) services – measure of non-IA service use
 - their desired goal for T2 – measure of goal attainment.

¹⁸ All other non-IA services, including public and voluntary sector – see Annexes 7 to 10 for more details of what these might include.

Data from disabled people will be collected via a structured face-to-face interview lasting about one hour. The interview schedule used will be a combination of existing standardised measures and questions developed specifically for this project as explained above. It will collect information about age, gender, ethnicity, and impairment¹⁹. It will also focus on collecting information (from participants in all groups unless stated otherwise) in the following areas:

- **Current situation** – this will include perceptions of choice and control in relation to one of the four situations as appropriate. Measure of choice and control to be designed.
- **Issues to be addressed by IA** – this will be collected for all Group A and B participants. If appropriate, the measure will be included as part of the Goal Attainment Scaling tool.
- **Use of the IA service** – the list of core activities of the IA service generated during Stage 3 (see above) will be used to design a measure of IA service use to identify which services disabled people in Group A have used, and which services people in Groups A and B are hoping to use and in what time frame. Measure to be designed based on data collected during Stage 3²⁰.
- **Use of other (non-IA) services** – health, social care, advice and other services currently used by the disabled person and (informal) social support networks and relationships. Measure to be designed^{21,22}.
- **Desired goal/outcome for T2** – Measure suggested: Goal Attainment Scaling.

¹⁹ We would hope that the majority of this data should be available, with permission of participants, from the IA service and could be collected in advance of the interview.

²⁰ See Annex 6 for our early thoughts on what IA service use and costs collection might involve.

²¹ Work by Jeni Beecham and colleagues from SPRU and PSSRU (Greco et al 2005) on the costs and effectiveness of key worker services involved the development of a tool for measuring use of ‘other’ (in this context, non-key worker) services (including health care, social care, school/education, and other) which might feasibly be adapted for this study.

²² See Annexes 7 to 10 for our early thoughts on what non-IA service use and costs collection might involve for each of the four areas.

The formal/structured measures will need to be supplemented with semi-structured questions, both to provide illustrative case material and to tease out some of the complexities of situations that are likely to be encountered.

2.4.3 Estimating the costs of IA and non-IA service use

The second objective at Stage 4 is to collect cost data associated with the mapped scenarios of all participants at T1. These costs would include the costs of IA services used by each participant as well as the costs of other non-IA goods and services used by each participant.

Costs of IA service use

Costs of IA service use can be estimated using the unit costs of core activities of each IA service (see section 2.3.2). Costs per participant can be calculated using information from each mapped scenario.

Unit costs of non-IA service use

Additional information will be required to derive estimates of the unit costs of non-IA service use. Sources of data include existing administrative data sets produced or held by local authorities and other agencies (for example, on the costs of child safeguarding processes and of placements of children), and nationally published unit costs (for example from PSSRU, University of Kent). These will need to be supplemented by assumptions to generate best guess estimates about the unit costs of non-IA service use (by all participants). It is expected that unit costs are available for nearly all the actual or similar services likely to be used. The expert panel should be used to validate assumptions about what are likely to be similar unit cost services where data is not available about the actual service.

2.5 Stage 5: Follow up T2 data and costs collection

The objective of this stage is to collect data from Group A, B and C participants relating to the extent to which the desired goal(s) they specified at T1 have been attained.

For Group A (and Group B participants who receive IA within the follow-up period), data will need to be collected (using the methods described in section 2.4.2) about the impact of the IA intervention in relation to choice and control outcomes and the goal(s) specified at T1. Data will also need to be collected about the impact of any non-IA services received alongside the IA intervention on choice and control outcomes and the goal(s) specified at T1.

For Group B and C participants who do not receive IA, data will need to be collected about the perceived process and outcome benefits (if any) of the non-IA services received in relation to choice and control outcomes and the goal(s) specified at T1 (using the methods described in section 2.4.2).

An additional objective of this stage will be to collect further cost data from all participants (using the methods described in section 2.4.3) at a second point in time (T2). For some participants, this may simply be a case of updating existing data already collected.

The length of time between T1 and T2 data collection will need to be negotiated with each service/participant to take local/contextual factors into account. However, it should be long enough for the IA intervention to have been completed, plus three to six months (variation is likely across the four situations) to explore whether there are likely to be longer term impacts.

2.6 Stage 6: Cost-effectiveness analysis and economic modelling

By this point of the study, a range of costs and outcomes will have been identified relating to the impact of IA on choice and control, and individual goal attainment for disabled people in each of the four situations. Economic modelling is then needed to assess the potential effectiveness and cost-effectiveness of the 12 IA services in terms of their impact on disabled people. This stage will involve significant analysis, both of the qualitative data and of the quantitative costs data. The steps involved in this process will involve:

1. description of the findings
2. assessment and comparison of costs
3. assessment and comparison of outcomes
4. cost-effectiveness analysis
5. economic modelling and the calculation of an incremental cost-effectiveness ratio (ICER).

2.6.1 Description of findings

The first step will be to describe the findings in relation to the following areas:

- details of services that are currently providing (good quality) IA to disabled people in each of the four situations
- a description of the core components of these services in each of the four situations
- the number of disabled people sampled from each of the four situations who are currently receiving IA from each service (Group A)
- the number of disabled people sampled from the waiting lists for each service and therefore not receiving IA at present (Group B)

- the number of disabled people sampled from sites where there is no IA activity and therefore not receiving IA at present (Group C)
- the nature/extent of support services (including IA) received by people in Groups A, B and C.

2.6.2 Assessment and comparison of costs

The next step is to assess the costs of IA and non-IA service use for each participant at T1 and T2, and to compare any differences between these results. This will involve describing:

- the costs of providing IA to Group A (and Group B participants who receive IA within the follow up period) at T1 and T2
- the costs of providing non-IA services to Groups A, B and C at T1 and T2
- a comparison of costs between T1 and T2 for Group A
- a comparison of costs between T1 and T2 for Group B
- a comparison of costs between T1 and T2 for Group C
- a comparison of Group A costs with Group B costs at T1
- a comparison of Group A costs with Group C costs at T1
- a comparison of Group A costs with combined Group B and Group C costs at T1
- a comparison of Group A costs with Group B costs at T2
- a comparison of Group A costs with Group C costs at T2
- a comparison of Group A costs with combined Group B and Group C costs at T2
- a comparison of the total costs incurred between T1 and T2 between Group A and Group B
- a comparison of the total costs incurred between T1 and T2 between Group A and Group C
- a comparison of the total costs incurred between T1 and T2 between Group A and the combined costs of Groups B and C.

2.6.3 Assessment and comparison of outcomes

The third step will be to assess the outcomes of IA and non-IA service use for each participant at T1 and T2, and to compare any differences. This will involve describing:

- the outcomes for Groups A, B and C, in terms of goals attained and choice and control at T1 and T2
- a comparison of outcomes between T1 and T2 for Groups A, B and C
- a comparison of Group A outcomes with Group B outcomes at T1
- a comparison of Group A outcomes with Group C outcomes at T1
- a comparison of Group A outcomes with combined Group B and Group C outcomes at T1
- a comparison of Group A outcomes with Group B outcomes at T2
- a comparison of Group A outcomes with Group C outcomes at T2
- a comparison of Group A outcomes with combined Group B and Group C outcomes at T2
- a comparison of the total outcomes incurred between T1 and T2 between Group A and Group B
- a comparison of the total outcomes incurred between T1 and T2 between Group A and Group C.

2.6.4 Cost-effectiveness analysis

By this point, the analysis will have generated approximately 250 individual case studies of costs and outcomes of IA and non-IA use and data relating to differences between these at two time points. Other variables that might usefully be explored at this stage include:

- proportion of non-IA service use by Group A participants compared with Group B and Group C participants (ie: less or more non-IA services used by Group A?)

- cost of non-IA service use by Group A compared with Group B and with Group C (ie: any cost savings as result of IA service use?)
- any differences in service use and cost for different impairment groups
- any differences in service use and cost across the four situations
- any differences in outcomes for different impairment groups
- any differences in outcomes across the four situations
- any differences in costs between different models of IA services (with reference to the core components of service use)
- any differences in outcomes between different models of IA services.

Descriptive analysis will be used to summarise the quantitative data collected. This will include estimation of mean (average) values and standard deviation for each of the outcome, service use and cost measures. Regression and causal analysis methods will be used to statistically control for the effect of confounding factors, such as the characteristics of participants and services, local settings, models and timing of IA, and assess:

- key determinants of outcome
- whether participant outcomes and costs change between T1 and T2
- the net costs (savings) and outcomes of IA (Group A) when compared to people on the waiting list for IA (Group B) and when compared to people with no access to IA (Group C).

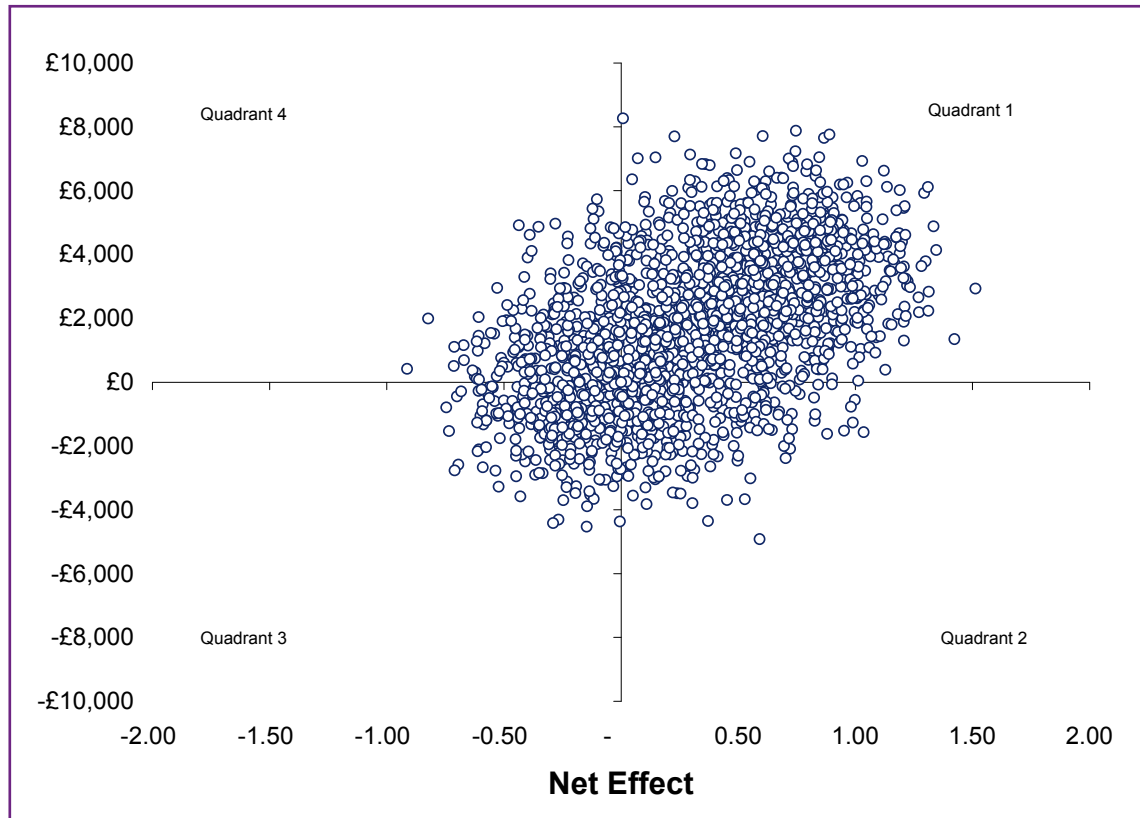
The statistical analysis may include methods such as analysis of covariance (ANCOVA), two stage least squares and instrumental variable approaches combined with longitudinal modelling to minimise the impact of confounding variables on the estimates of effect and costs. The potential impact of these confounding variables can also be explored by the subgroup or scenario analyses suggested in section 2.6.5 below.

For each comparison, the net costs and effects of IA will be distributed across four possible cases:

- IA is more costly compared to no IA, but also more effective (Quadrant 1, Figure 1). This means a trade off is required to assess whether the additional benefit is worth the additional cost.
- IA is more effective, but also less costly compared to no IA. In this case, IA would be a cost-effective option (Quadrant 2, Figure 1).
- IA is less effective, but also less costly than no IA. This means a trade off is required to assess whether the savings of IA outweigh the loss in benefit (Quadrant 3, Figure 1).
- IA is less effective and more costly than no IA. In this case, IA is not a cost-effective option (Quadrant 4, Figure 1).

The diagram in Figure 1 represents a cost-effectiveness plane, which illustrates a possible distribution of net costs and net outcomes that could be associated with IA. Each dot represents a pair of potential net cost and net outcome. In this case, the majority of dots lie in Quadrant 1, suggesting that IA would be likely to result in net costs and net benefits. However, Figure 1 demonstrates that in some cases, the net costs and outcomes lie in Quadrants 2 to 4. This represents the level of uncertainty associated with the estimates of cost-effectiveness. It is important that the cost-effectiveness analysis includes an assessment of this uncertainty, this is discussed further below.

Figure 1 – Example of a cost-effectiveness plane



2.6.5 Economic modelling and ICER

Economic decision modelling techniques can be used to synthesise all the data from the different sources, to explore the expected costs and benefits of IA in different scenarios.

The economic model will be used to estimate the additional cost (or saving) of IA and compare this to the additional benefit or gain in outcome of IA. Formally, this is calculated as the incremental cost-effectiveness ratio (ICER):

$$\frac{\text{Cost of IA} - \text{Cost of no IA}}{\text{Outcome of IA} - \text{Outcome of no IA}}$$

A key use of the economic model is to assess the level of uncertainty in the data collected, the level of uncertainty due to variability in the data collected and uncertainty due to the level of variability associated with the characteristics of participants, services and settings. The economic model can be used to help inform discussion and decisions on the need for, and design of, further, larger scale research if necessary. For example, if the model indicates the data vary substantially between individuals, after controlling for socio-demographic characteristics, this suggests a high level of uncertainty. A larger scale evaluation with a bigger sample size may be required. The economic model may also suggest which socio-demographic or other characteristics are important to collect in future evaluations. Alternatively, the economic model may indicate that the costs and benefits of IA are sensitive to the time frame, population or setting concerned. This would suggest that further research is needed to understand the process of IA and its implementation in more detail, and to refine or develop IA service models.

For each data item required for the model, a base case or best guess estimate should be derived, with a measure of variance or minimum and maximum likely value. For example, the service mapping exercise may suggest that overall a disabled person probably has six contacts with the advocate, but that some people have no contacts with the advocate (where the disabled person is referred to the IA service, but no contact is established between the person and the advocate) and others see the advocate up to 30 times. In this case, the best guess is six contacts, with a minimum of zero and a maximum of 30 contacts. Alternatively, the observed data from the study may show that the average number of contacts a disabled person has with the advocate is a mean of five, with a 95 per cent confidence interval of 1-15. In this case, the base case or best guess estimate is the average number of five contacts, and the measure of variance is the 95 per cent confidence interval. The measures of variance and ranges will be used to test the robustness of the results and level of uncertainty associated with the estimates of cost-effectiveness produced by the model.

Simulation and probabilistic sensitivity analysis should be used to assess the level of uncertainty associated with the data. These analyses should be repeated for each of the scenarios or case studies evaluated to assess the level of uncertainty due to structural factors. This may include looking at different:

- situations and groups of disabled people
- models and timing of IA (such as early access versus crisis IA)
- time frames, populations and settings.

It is possible that the structure of the economic model will vary by the situation of the disabled person or by the characteristics of different IA services, so a separate economic model is needed for each situation. By contrast, it is the data, rather than the structure of the model that will vary in different time frames, populations and settings, so these differences should be used to construct alternative scenarios or combinations of the costs and outcomes of IA, to be tested in each of the economic models.

The scenario and case study analyses will include using the descriptive vignettes to generate a series of case studies for which the costs and outcomes of IA can be estimated. For each vignette, which describes the characteristics of a hypothetical disabled person, the situation they face, and the pathway they take in terms of the range of services used, the data collected will be used to generate estimates of the costs and outcomes of IA compared to no IA.

It is unlikely that all the relevant benefits potentially associated with IA can be measured and quantified using a single measure of outcome, or that the outcomes selected can be valued and combined into a single measure using a common metric such as money. So the model should also explore the extent to which IA is likely to be cost-effective using alternative measures, or combinations of measures, as the primary or most important outcome(s) for incremental cost-effectiveness ratios. The relative cost-effectiveness of IA may vary according to the outcome measure used. In this case, it is useful if the analysis estimates measures of cost-effectiveness in relation to the net cost (saving) per person.

Cost-effectiveness acceptability analysis can then be used to explore the extent to which IA is likely to be cost-effective at different levels of willingness to pay to achieve an additional unit of outcome. For example, IA may improve outcomes for a disabled person, but at an additional overall cost of say, £200 per person. There are then two questions:

- How likely is it that the cost per person with increased choice and control is £200?
- Are decision makers willing to pay this amount to achieve the outcome?

The economic model may indicate that the cost per person with improved outcomes ranges from a net saving of £200 to a net cost of £2,000. Discussion with members of the advisory group and other stakeholders may indicate that they would value a gain of increased choice and control for one disabled person at up to £2,000. This implies a set of thresholds between £0 and £2,000. Each threshold indicates willingness to pay or willingness to use service budgets to gain increased choice and control for one disabled person. Cost-effectiveness acceptability analysis combines these two sets of information in a set of simulations, to estimate the probability that IA is cost-effective at different willingness to pay values to gain increased choice and control for one disabled person.

The economic modelling approach outlined above will provide information about the extent to which the results are transferable from the study settings and participants used in the research to other settings and groups of disabled people in general. The model will also highlight where there may be high levels of uncertainty about the transferability or scalability of the results. This information can then be used to design further research to address the areas of uncertainty identified. It is important to note that, as with all research areas, it is not possible or feasible to design and implement a single study that will produce data and conclusions that are generalisable to all settings, participants and time frames outside those of the study.

03

Comments on feasibility and challenges of proposed approach



03

Comments on feasibility and challenges of proposed approach

3.1 General issues

3.1.1 Designing research tools and outcome measures from scratch

The research team undertaking this study will need to design some tools and measures from scratch, as most of the research about outcomes of advocacy has taken a qualitative/case study approach to describing process and outcome benefits. Moreover, as the outcomes of advocacy have been recognised as being both difficult to measure and evaluate (Chase et al 2006, Rapaport et al 2005), designing appropriate tools and capturing adequate data in this context may prove challenging and time consuming. Since there is virtually no past research on costs of IA services, costs data collection tools will also need to be designed, though similar tools used for cost data collection in other service settings can be built upon.

3.1.2 Exploring longer-term outcomes

The research approach set out here intends to explore some of the longer-term outcomes of independent advocacy and this has been acknowledged as an important, though hitherto not researched, area for investigation (Rapaport et al 2005). This presents some difficulties as it can be hard to follow-up individuals over a longer time frame, so sample attrition can threaten or weaken the validity of the findings. Moreover, there is greater potential for the impact of confounding factors on any longer-term outcomes, making it difficult to attribute positive changes to the independent advocacy input specifically.

3.1.3 Exploring downstream benefits

Existing work has shown that independent advocacy services can also have downstream benefits, such as positive outcomes for the wider community (Jones 2004, Scottish Independent Advocacy Alliance 2008).

‘Independent advocacy can benefit local communities in a number of ways. For people who use advocacy services it provides a safeguard for vulnerable adults and children and empowers people who may rely on other health services. For local communities it provides a base of trained and supported individuals who have an understanding of inequalities that exist and the needs of vulnerable people in their community. Therefore it benefits communities overall by ensuring that systems and barriers are challenged to everyone’s benefit and empowers individuals to take action for their own and their community’s behalf...It can provide valuable information and feedback as well as healthy challenges to those who commission and provide services, it can provide constructive challenges to service providers and help professionals to redesign and refine the system so that it works better for everyone and it helps us to keep our focus on people who are most at risk.’

(Scottish Independent Advocacy Alliance 2008)

Future research must ensure that the outcomes employed will also capture such downstream benefits.

The data collection and cost-effectiveness model proposed in this paper will capture some of these downstream costs and benefits (or savings if IA reduces the use of these services) if they occur within the follow-up period of the study. Annexes 7-10 give details of the downstream costs associated with the use or otherwise of non-IA services. These include the use of:

- education and training services, employment, residential services and other community services by young people in transition to adulthood

- legal services, child protection and care services, family support services and other health care services used by disabled people (and their children) whose children are subject to safeguarding procedures
- residential and home support services, community support and other social care services, health care and legal services for people at risk of entering residential care
- legal services, community support services, health and residential care services for people who are victims or offenders in allegations of anti-social behaviour.

3.1.4 Comparability of cases between groups

The research approach described in this paper relies on the use of three groups, for purposes of comparison, to be able to draw conclusions about the benefits (or not) of advocacy interventions in terms of costs and outcomes for those involved. We have made suggestions about how to try to ensure that cases (ie the participants of each of the three groups) are as comparable as possible in terms of demography. It will be important to ensure the participants are similar in terms of their situation and the stage that they are at in terms of input from services (IA and non-IA).

There are two levels of potential difficulty inherent in this approach. At the first level, it will be necessary to adhere to strict criteria governing comparability to identify participants for a sampling frame. For example, this might be measured in terms of service use, the precise nature of the situation which the disabled person is currently experiencing, and the type of IA service they are accessing²³ (if relevant). At the second level, participation in the research will depend on informed consent, so will, to some extent, mean that

²³ For example, some more specialist advocacy services exist which are designed to support people in very specific situations, such as disabled parents going through childcare proceedings and young disabled people going through transition. However, other advocacy services will be set up to be more generic and to support disabled people experiencing a range of situations.

participants 'self-select' and that completely comparable samples may be difficult to obtain due to the characteristics of those who come forward. These issues are not insurmountable however, and good, early project publicity and a period of raising awareness with stakeholder groups may help significantly in terms of participant take-up rates.

3.2 Situation-specific issues

Each of the four situations explored in this report has specific associated challenges for evaluative research:

3.2.1 Disabled people during transition to adulthood

There are potential difficulties in 'tracking' young people post-transition which make it difficult to explore the outcomes of advocacy for them. CSCI's (2007) research found that 85 per cent of local authorities questioned were unable to track the most recent cohort of young disabled people to adult services.

There are many confounding factors here, such as availability (or lack of) of post-transition options/opportunities (such as employment, education and training), as well as input from other services, that could affect the outcomes being measured. A robust evaluation of IA services will need to take account of these to ensure it is the impact of the IA specifically that is being measured.

3.2.2 Disabled parents whose children are subject to safeguarding procedures

A clear definition of what counts as IA for parents involved in child protection proceedings is needed prior to evaluation of this type of service. Does it refer to crisis advocacy, longer-term advocacy input or both? It is also important to draw the distinction between specialist advocacy designed to support disabled parents specifically involved in child protection proceedings, and other more generic advocacy services which may support parents from pregnancy through birth and onwards.

It may be difficult to identify the outcome benefits that might be used in data collection. Researchers would need to decide if child custody loss or maintenance is an appropriate measure. Other factors such as a reduction in discrimination by service professionals and others against disabled parents may be pertinent, but challenging to measure.

Research must also account for, and explain, outcomes that are due to other variables such as input from other services, the availability of wider family support etc.

3.2.3 Disabled people when entry to residential care is a possibility

One of the primary difficulties in further research around the effectiveness of IA for disabled people at risk of entering residential care is that we have been unable to identify any services that specifically offer this. Currently, therefore, it would be necessary to work with a number of more generic advocacy services to collect data on relevant cases.

There is no data available about the number of disabled people at risk of entering residential care and therefore even the level of potential need for dedicated IA services here is unclear.

Generational differences and varying needs may mean there are fundamental differences between younger disabled people and older disabled people in relation to their need for IA if they are at risk of entering residential care. It may be inappropriate to view all these people as a homogenous group in the same situation.

3.2.4 Disabled people who are victims or alleged perpetrators of anti-social behaviour

There is a need to determine what exactly constitutes independent advocacy when disabled people are involved, as victims or offenders, in allegations of anti-social behaviour. There are no clear guidelines as to the tasks of an independent advocate in this situation and there are many different people (for example Appropriate Adults and court intermediaries) who may perform some of the functions of an independent advocate at specific stages of the relevant criminal justice process.

The effectiveness of the IA may instinctively be judged on the outcome of court cases. For example, if a disabled person was the victim of anti-social behaviour then they might approach an advocacy service to help them report such behaviour with the aim of obtaining a successful prosecution. In such a scenario, the IA may only be deemed to be effective if it results in the conviction of the offender. However, it may prove impossible for a conviction to be brought against the offender, as they may not even be identifiable. This would not necessarily mean the IA was of a lower quality than in another case where a successful prosecution is brought. Overcoming such complicated issues will be a challenge to future research in this area.

The description 'disabled people who are victims or alleged perpetrators of anti-social behaviour' covers a plethora of scenarios. Such research would need to include advocacy services in the community that support victims and advocacy services that support offenders, in addition to advocacy services for those in prisons or high-security hospitals. It would not be appropriate to compare services in such different settings.

As prison placements are very expensive, any IA that increases the rate of successful prosecutions of people who have exhibited anti-social behaviour towards a disabled person will be unlikely to demonstrate any cost benefit. However, such services may help justice to be obtained. It could be argued that it is inappropriate to attempt to put a price on this.

04

Concluding comments



04

Concluding comments

This paper has set out a proposed framework for future research to investigate the cost-effectiveness of independent advocacy (IA) for disabled people in each of the following four situations:

- during transition to adulthood
- when the children of disabled parents are subject to safeguarding procedures
- when entry to residential care is a possibility
- when disabled people are victims or alleged perpetrators of anti-social behaviour.

Using a six-stage approach, the research aims to assess the costs and impact of IA for disabled people in each of the four situations, and to consider the cost-effectiveness of IA across and within each setting.

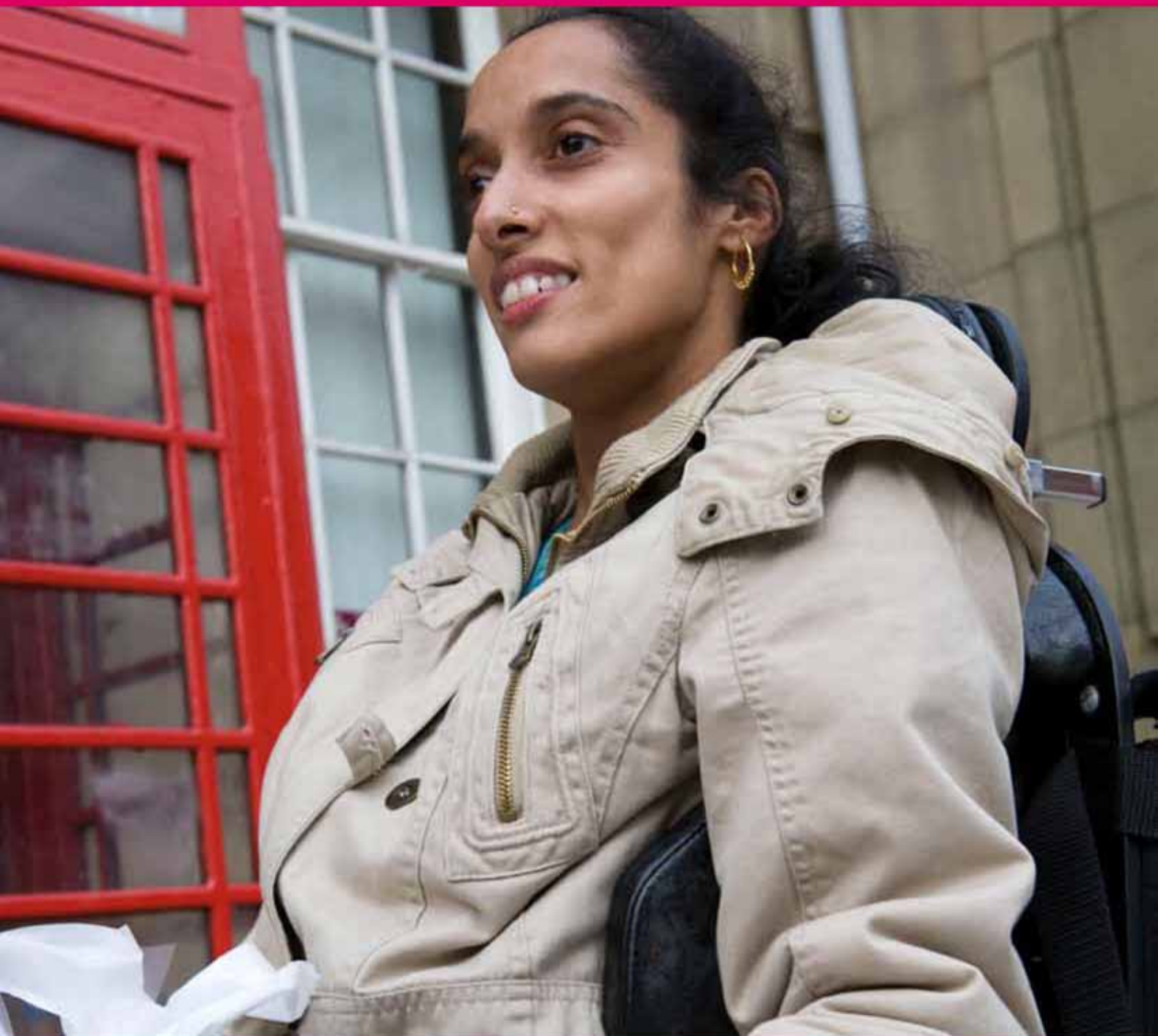
The research approach proposed here is intended to contribute to our knowledge about the costs and impact of different models of IA services for disabled people in different situations and to examine the cost-effectiveness of these services by considering a number of different variables or characteristics. The co-productive approach proposed to define desirable outcomes, effective consultation with disabled people (as recipients of IA services and beyond) and an advisory group of relevant stakeholders, should ensure that the views of disabled people are at the centre of the debate about how IA can best support individuals' desires for choice, control and aspirations for independent living.

The proposed data collection and cost-effectiveness model will capture some of the downstream costs (or savings if IA reduces the use of these services) and benefits associated with IA, if they occur within the follow-up period of the study.

The lack of evidence highlighted by the systematic review (Townshley et al 2009) means that the suggested research is, of necessity, exploratory. The approach will however highlight where there is likely to be high levels of variability and the level of uncertainty associated with the data and results, and the applicability of the results in other settings and populations. The analytic strategy and cost-effectiveness model suggested will help to identify key factors that may limit or facilitate assessment of the generalisability of the results and where future research is needed.

We hope this paper will help to inform any subsequent decisions on the potential commissioning and timing of further, substantive, research to fill the significant evidence gaps identified and provide direction to potential policy development in the field of IA.

Annexes





Annexes

Annex 1 – Action for Advocacy – Quality Performance Mark

Action for Advocacy exists to promote good practice in advocacy and they have developed the Quality Performance Mark (QPM). This is the only national, advocacy-specific, quality assessment system which applies to all forms of one-to-one advocacy. It has been developed on the basis of advocacy principles and standards which have been examined by the advocacy sector. As an umbrella organisation, Action for Advocacy does not provide advocacy services and therefore there is no conflict of interest.

The QPM is a three-stage process consisting of self-assessment, desktop assessment and site assessment. Action for Advocacy has developed a set of seven quality indicators that underpin the provision of high-quality independent advocacy:

1. independence
2. clarity of purpose
3. confidentiality
4. equality, accessibility and diversity
5. empowerment and putting people first
6. supporting advocates
7. accountability and complaints.

A portfolio of evidence from services applying for the QPM will be reviewed against these quality indicators. If the service meets these standards, a trained assessor will visit the advocacy service to interview staff and service users and compile a report on the service.

The standard for the QPM has been set high to ensure it is a meaningful mark of a quality service and the schemes that are successful in meeting this standard will be awarded the QPM for three years.

Action for Advocacy plan to publish a list of schemes that have earned the QPM on their website. Therefore this is one possible method of identifying high-quality advocacy services for future evaluation.



Annex 2 – IA service evaluation tools

Tools currently being used to evaluate IA services (and referred to in Rapaport et al 2006):

- ANNETTE – ANN (2004) Evaluation of citizen advocacy in Newcastle Advocacy Centre, October 2003-March 2004, Newcastle: Council for Voluntary Service – designed to meet Best Value objectives and uses tables to count the number of tasks undertaken, the time taken to complete the tasks and the nature of the different advocacy roles. More suited to representational advocacy rather than long term. Appreciated by funders. But other problems noted (see Rapaport et al 2006, p200).
- A Guide to Evaluation and A Resource Pack for Evaluators – Advocacy Safeguards Agency, 2003a,b Edinburgh, Advocacy Safeguards Agency – identifies core criteria applicable to the evaluation of all forms of advocacy and specific criteria relation to particular case scenarios. It spells out the advocacy process, the scope of the evaluation and whom it should involve. But lots of problems with it also (see Rapaport et al 2006, page 201).

Main issues noted in Rapaport et al 2006:

- evaluation is not universal for IA services
- existing tools are not well known and rarely used
- Scottish Executive model (see above) is comprehensive but cumbersome
- there are problems in defining standard objectives in the light of diversity of schemes.

Annex 3 – Potential outcome measures relating to choice and control

Personal Social Services outcomes

This research has attempted to quantify, in monetary terms, ‘quality gains’ in the provision of personal social services (PSS). This approach separates the ‘capacity for benefit’ that the service could **potentially provide** from the quality that **is provided in practice** (Netten et al 2006, Burge et al 2006).

The nine outcomes identified each cover fundamental aspects of people’s lives, where the benefits of the service might be measurable:

- personal dignity and comfort
- social participation and involvement
- control over daily life
- meals and nutrition
- safety
- accommodation cleanliness, order and accessibility
- employment and occupation
- role support (as a carer or parent)
- living in your own home.

This research has demonstrated a potential methodology for quantifying efficiency gains through improvements in quality, in domains that are meaningful to the individual service user.



IBSEN domains

The recent research evaluating the Individual Budgets (IB) pilot programme (Glendinning et al 2008) collected data on outcomes for individuals in terms of their:

- quality of life
- aspirations
- social care needs (and how far these were met)
- psychological well-being
- self-perceived health.

The outcome measures used in this research could potentially be employed in research evaluating IA, although they are far more wide ranging than the outcomes identified in section 2.4. In addition, some difficulties were revealed with the measures in practice, as the questions were difficult for a proxy respondent to answer. This research also assessed the costs of support received by Individual Budget holders and the costs of support for those in the comparison group, who were not in receipt of Individual Budgets.

Scottish Executive outcome measures

The Scottish Executive produced a guide for commissioners on the provision of Independent Advocacy services (Scottish Executive 2000). They recommended that such services should run for three years before they are evaluated. The guide suggests that indicators of the **quality** of an advocacy services are likely to include:

- the number and diversity of partnerships created and supported
- the quality of match between advocates and partners
- the strength of relationship between advocates and partners
- the diversity of issues which have been tackled
- the difference that advocacy has made in people's lives.

Only the last of these indicators would be directly relevant to the kind of evaluation of the costs and benefits of IA proposed here.

However, this indicator is not itself an outcome measure, since there is no existing accompanying guidance or set of questions to use to identify what difference advocacy has made to people's lives.

We would see the second and third indicators identified above as 'mediating factors' in IA, that is, factors that influence its effectiveness from the perspective of the disabled person.

Existing Government measures

Previous ODI work has developed questions to measure the degree of choice and control that disabled people feel they have in their daily lives. The seven questions used in the Office of National Statistics (ONS) Omnibus Survey (relating to Public Service Agreement, or PSA, Delivery Agreement 5) seek to explore people's choice and control over the assistance and equipment they need to live independently. Although some of these might be adapted for an evaluation of Independent Advocacy services only Q24 could really be potentially directly relevant to the proposed evaluation, namely:

Thinking about your current situation, how often would you say you have choice and control in your life to live your life the way you want to?

In its current form this is a fairly crude question which would need to be related directly to the provision of Independent Advocacy to be relevant to the proposed study.



Annex 4 – Scope Independence Quiz

**Are you
in control of
your life?**

Take our Quiz to find out.
Great prizes to be won!

Time to get equal
scope
About normal things.
For disabled people achieving equality.

**disability
now**
your rights, your voice, your life

Please see the following link to access the text of this document:

www.scope.org.uk/disablism/audit/docs/scope-independencequiz08.pdf

Annex 5 – ODI questionnaire: ‘Your experiences of independent living’

1. Thinking about your current situation, do you need any assistance and/or equipment to go about your daily life in the way you want to?

1. Yes

2. No

2. How often do you get the assistance and/or equipment you need to go about your daily life the way you want to?

1. Always

2. Often

3. Sometimes

4. Rarely

5. Never

3. Thinking about your current situation, how often do you have a say over what assistance and/or equipment you receive?

1. Always

2. Often

3. Sometimes

4. Rarely

5. Never



4. Currently, how often do you have control over how this assistance or equipment is provided?
1. Always
 2. Often
 3. Sometimes
 4. Rarely
 5. Never
5. Currently, how often do you have control over how you make use of this assistance and/ or equipment?
1. Always
 2. Often
 3. Sometimes
 4. Rarely
 5. Never
6. Again, thinking about your current situation, overall, how often would you say you have choice and control in your life, to live your life the way you want to?
1. Always
 2. Often
 3. Sometimes
 4. Rarely
 5. Never

7. How easy is it for you to get your views and opinions listened to?
- 1. Very easy
 - 2. Fairly easy
 - 3. Fairly difficult
 - 4. Very difficult
8. Do you go out when you feel like it?
- 1. Yes
 - 2. No
9. Do you go out where you want to?
- 1. Yes
 - 2. No
10. What prevents you from going out (when/where) you would like to? Tick any that apply
- 1. Too busy/not enough time
 - 2. Financial reasons
 - 3. A health condition, illness or disease
 - 4. A disability
 - 5. Difficulty with transport
 - 6. Difficulty getting into buildings
 - 7. Difficulty using facilities



- 8. Lack of special aids or equipment
- 9. Lack of personal help or assistance
- 10. Unsuitable surroundings
(uneven, slippery, surfaces, stairs)
- 11. Fear of crime
- 12. Lack of confidence
- Other reasons (specify)

Annex 6 – Preliminary range of costs of IA and data sources

Cost item	Data sources	
	Service use	Unit costs
Independent Advocacy Service		
Staff eg: Advocates and health and social care professionals, administrative and managerial staff, other staff	a) Interviews and surveys with IA service providers to estimate time spent on service and non-service activities	IA accounts and records National salary scales National reference or unit costs (eg DH, PSSRU)
Facility costs eg: buildings or office space, furniture, equipment, maintenance	a) Interviews and surveys with IA service providers and funders b) IA accounts and records to identify resources used	IA accounts and records National or representative costs for items (eg average rental costs)
Other overheads eg: cleaning, utilities, communication services, consumables	a) IA accounts and records	IA accounts and records
Travel and other personal expenses for staff and clients	a) Interviews and surveys with IA service providers b) IA accounts and records	IA accounts and records



Annex 7 – Preliminary range of costs of non-IA service use by young disabled people at transition to adulthood

Areas of service use:

Education and training services

- Further/special education
- Vocational training
- Work place training
- Life skills training

Paid and unpaid employment

- Supported work placements
- Advice and support services to find and maintain employment

Residential services

- Staffed and non-staffed accommodation (public, voluntary and independent)
- Support to find appropriate accommodation

Community support and other social care services

- Housing, counselling, support networks and groups, information and advice,
- Leisure and activity centres and networks
- Other day services
- Social work and keyworker services

Health care

- Multi-disciplinary health teams
- Primary medical, dental and eye health care services

Legal services

- Court appearances
- Legal consultations, legal advocacy, other legal support

Sources of service use data:

- a) Interviews and surveys with clients, IA service providers to identify what services used.
- b) Interviews, surveys, record review with key non-IA service providers to quantify staff time and other services used.
- c) Review of national statistics and literature: education, residential services, community support and social care, health.

Sources of unit cost data:

- a) Review of Department for Children, Schools and Families statistics and reports, social service and local authority statistics and reports, other child agency statistics and reports.
- b) Review of national statistics and literature, health and personal social services²⁴.
- c) Review of other relevant national statistics and literature.
- d) Salary scales relevant to staff time.

²⁴ Annual reference costs published by the Department of Health (www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_082746) and annual Unit costs of Health and Social Care published by the Personal Social Services Research Unit (www.pssru.ac.uk/uc/uc.htm)



Annex 8 – Preliminary range of costs of non-IA service use by disabled people whose children are subject to safeguarding procedures

Areas of service use:

Legal services

- Court appearances
- Legal consultations, legal advocacy, other legal support
- Legal Aid

Child protection and care services

- Long-term residential care, foster care, respite care, day care and day support services, other social services for 'looked after children'

Family support services

- Housing, child care training, counselling, support networks and groups, information and advice,

Other health and social care

- Multi-disciplinary health teams, secondary and tertiary health care hospital-based services
- Primary medical, dental and eye health care services
- Community health care services

Sources of service use data:

- a) Interviews and surveys with clients, IA service providers to identify what services used.
- b) Interviews, surveys, record review with non-IA service providers to quantify staff time and other services used.
- c) Review of national statistics and literature: legal system and child protection, child protection, care and support, family support services.

Sources of unit cost data:

- a) Review of Home Office statistics and reports, social service and local authority statistics and reports, other child agency statistics and reports.
- b) Review of national statistics and literature: legal system & child protection, care and support, family support, health and personal social services²⁵.
- c) Salary scales relevant to staff time.

²⁵ Annual reference costs published by the Department of Health (www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_082746) and annual Unit costs of Health and Social Care published by the Personal Social Services Research Unit (www.pssru.ac.uk/uc/uc.htm)



Annex 9 – Preliminary range of costs of non-IA service use by disabled people at risk of entering residential care

Areas of service use:

Residential and home support services

- Staffed and non-staffed accommodation (public, voluntary and independent)
- Home-based support services to enable the person to remain in their own home
- Other residential support services

Community support and other social care services

- Housing, counselling, support networks and groups, information and advice
- Leisure and activity centres and networks
- Other day services
- Social work and keyworker services

Health care

- Multidisciplinary health teams, secondary and tertiary health care hospital-based services
- Primary medical, dental and eye health care services
- Community health care services

Legal services

- Court appearances
- Legal consultations, legal advocacy, other legal support

Sources of service use data:

- a) Interviews and surveys with clients, IA service providers to identify what services used.
- b) Interviews, surveys, record review with key non-IA service providers to quantify staff time and other services used.
- c) Review of national statistics and literature: residential services, community support and social care, health.

Sources of unit cost data:

- a) Review of social service and local authority statistics and reports.
- b) Review of national statistics and literature: health and personal social services²⁶.
- c) Review of other relevant national statistics and literature.
- d) Salary scales relevant to staff time.

²⁶ Annual reference costs published by the Department of Health (www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_082746) and annual Unit costs of Health and Social Care published by the Personal Social Services Research Unit (www.pssru.ac.uk/uc/uc.htm)



Annex 10 – Preliminary range of costs of non-IA service use when disabled people are involved, as victims or offenders, in allegations of anti-social behaviour

Areas of service use:

Legal services (for victims and perpetrators)

- Court appearances
- Legal consultations, legal advocacy, other legal support
- Police, probation and community service teams
- Victim support networks and services
- High-security, prison and detention services
- Tribunals, adjudication and discrimination services

Community support and other social care services

- Counselling, support networks and groups, information and advice
- Social work and keyworker services

Health care

- Community and hospital-based mental health services
- Other health care services

Residential and home support services

- Staffed and non-staffed accommodation (public, voluntary and independent)
- Home-based support services
- Other residential support services

Sources of service use data:

- a) Interviews and surveys with clients, IA service providers to identify what services used.
- b) Interviews, surveys, record review with key non-IA service providers to quantify staff time and other services used.
- c) Review of national statistics and literature: legal system, residential services, community support and social care, health.

Sources of unit cost data:

- a) Review of Home Office statistics and reports, social service and local authority statistics and reports.
- b) Review of national statistics and literature: health and personal social services²⁷.
- c) Review of other relevant national statistics and literature.
- d) Salary scales relevant to staff time.

²⁷ Annual reference costs published by the Department of Health (www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_082746) and annual Unit costs of Health and Social Care published by the Personal Social Services Research Unit (www.pssru.ac.uk/uc/uc.htm)

Glossary and References





Glossary

A4A	Action4Advocacy
ANCOVA	Analysis of covariance
GAS	Goal Attainment Scaling
ICER	Incremental cost-effectiveness ratio
IA	Independent Advocacy
IB	Individual Budgets
ODI	Office for Disability Issues
ONS	Office of National Statistics
PSS	Personal social services
QPM	Quality Performance Mark



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