# Office for Disability Issues
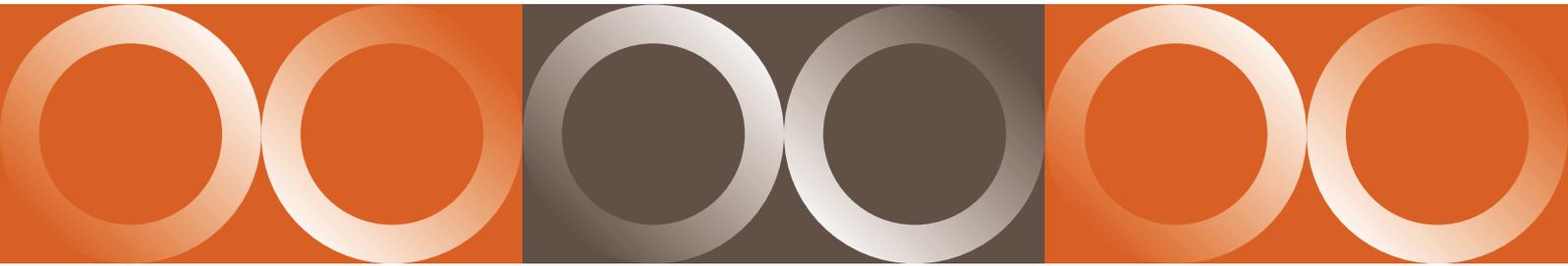
HM Government

# Access to independent advocacy: an evidence review

## Report for the Office for Disability Issues

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**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.

# Contents

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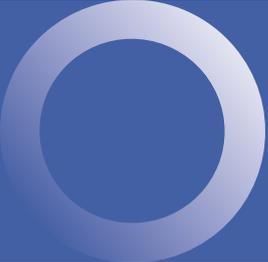
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# Summary

# Summary

Independent advocacy involves[1] 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 that it is crucial to achieving the Government's vision of more choice and control for all disabled people.

The Independent Living Strategy, launched in March 2008, committed the Government to investigate the effectiveness and cost benefit of advocacy support for disabled people in situations where they are at particular risk of losing choice and control. This review delivers on that commitment by systematically identifying, evaluating and synthesising the evidence relating to the need, the benefits and the costs associated with independent advocacy for disabled people in the four situations specified by the strategy, namely:

- 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.

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

The searches for evidence related to people with mental health support needs, people with learning disabilities and people with physical/sensory impairments. This report summarises key themes from the UK and international research literature, and also highlights the extent and nature of gaps in the current evidence base.

# 1.  Scope of the review

This review is the first part of a two-stage study: (1) to investigate the nature of existing evidence and the gaps therein, (2) to determine how evidence could be collected to fill any information gaps identified. This report describes the findings of the first stage of the work, the evidence review.

The review involved a systematic search of seven major bibliographic databases of all records in English published since 1997. The research team also searched for grey material, held in reports or unpublished form. Once obtained, items were read in full, key data was recorded using a tailored reading tool and each publication was appraised for quality.

According to leading voluntary sector organisations active in the field of advocacy, 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 budgets[2]).

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[2]  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)

This set of criteria may be seen as the 'gold standard' for defining advocacy services that are truly **independent**. However, national debate and agreement on the key components of independent advocacy is a fairly recent development and most current 'independent' advocacy services are still not truly independent in terms of the criteria outlined above.

For the purposes of this review, therefore, a broad definition of independent advocacy was taken which included paid, professional advocacy, unpaid, citizen advocacy and peer advocacy, but not self-advocacy. The research team also had to accept that the nature of provision, funding and governance arrangements for advocacy services described in the documents reviewed may be unclear, or not wholly independent in terms of the criteria outlined above.

## 2.   Evaluating the benefits of independent advocacy

This review set out to investigate the nature and extent of evidence relating to independent advocacy for disabled people at risk of losing choice and control in four specific situations. In doing so, it describes and evaluates evidence about the need, the benefits and the costs associated with independent advocacy.

An analysis of the evidence relating to **benefits** established that there is an important distinction to be drawn between benefits emanating from the **process** of independent advocacy, and benefits resulting from the **outcomes** of this process. The research reported in this review also found that outcomes from advocacy may not always be perceived as **benefits**, even where the process of advocacy is seen as positive by those involved. This distinction, and the lack of a clear causal relationship between a positive process and a positive outcome, is key to the findings of this review.

## 3. Independent advocacy for young disabled people during transition to adulthood: evidence about need, benefits and costs

The searches relating to transition covered young disabled people aged 14 to 25. Evidence relating to focused support and advocacy carried out by parents of young disabled people, by Connexions Personal Assistants, by other transition workers, in groups, and by peers was included.

- There is very limited evidence relating to levels of need and unmet need in this area, possibly due to a lack of information about the number of young disabled people at transition, and the fact that specialist advocacy services for this group are scarce.

- Reasons why independent advocacy may be needed at transition include:

  - the need to ensure that young people's views are heard, while maintaining family involvement

  - the need to support young disabled people at transition who are 'looked after'[3] or live 'out of area'

  - the need to promote better involvement of young disabled people in decision making at transition

  - the need to provide emotional support at transition.

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[3] The 1989 Children Act introduced the term 'looked after' to describe the situation when children and young people are 'in care' or 'accommodated' by a local authority. When a child is 'accommodated', they are looked after by their local authority by voluntary arrangement and their parent(s) retains 'parental responsibility' and can decide to cancel the arrangement at any time. A young person can only be correctly described as 'in care' if a Care Order has been made by a court. A Care Order remains in force until a child is 18 years old (unless it is revoked before that time) and gives joint parental responsibility to the child's local authority and parent(s).

- The limited evidence base relating to the process benefits of advocacy suggests that advocacy input at transition may lead to:

  ○ increased involvement and better quality involvement of young disabled people in transition planning

  ○ a positive impact on the behaviour and knowledge of professionals regarding disability and disabled people

  ○ advocating for more and better quality opportunities post-transition.

- The evidence base for outcome benefits is stronger methodologically, but limited by a small number of studies. These suggest that advocacy input for young disabled people at transition may lead to benefits in terms of personal development (ie increased confidence and self-esteem, raised expectations about what is possible, and a more positive self-identity as a disabled person).

- Two studies found that employment-related input at transition appeared to improve access to employment and, more specifically, to desired employment. However, these services did not fall within the tightly defined definition of independent advocacy used. They are therefore indicative of the **potential** impact that could be achieved if independent advocates were to support young disabled people at transition in a similar way.

- This review revealed no published research evidence of costs or cost-benefits of advocacy at transition.

## 4. Independent advocacy for disabled parents whose children are subject to safeguarding procedures: evidence about need, benefits and costs

- There is currently no reliable national data set relating to the number of disabled parents involved in child protection proceedings. Thus the full extent of potential need for independent advocacy in this context is not wholly clear, although fragmentary findings from good quality research suggest need is likely to be high.

- The reasons why disabled parents involved in child protection proceedings need advocacy include:

  - the over-representation of certain groups in the child protection system include parents with learning disabilities and parents with mental health support needs

  - the need to educate professionals working with disabled parents

  - parents' need for support to understand and to speak up throughout the child protection process

  - the need to reduce institutional discrimination

  - evidence that disabled parents want independent advocacy.

- Evidence around process benefits of advocacy input for disabled parents is limited, but small-scale studies suggest that advocacy can lead to:

  - increased and better quality involvement of parents throughout the child protection process, including increased understanding of the process by parents

  - increased knowledge and understanding among other professionals of the needs of disabled parents

  - better communication and decreased antagonism between parents and professionals.

- The evidence base for outcome benefits is also limited in size and scope and has focused solely on the outcomes of advocacy for parents with learning disabilities. Findings relate to two key areas:

  - Positive impact on empowerment and personal development of parents involved in child protection proceedings. Specifically, an increased understanding of the reasons for loss of custody of their child, where this was an outcome.

  - Impact on maintaining child custody. There is not, as yet, conclusive evidence of a causal link between providing the context and resources for a positive process and bringing about a positive outcome for the parents in terms of maintaining their child at home. However, research is lacking in terms of quantity and quality, so current evidence is contradictory and incomplete.

- One study involved analysis of two contrasting scenarios and suggests that advocacy and support to enable parents with learning disabilities to maintain custody of their child at home is cheaper than the costs of adoption.

## 5. Independent advocacy for disabled people when entry to residential care is a possibility: evidence about need, benefits and costs

- There were no studies identified which specifically researched the benefits of independent advocacy for disabled people when entry to residential care is a possibility. Both policy and older peoples' organisations have called for more, and improved, advocacy services for older people.

- The proportion of referrals to generic advocacy services relating to a change of accommodation suggests a need for advocacy services to provide support in this area. However, the evidence base is limited due to a lack of research exploring the numbers of people in this situation and the current levels of independent advocacy available for them.

- It is likely that a large proportion of disabled people who may enter residential care will be older people. Research with older people has shown a low level of awareness of advocacy services and a lack of understanding of the concept of independent advocacy.

- This review found no research evidence of costs or cost-benefits in relation to advocacy services specifically for disabled people when entry into residential care is a possibility. There is only very basic data exploring the costs of a general advocacy service for older people which estimated the savings made to the statutory sector.

# 6. Independent advocacy when disabled people are victims or alleged perpetrators of anti-social behaviour: evidence about need, benefits and costs

The searches relating to disabled victims of alleged anti-social behaviour included evidence relating to a continuum of experiences from harassment through to murder. The searches relating to disabled perpetrators of an anti-social behaviour looked at evidence from a variety of settings including services in the community, prisons and high-security hospitals.

## Disabled victims

- There is a strong evidence base, from a number of large studies, of high levels of anti-social behaviour towards disabled people. This review has found a range of studies that show that all groups of disabled people are more likely to be physically or verbally abused than the general population.

- Disabled people are less likely to report crime against them in comparison to the general population. Research has identified factors that affect this under-reporting. These include people not knowing how to report a crime, or not having the appropriate support to do so. The research suggests that disabled people feel the police do not take their claims seriously and do not always investigate them appropriately. There is a role for independent advocacy in addressing these barriers.

- This review identified some research exploring the benefits of advocacy for vulnerable adults who had been victims of abuse. This showed that in the majority of the cases reviewed the goals of the advocacy were met and the abuse was stopped. However, this research was from the perspective of the advocates, not the service users.

- This review did not identify any research exploring the related costs of independent advocacy services for disabled victims of crime.

## Disabled perpetrators of anti-social behaviour

- This review found high-quality evidence concerning the high rates of prisoners with learning disabilities or mental health problems. Many of these prisoners are inappropriately placed and do not have appropriate support or access to advocacy. There is evidence that over a fifth of prisoners with learning disabilities did not understand what was going on during their court case and they identified the need for someone to explain difficult words to them. Once in prison they needed help with filling in written forms.

- One high-quality piece of research demonstrated the need for an independent advocacy service in a high-security hospital. This study also identified benefits and outcomes of the service and found the patients and the staff viewed the service positively. Both patients and staff felt there were benefits from the process of the advocacy service even when desired outcomes were not possible. The process benefits included getting rid of anger and the outcome benefits included access to useful information. This study collected data in relation to the time spent by advocates, but there was no cost analysis performed.

- There are high costs involved with prison placements, but there is no research around the cost-benefits of schemes that work to divert disabled offenders from prison.

## 7.  What are the gaps in the current evidence base?

## Need for independent advocacy

This review has demonstrated there is a very limited evidence base relating to the extent of the need for advocacy for disabled people in all the areas considered. More information is needed about the number of people at risk of losing choice and control in these situations who may be able to benefit from independent advocacy. More information is needed about what services exist to meet this need and, where such services are available, about the levels of unmet need. Primary research is needed to define and describe the extent and nature of need in each of the four situations.

# Benefits of independent advocacy

This review has demonstrated that there is a paucity of robust research which has investigated the benefits of independent advocacy for disabled people. Evidence of the effectiveness of independent advocacy for disabled people at transition is limited. There are some good quality studies, but further work is required in this area to establish a solid evidence base.

There is a stronger evidence base in relation to disabled parents and advocacy services, but this is still limited in size and scope, particularly in regard to parents with physical/sensory impairments. Further research is needed to explore how independent advocacy can benefit these parents.

There were no studies retrieved that specifically explored the benefits of independent advocacy for disabled people when entry to residential care is a possibility. There were evaluations of services which might be used by people in this situation but, in general, the evidence base in this area is lacking in terms of quantity, quality and scope.

There is an absence of research exploring the potential benefits of independent advocacy for disabled victims of crime. In relation to independent advocacy services for disabled offenders, there is a high-quality study exploring these from the perspectives of both service users and professionals. This research needs to be built on to establish a solid evidence base of the benefits of an independent advocacy service in this type of setting.

There is a need for larger scale studies, with larger samples and multiple service settings using comparative approaches, as opposed to small-scale case studies which have previously characterised research in this domain. There is also a need for research to explore the longer term outcomes of independent advocacy.

Future research would also need to investigate the variables that affect both the process and outcome benefits of independent advocacy, so that the factors determining the effectiveness of advocacy intervention are clearly understood. For example, this review has highlighted that across all four areas, the nature of the

advocacy role (including the tasks which advocates undertake) was an important variable in bringing about benefits for disabled people. The evidence showed that there were certain factors which appeared to promote the process and outcome benefits. These included:

- a relationship built on trust and developed over time

- credibility and 'clout' with other providers

- acting as an educator, mediator and campaigner

- a clearly defined role which includes a number of key components relating to specific (and specialist) skills, knowledge and experience.

Future research would need to carefully consider these, and other significant variables in any assessment of the effectiveness of independent advocacy for disabled people.

## Costs of independent advocacy

We found just one study that estimated the costs of providing advocacy and contrasted this with an alternative form of support. This study quantified input to parents with learning disabilities involved in child protection proceedings, and contrasted this with the costs of adoption. However, its focus was parents with learning disabilities and the scenarios associated with other groups of parents are likely to involve different sets of costs. Moreover, this study only looked at the costs. It did not evaluate the benefits of each scenario for those involved. Evaluating the cost-effectiveness of such services may prove to be more complex, given the likely difficulty of identifying outcomes that both professionals and parents agree constitute 'success'.

The research relating to the Independent Mental Capacity Advocate service contains data about time spent working on referrals and this includes change of accommodation referrals and adult protection cases. Similarly, there is some data about time spent on providing advocacy within a high-security hospital.

There is an urgent need for cost-effectiveness analysis in all of the four areas considered in this review. These would need to accurately explore the costs involved in providing independent advocacy in each of the situations and quantify both the process and outcome benefits related to the advocacy intervention.

# 8.  Next steps

As explained previously, the evidence review is part of a two-stage study with the second stage of the work involving a scoping study to determine how evidence could be collected to fill the gaps identified in this report.

A 'framework paper' relating to this second stage is now available from the Office for Disability Issues. It sets out a proposed framework for future research to investigate the cost-effectiveness of independent advocacy for disabled people in each of the four situations. We hope that this report and the associated framework paper will help to inform any subsequent decisions on the potential commissioning and timing of further, substantive, research to fill the evidence gaps identified and provide direction to potential policy development in the field of independent advocacy.

# 01

## Setting the scene:
## background and methodology

# 01 Setting the scene: background and methodology

This report aims to identify and synthesise the evidence relating to the need, benefits and costs of independent advocacy for disabled people in each of the following 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.

It summarises key themes from the UK and international research literature and also highlights the extent and nature of gaps in the current evidence base.

## 1.1    Definitions of independent advocacy

Independent advocacy involves[4] 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.

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

In November 2008, the National Forum for Independent Advocacy with Older People (a group representing over 60 organisations from the voluntary advocacy sector in all four countries of the UK) agreed on and accepted a definition for independent advocacy.

> Independent Advocacy supports and enables people who have difficulty representing their interests, to exercise their rights, express their views, explore and make informed choices. Independent Advocacy supports the person regardless of the demands and concerns of other people and bodies. It challenges the causes and effects of injustice, oppression and abuse and upholds human rights.
>
> (OPAAL 2008a, page 1)

The Forum went on to make the distinction between independent advocacy and advocacy:

> Forum members recognise that many people advocate for older people…Most frequently these people are family members, friends or carers. In addition many people advocate as part of their professional occupation, for example nurses, social workers and care workers. However these people often have a conflict of interest between the needs of older people and their employers who are often either directly supplying or/ and funding the service(s) used by older people and therefore cannot be said to be independent.
>
> (OPAAL 2008b, page 2)

The Equality and Human Rights Commission (EHRC) takes the view that to prevent any conflict of interest between the advocacy provider and the person needing advocacy support, the most crucial element of any type of advocacy provision is its independence from public bodies (EHRC 2008, personal communication). To fulfil this, the EHRC (2008) believes that all independent advocacy providers must strengthen their independence through governance arrangements, such as having management committees which include advocacy users, advocates and other local residents. It also suggests that placing a duty on public bodies to fund independent advocacy services would prevent public bodies from withdrawing funding from advocacy services critical of them.

The Scottish Executive (2000) provides a clearly defined vision of independent advocacy in their guide for commissioners of such services. The guide states that good independent advocacy services should:

- be firmly rooted in, supported by and accountable to a geographical community or a community of interest

- be constitutionally and psychologically independent of local and national government

- not be providers of a service and advocates of users of that service

- be aware there is no one best model and that different approaches are needed

- maintain a clear and coherent focus for their work

- undergo regular and independent evaluation of their work, with financial assistance from commissioners.

These definitions, with their separation of independent advocacy from other forms of service provision, independent governance, and pooled funding arrangements (such as pooled budgets[5]), may be seen as the 'gold standard' for the provision of independent advocacy services. However, the reality of actual service provision in this sector is less clear than these definitions might suggest and, in practice, there is still confusion about what independent advocacy is and how this is interpreted by advocates and those they advocate for (their advocacy partner).

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[5]  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 Independent advocacy: the national picture

Advocacy Consortium UK (2009) estimates that there are over 1,000 independent advocacy organisations in the UK providing various forms of independent advocacy to disabled people, using both paid staff and volunteers. A mapping exercise for the Office for Disability Issues (ODI) (Ward and Strong unpublished) found that these services are characterised by patchy geographical provision, lack of sustained funding and are often not easily accessible to people from black and minority ethnic (BME) communities.

Similarly, the Improvement and Development Agency's (2009) report on the role of access to information, advice and advocacy in transforming adult social care, found that most local authorities lacked strategies for ensuring standards and quality assurance in the provision of information, advice and advocacy services, and services had difficulties in meeting the needs of socially excluded people. The report, based on a literature review and primary research with local authorities in England, aimed to scope current activity and thinking in relation to information, advocacy and brokerage. It found that most advocacy, information and advice services are delivered through a patchwork of one stop shops, libraries, health centres and other mechanisms, such as local advice centres, outreach work and Centres for Independent Living. However, as the authors point out, this situation is not satisfactory, as access to advocacy, information and advice is an essential building block underpinning the personalisation of social care since it is crucial to enable control and to support choice.

In 2007, Action for Advocacy (2008) undertook a survey of paid staff working in the advocacy sector in England and Wales. They found that many of the respondents had difficulty defining advocacy, or their role as an advocate. The Scottish Independent Advocacy Alliance (2008) collected 'stories' from advocates and their partners which show how the exact role of an advocate is open to negotiation between the advocate and the advocacy partner depending on the nature of the advocacy situation and the outcome sought.

> Independent advocates support people to gain access to information and explore and understand the options available to them…In practice, what this amounts to is help with the often stress-inducing trials and tribulations of day to day living. The advocacy worker is there to side with the service user, to listen, to encourage, to explore options and to communicate…And just being there for the service user can be a great leveller, enough to make 'the other side' sit up and take notice, the difference between being listened to and being fobbed off or ignored.
>
> (Scottish Independent Advocacy Alliance 2008, page 9 and page 77)

Nonetheless, there are some core components of the advocacy role which include:

- 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 (adapted from a set of national standards for advocacy, Voice for the Child in Care, undated).

Indeed, despite the work done on reaching a national definition by the National Forum for Independent Advocacy with Older People (OPAAL 2008a and b), a more recent report by Advocacy Consortium UK (ACUK 2009) has highlighted the need for more national agreement and clarity on a definition of independent advocacy. ACUK undertook a survey of advocacy services and held two focus groups to explore the desirability and feasibility of a National Strategic Framework (NSF) for advocacy. Of the advocacy services who responded to the survey, 70 per cent were in favour of such a framework and the results of the research suggested that the content of such an NSF should include:

- core principles, a common definition and overview of advocacy which recognises the diversity of advocacy schemes and clarifies the importance of independence

- access to advocacy and coverage, including a commitment to mapping out current provision and identifying need

- increasing the resourcing of advocacy, improving commissioning and pump-priming advocacy where there are identified gaps

- improving the accountability of advocacy through bringing together and building on initiatives in quality, monitoring standards and training, and clarifying what is needed in terms of accreditation and registration.

Others have also highlighted a need to monitor standards in advocacy (Action for Advocacy 2006a, 2006b, Voice for the Child in Care undated) and for research to identify potential and actual outcomes of advocacy (Atkinson and Forbat 2003, Scottish Independent Advocacy Alliance 2008, Improvement and Development Agency 2009).

## 1.3    Researching the process and outcomes of advocacy

This review set out to investigate the nature and extent of evidence relating to independent advocacy for disabled people at risk of losing choice and control in four specific situations. The following chapters examine the research evidence that is currently available and spell out the gaps inherent in this. However, it is worthwhile setting the scene in terms of the current overall research context for advocacy in a more generic sense.

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.

According to the Scottish Executive (2000), measuring the effectiveness of independent advocacy is complicated and can involve the following methods of data collection and analysis:

- listening to people's stories about the difference it has made to their lives

- valuing relationships as well as results

- balancing the visible stories of success with the invisible work of preventing worse things from happening

- assessing the impact of advocacy on policies and practice in the service system both in relation to individuals and more generally.

With the exception of the last bullet point, this list represents methods for collecting data relating to the **process of** advocacy, and for measuring the benefits therein. The process of advocacy (which includes, for example, the nature of the relationship between the advocate and advocacy partner, the meetings attended and actions taken in pursuit of a specific advocacy goal) has the potential, in its own right, to bring about important benefits for disabled people.

These **process benefits** might include, for example:

- more choice and control

- improved empowerment

- changes to attitudes and practices

- advocacy partner's voice now heard

- advocacy partner able to participate in community

- people learn new skills and insights

- greater understanding of issues

- increased awareness of access to rights

- expectations raised

- advocacy partners more actively involved in case conferences planning meetings and policy making

- improved personal independence and life skills

- improved social well-being and psychological health

- improved self-confidence and self-esteem (Advocacy and Resource Exchange 2004).

As the body of this report will show, research on advocacy to date has, in the main, focused more on the process of advocacy than on the **outcomes** of advocacy. This may be because there is a recognition by researchers (and practitioners) in this field that outcomes are difficult to measure and evaluate (Chase et al 2006, Rapaport et al 2005). Moreover, the initial goals of the advocacy input may change during the process itself (OPAAL 2009).

It may also be difficult to specify universal outcomes that might be expected of advocacy, since the nature of the service is inherently individual, and is personally tailored to the specific needs and concerns of the disabled person who is the focus. However, a leading organisation in the advocacy field suggests that advocacy has the **potential** to bring about some of the following positive outcomes:

- concerns and issues resolved

- changes to how services operate

- policies change

- advocates get skills and jobs

- advocacy partners get skills that help them to self advocate. (Advocacy and Resource Exchange 2004).

It is important to note, however, that outcomes of advocacy may not always be perceived as positive by those concerned, but that this does not necessarily reflect the nature of the process of the advocacy input itself. In particular, questions arise about how to measure the effectiveness of advocacy with no obvious positive outcomes, but where the process is supportive and enjoyable for those concerned (Rapaport et al 2005). For example, a disabled young person might receive good quality advocacy input, enabling them to participate effectively during transition reviews and to state their aspirations (or perceived/agreed **outcomes**) for the future in terms of independent living or employment goals. The advocate may then go on to support the young person to attain these perceived/ agreed **outcomes**, but however good the advocacy input, there may be many reasons why these aspirations are not met. Such a situation would involve benefits for the disabled person in terms of the process of advocacy, but not in terms of the outcome of the advocacy input. This distinction, between **process benefits** and **outcome benefits**, and the lack of a clear causal relationship between the two, is key to the findings of this review and is something we will return to in subsequent chapters.

## 1.4    Policy relating to independent advocacy

The EHRC's recent report on the future of social care and its role in transforming human rights (EHRC 2009) highlighted access to independent advocacy as essential to ensure quality in the personalisation of social care and support. The report includes a commitment from EHRC to conduct research concerning the availability and quality of independent advocacy across England, including grant funding for the piloting and evaluation of a series of independent advocacy projects. In May 2009, the EHRC announced a £10.2 million Strategic Funding Programme providing three-year project-based funding for community and voluntary sector organisations. The Programme aims to fund organisations providing guidance, advocacy and advice, as well as providing support for capacity building where there are gaps in local advocacy provision. A second programme, launched in June 2009, will provide support for legal advice and awareness of legal rights.

The central government's commitment to providing independent advocacy is set out in 'Improving the Life Chances of Disabled People' (Prime Minister's Strategy Unit, Cabinet Office 2005) as part of a more general commitment to full and equal citizenship for all disabled people. An Independent Living Review was set up in 2006 to make progress on these commitments and the cross-government Independent Living Strategy was subsequently published in 2008. This concluded that disabled people cannot achieve full and equal citizenship unless they have choice and control over the support needed to go about their daily lives, and equal access to housing, employment, health, education, and mobility opportunities. Effective support, advocacy, information and brokerage services were identified as crucial to enable disabled people to make choices for themselves that might otherwise be made for them by other people.

More specifically, the Strategy identified a potential need for independent advocacy in the following situations:

- during transition to adulthood

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

- when entry into residential care is a possibility

- and when disabled people are victims or alleged perpetrators of anti-social behaviour (paragraph 8.2).

Following the Independent Living Strategy, the Government (through the ODI) commissioned an evidence review and scoping study to examine the need, benefits and costs of independent advocacy in the situations noted above. The study is in two stages: a review of existing evidence and the gaps therein, followed by a scoping study to determine how evidence could be collected to fill any information gaps identified. This report describes the findings of the first stage of the work, the evidence review.

## 1.5 About this review: definitions and methods

The purpose of this review was to systematically identify and evaluate the evidence relating to the need, the benefits, and the costs associated with independent advocacy for disabled people in the four specific situations previously outlined, namely:

- 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.

## 1.5.1  Definitions

Our first task was to explore and agree some core definitions to inform the development of the search terms and to set inclusion/exclusion parameters for the evidence search and review. In consultation with ODI and a number of expert advisers to the project, the following core definitions were adopted at the outset of the project.

### Independent advocacy

The starting point was the Disability Rights Commission's (DRC) definition of advocacy as 'an individual being supported to express views, communicate choices and receive services or participation as a result' (DRC 2006, page 3). The DRC (now subsumed in the EHRC) suggested that there are several types of advocacy.

- Citizen advocacy – where an independent person (ie not working for a party involved in service provision, a local authority or health organisation for example) supports a disabled person to speak up for him/herself.

- Self-advocacy – where people are enabled to set up groups to support each other to speak up.

- Peer advocacy – where a person with certain experiences supports another person with similar experiences to make their views known and to have their views presented and acted upon.

- Professional advocacy – where a person is supported by a paid advocate employed by a service such as the health service, Independent Complaints Service or the Independent Mental Capacity Advocacy Service (DRC 2006, page 3).

For the purposes of the this review, therefore, a broad definition of independent advocacy was taken which included paid, professional advocacy, unpaid, citizen advocacy and peer advocacy, but not self-advocacy. The research team also had to accept that the nature of provision, funding and governance arrangements for advocacy services described in the research reviewed may be unclear from the material available, or not wholly independent in terms of the 'gold standard' criteria outlined in section 1.1 above.

## Transition to adulthood

In defining the parameters for 'transition', we took on board the Transition Information Network's statement (www.after16.org.uk) that between the ages of 14 and 25, young disabled people often make important decisions about their education, leave home, get a job and start having relationships. These decisions and changes can be confusing and complicated, so young disabled people need good support, including (for some) access to independent advocacy, to fully explore their needs and choices. The search terms used in the review covered young people from age 14 up to the age of 25, including some groups who might be expected to have a special need for advocacy:

- unaccompanied young disabled refugees

- disabled children/young people in the criminal justice system

- young disabled people in residential colleges/settings.

A prior knowledge of some of the literature in this field (Townsley 2004) led us to expect that an advocacy role at transition might be played by a range of different people and organisations, including peers, and that our definition of independent advocacy at transition should thus be flexible to reflect this.

## Disabled parents whose children are subject to safeguarding procedures

Safeguarding procedures are instigated when there is concern about a child's well-being, and extend from first contact with child protection professionals through to any legal proceedings that may result. The Independent Living Strategy identified disabled parents whose children were subject to safeguarding procedures as being particularly at risk of losing choice and control in their lives, and therefore in potential need of access to independent advocacy. A subsidiary research aim of this strand of the study, posed by ODI, was to examine whether there is any evidence to suggest that provision of advocacy and support at an earlier stage would reduce the number

of children of such parents being identified by children's services as being at risk. For the purposes of this study, the definition of disabled parents includes parents with learning disabilities, parents with mental health support needs and parents with physical/sensory impairments.

## When entry to residential care is a possibility

The Centre for Policy on Ageing advised on the scope of this topic, although potentially it covers situations when a disabled person of any age is at risk of losing choice and control over where they live. This includes entry into residential and nursing homes, extra care housing and special hospitals, but not into residential colleges (which are covered in transition to adulthood). The main groups covered are older people unable to live independently due to physical or cognitive limitations and younger disabled people with high support needs, including those with learning disabilities and dementia, which can affect some groups of younger people with Down's Syndrome from around age 40 onwards.

## Anti-social behaviour

This topic covers both victims and perpetrators of alleged anti-social behaviour. The Home Office definition of anti-social behaviour encompasses a variety of aggressive behaviour, including 'yobbish behaviour and intimidating groups taking over public spaces'. In relation to disabled victims, we have viewed anti-social behaviour as a continuum of experiences from bullying and harassment through to murder and therefore included research about hate crime. In relation to disabled offenders, evidence from a variety of settings, such as services in the community, prisons and high-security hospitals, was all eligible for inclusion in the review.

## 1.5.2  Systematic and grey literature search

Our primary search strategy was to conduct a systematic search of bibliographic databases (see Annex 1 for full details). In addition to the systematic search of formal literature, the research team also searched for grey material, held in reports or unpublished form (see Annex 2 for full details).

### 1.5.3  Data extraction

Across all topic areas, the systematic search identified 45 publications to include for data extraction and critical appraisal. Our search of the grey literature generated an additional 47 items. Other additional items were read for background and context (policy documents for example), even though these were not suitable for inclusion in the critical appraisal process.

Once obtained, items were read in full and key data extracted and recorded using a tailored 'reading tool' (see Annex 3). This included basic bibliographic details as well as more detailed standard information for each item of literature, such as:

- type of research

- aims

- methods (including methods of data analysis)

- sample details

- country/geographical spread

- involvement of disabled people

- any ethical issues

- key findings (on the need, costs, benefits of advocacy)

- stated gaps in evidence

- other gaps noted by researchers

- if non-UK, are findings applicable to UK setting?

### 1.5.4  Quality appraisal

Each publication was appraised for quality, using a scoring scale agreed with ODI (see Annex 4). This process was useful in that it helped to prompt the research team to evaluate each piece of literature in a similar way, using a standard set of criteria. The combined scores from the scale gave the research team a basic means of estimating the relative 'quality' of the different studies reviewed, and of gauging the extent to which particular findings were based on a robust research methodology, where a report of this existed.

# 02

# Independent advocacy for young disabled people at transition

# 02 Independent advocacy for young disabled people at transition

This chapter presents evidence relating to the need, benefits and costs of independent advocacy for young disabled people at transition. In doing so, a total of 23 items of research literature were critically reviewed (for further details see Annex 1).

- There is very limited evidence relating to need and unmet need in this area, possibly due to a lack of information about the number of young disabled people at transition, and the fact that specialist advocacy services for this group are scarce.

- Reasons why independent advocacy may be needed at transition include:

  - the need to ensure that young people's views are heard, while maintaining family involvement

  - the need to support young disabled people at transition who are looked after or live 'out of area'

  - the need to promote better involvement of young disabled people in decision making at transition

  - the need to promote and support emotional well-being at transition, particularly for young disabled people with mental health support needs.

- There is a very limited evidence base on the benefits relating to the process of advocacy, but to date these studies suggest that advocacy input at transition may lead to:

  - increased involvement and better quality involvement of young disabled people in transition planning

- ○ more understanding of the needs/entitlements of young disabled people and better practice by professionals involved in transition planning

- ○ increased requests for better quality provision post-transition.

- The evidence base for benefits relating to the outcomes of advocacy at transition is stronger methodologically, but limited by a small number of studies. These suggest that advocacy input for young disabled people at transition may lead to benefits in terms of the personal development of the disabled young person (increased confidence and self-esteem, raised expectations about what is possible, and a more positive self-identity as a disabled person).

- We also considered two studies which investigated the impact of specific employment-related input at transition for young disabled people with physical impairments. They found that this type of input appeared to improve access to employment per se, and more specifically to desired employment. While these studies do not provide direct evidence of the impact of independent advocacy in this context, the input they investigated was very similar to that which an independent advocate might provide in this context. Thus we felt it was useful to highlight their findings as indicative of the **potential** impact that could be achieved in terms of access to employment if independent advocates were to support young disabled people at transition in a similar way.

- The evidence shows that there are certain factors which appear to promote the process and outcome benefits listed above. These include:

- ○ a relationship between advocate and client built on trust and developed over time

- ○ credibility of the advocate and their 'clout' with other providers

- ○ a clearly defined role for the advocate which includes a number of key components relating to specific skills, knowledge and experience.

- This review revealed no published research evidence of costs (or cost-benefits) of advocacy at transition.

- The systematic review has shown that the evidence base in this area is lacking in terms of quantity and quality of research specifically relating to independent advocacy at transition for young disabled people:

  - primary research is needed to explore the extent and nature of existing input from independent advocacy at transition

  - primary qualitative and quantitative research is needed to explore and define process and outcome benefits of advocacy input at transition

  - primary research is needed to quantify the costs of independent advocacy at transition and to assess the cost-benefits of this type of input.

## 2.1 What does independent advocacy look like for young disabled people at transition?

For the purposes of this review, we have, of necessity, taken a broad view of the definition of independent advocacy. The lack of studies with a specific focus on **independent** advocacy at transition meant that our definition of advocacy included focused support and advocacy carried out by parents of young disabled people, by Connexions Personal Advisors (PAs)[6], by other transition workers and by young disabled people supporting each other through group advocacy[7]. While this affects the conclusions we are able to draw relating specifically to independent advocacy, it reflects the reality of provision for children and young people in that advocacy at transition is offered by a variety of people (including family, friends, volunteers, peers and professionals) and that boundaries between roles are often blurred (Knight and Oliver 2007).

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[6] The role of a Connexions PA has many similarities in purpose to that of an independent advocate. PAs are employed by Connexions, so they are independent of education, health or social services and are tasked with listening and responding to the views, concerns and aspirations of young people.

[7] Where young people attend groups facilitated by a professional with the express aim of supporting each other through the transition process.

# The story of Sheila and Ethan

Sheila is an advocate at Midshire Young People's Advocacy Project. She has had an advocate partnership with Ethan since he was referred to the project by a teacher at his school. The project provides advocacy for any young person (aged 20 or younger) with mental health support needs.

**Ethan**

Last summer I was at a very low point in my life. I had a lot of problems in school as I'd missed a lot coursework...I also had a meeting with [school staff] about my attendance...I was also having problems with anxiety and depression as a result of harassment within my school and outside. I was struggling to get the school to understand the situation. After Sheila got involved, things changed a lot. She was able to speak to my year head on my behalf, explain the situation and reach big compromises with her about my school work. She also made sure that the staff were made aware of my views and feeling on things with the school. When the [transition review meeting] happened I was a lot more comfortable about it, having had help from Sheila. She helped me to prepare beforehand and having her with me in the meeting helped to make sure I got my points across and the school took them seriously. As well as this, Sheila provided a lot of resources on handling stress and anxiety that helped me a lot. I'm a lot more confident in myself now and less worried about losing control of things or getting out of my depth.

**Sheila**

When I first met Ethan, he was anxious and depressed…I encouraged him to talk to his doctor, who then referred him to the Child and Adolescent Mental Health Team for support. I have found my partnership with Ethan very rewarding and it has been great to see his resilience improve and although we are still in an advocacy partnership, Ethan is becoming more confident in self-advocating in most situations...Ethan clearly says that he now feels that others are listening to him and taking his views into consideration before making decisions and judgements about him. He now feels more involved in this process.

Adapted from a case study presented by the Scottish Independent Advocacy Alliance (2008).

## 2.2 Policy and guidance supporting the concept of independent advocacy at transition

The recent emphasis in government policy on improving services and support to disabled children/young people and their families, via Aiming High for Disabled Children (AHDC), includes a focus on better support at transition. Central to this commitment is the recently announced Transition Support Programme, launched by the Department for Children, Schools and Families in December 2008. The aim of the programme is that by March 2011, transition services in all local areas in England will be able to give more support to young disabled people in their transition to adulthood and will routinely involve all young disabled people in their own transition process, and in shaping and developing provision for all young people. The National Transition Support Team will provide local advocacy groups with a range of tools, so they can better support young disabled people to be more included in the transition process in their local areas.

## 2.3 Evidence of the need for independent advocacy for young disabled people at transition

Although the evidence base is limited by its scope and lack of structure, there appears to be at least some level of stated need for independent advocacy at transition across all impairment groups.

### 2.3.1 Levels of need for independent advocacy at transition

There is a lack of information about the number of young disabled people at transition. The number of disabled children in the UK is thought to be around 570,000 (HM Treasury and the Department for Education and Skills 2007). But there is currently no accurate information available about the percentage involved at any one time in the transition process. All young people with a statement of Special Educational Need should have a transition review during

Year 9. However, depending on the needs and interests of the young person, their involvement in transition may last anywhere from 3-11 years, so could include all young people aged 14 to 25 who have an active transition plan (National Transition Support Team, personal communication). Moreover, fieldwork for the AHDC Review (HM Treasury and the Department for Education and Skills 2007) found that some local authorities do not have an accurate understanding of the profile or the size of their population of disabled children and young people, let alone those involved in transition.

Even if we did know the number of young disabled people at transition, there is currently no way of knowing whether or not they have a stated need for independent advocacy and thus to assess what the level of unmet need might be. There is some evidence to suggest that some specific impairment groups, such as young men with Duchenne Muscular Dystrophy, and young people with autism, are less likely than other young disabled people to be able to access support and advocacy at transition (Abbott and Carpenter 2009, National Autistic Society 2007). Similarly, young disabled people who are 'looked after'[8], or who are living 'out of area' at residential school or college, are often disadvantaged in accessing information and making choices at transition (Morris 2002, Heslop et al 2007). A Commission for Social Care Inspection (2007) evaluation and inspection of 12 social care services in England also found that young people with learning disabilities often did not get access to advocacy services that met their needs during transition.

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[8] The 1989 Children Act introduced the term 'looked after' to describe the situation when children and young people are 'in care' or 'accommodated' by a local authority. When a child is 'accommodated', they are looked after by their local authority by voluntary arrangement and their parent(s) retains 'parental responsibility' and can decide to cancel the arrangement at any time. A young person can only be correctly described as 'in care' if a Care Order has been made by a court. A Care Order remains in force until a child is 18 years old (unless it is revoked before that time) and gives joint parental responsibility to the child's local authority and parent(s).

Evidence suggests a distinct lack of specialist independent advocacy provision aimed at young disabled people. The Sounds Good Project (2006) surveyed advocacy schemes for people with learning disabilities in England and found that out of 300, only 35 were providing support for young people at transition. Reasons for this lack of specialist provision are unclear. However, it has been suggested this may be due to the need to pay additional regard to the children's legislation and, for example, to develop a Child Protection policy and be aware of other statutory guidance like the Children Act (Sounds Good Project 2006). However, no evidence was provided for this conclusion so this is an area which may warrant further investigation.

The lack of evidence relating to unmet need is likely to relate to the fact that there are no statistics relating to the number/profile of young disabled people at transition, and that specialist advocacy services for this group are scarce. This does not mean, however, that there is no need for independent advocacy – simply that need is currently difficult, if not impossible to measure, without the availability of this basic data.

## 2.3.2    Why is advocacy needed at transition?

Transition is a time of change, when decisions must be made and when good communication and coordination between the young person, their family (if they have one) and service providers is vital if the young person is to maintain choice and control. Evidence suggests that independent advocacy may be needed at transition for the following reasons:

### The need to ensure that young people's views are heard, while maintaining family involvement

The literature on transition highlights the essential nature of family involvement and the difference it makes to effective transition (Morris 2002, Blacher 2001, McNair and Rusch 1991, Hendey and Pascall 2001). It is well established that parents and carers have a central part to play at transition and should be fully involved in planning for the future with their son/daughter and other professionals. However, parents and young people will almost certainly have different views about some issues and these may go unnoticed or unexplored by professionals supporting transition planning.

Research by Abbott and Carpenter (2009) on the experience of transition for young men with Duchenne Muscular Dystrophy, found that when parents and young men opted to talk together it was hard to untangle parents' views and emotions from those of their sons. Similarly, research by Heslop et al (2007) found that parents are very often the lead people advocating for their son or daughter with learning disabilities at transition. This raises the question, how can services ensure that young people's voices are truly heard, and are distinct from those of their parents/carers, however supportive and involved that family might be? Independent advocacy could have an important role in enabling young people's views to be articulated separately from those of their parents.

Clearly there are sensitive issues for an independent advocate to take on board relating to the linked, but distinct, voices of young people and families. Rowland-Crosby et al (2002) research on the role of Connexions PAs in supporting young disabled people, points out that those from black and Asian communities may have very different views to their parents about what they want to do in the future. Connexions PAs may be in the very sensitive position of having to advocate for the young person **and** acknowledge the strong feelings of the parent.

A recent review by Christophides (2008), focusing on young disabled people and transition, also highlights the key role played by parents. The author hypothesises that the availability of advocacy services specifically designed to meet the needs of young people will be fundamental to the success of individual budgets. However, the report warns against letting families take on this advocacy role in addition to their other caring responsibilities and states that if young disabled people are to achieve true independence, they must be supported to make their own decisions. The report stresses the importance of ensuring that independent advocacy is available for young disabled people at transition who wish to manage their own individual budgets to secure adult social care services (Christophides 2008).

## The need to support young disabled people at transition who are 'looked after' or live 'out of area'

Morris (2002) reminds us that not all young disabled people have families and for those who are 'looked after', or have spent a lot of their life living away from home, there may not be anyone who will be there to act as advocate, information-seeker, and arbiter. Heslop et al's (2007) research on transition for young people with learning disabilities living 'out-of-area' at residential school or college highlighted the loss of peer support that many such young people face when they move back to their home area, even if they do have active and supportive families. This research analysed data collected over a two-year period from 15 young people with learning disabilities in out-of-area residential, special schools and colleges, as well as from their families and the professionals who supported them. The research examined the role of a named 'key worker' or 'lead professional' (with some similarity in role to an advocate) to support young people through the process of transition, a concept promoted in recent government guidance concerning disabled children (Department of Health 2003). Heslop et al (2007) confirmed previous research findings of the benefits of a key worker (Greco et al 2005, quoted in Heslop et al 2007) and pointed out it would be helpful if this role was extended through the age range with the same person able to support families and young people across the child/adult service divide.

## The need to promote better involvement of young disabled people in decision making at transition

Despite a body of research (for example, Heslop et al 2002) showing a history of low/poor involvement of young disabled people in transition planning, and despite policy and guidance designed to improve this situation, it still appears that very many young disabled people are excluded from planning meetings or feel unable to contribute through lack of preparation or support (Heslop et al 2007, Sounds Good Project 2006). Heslop et al (2007) found that although there was evidence of young people with learning disabilities working creatively in the classroom about their hopes and aspirations, this did not routinely permeate into plans, reviews and meetings about transition.

Decision making is an important part of both becoming an adult and the transition process itself. But young people with learning disabilities often get very little practice in making choices until they are presented with what can seem like an overwhelming array of decisions to make about the future (Townsley 2004). As well as opportunities for practice in decision making, young people and families also need support to make choices. The National Autistic Society's (2007) survey of young people with autism, carers and professionals, highlighted that the input of advocates (as well as other 'significant' people such as family members) to help young people express their views, was invaluable in building up a picture of the support needed by an individual to achieve their aspirations.

## The need to provide emotional support at transition

Transition to adulthood can be an emotionally demanding time. Not only are young people experiencing physical changes that can cause emotional 'ups and downs', but external changes (such as leaving school) and the need to make important decisions about the future can be very stressful. Townsley's review (2004) of literature on transition for young people with learning disabilities found that the emotional and psychological transition for young people has attracted very little study. She quoted the work of Williams and Heslop (2005) who talked with young people with learning disabilities and mental health needs about transition. They found that for all of these young people, their mental health had deteriorated at the time of transition, or new problems had emerged.

Many young disabled people consulted as part of Rowland-Crosby et al (2003) study said that thinking about the future was scary, and that they were very worried about moving on from school. However, they also said that talking with a Connexions PA had helped them not to worry so much. Access to emotional support is essential at transition. Offering emotional support might well be a major part of any role played by an independent advocate in supporting transition for young disabled people and will involve a careful, sensitive and well-informed approach.

## 2.4 Evidence of process and outcome benefits of independent advocacy for young disabled people at transition

The research team found limited published material relating to the benefits of independent advocacy at transition. The review indicates that there is no research to date that has developed a framework for measuring, synthesising and comparing outcomes for young disabled people in this area. In our analysis of the limited literature focusing more generally on outcomes at transition, we looked to see if there was any consensus about what counts as outcomes for this group.

Hoggarth et al's (2004) detailed and extensive study of the role of Connexions in England with young people at risk, suggests that the Connexions service has a multi-faceted impact on outcomes in different areas of young people's lives at transition. These include **process outcomes** such as personal development and dealing with urgent or underlying risks, as well as **destination outcomes** in education, employment or training. For most young people at risk (which includes young disabled people) impact is needed in both process and destination outcome areas. The authors noted that further work is needed to develop ways of measuring and recording process outcomes.

Although in some circumstances there may be links between process and outcome benefits (for example, a good experience of independent advocacy may deliver good outcomes), Heslop et al (2007) suggested that this relationship is far from clear. In their research, poor planning did not always correspond with poor outcomes, if good quality employment, training or education options were available for the young people with learning disabilities involved in their study. Conversely, some young people who reported a positive process of transition planning ended up with disappointing destination outcomes due to a lack of choice and last-minute decision making.

## 2.4.1     Process benefits

We found five studies reporting process benefits as a result of some form of advocacy work with young disabled people at transition. Of these, three were well-designed mainly qualitative studies with appropriately sized samples (Hoggarth et al 2004, Balcazar et al 2004, Grove and Giraud-Saunders 2003). The remaining two studies (Sounds Good Project 2006, Pennington 2001) could loosely be described as action research projects. They had smaller samples, less methodological detail given in the written material and consequently less robust findings.

### Increased involvement of young disabled people in transition planning

Several of the studies suggest the involvement of adults/peers acting in an advocacy role may have an impact on whether or not young disabled people were involved in the process of planning their own transition. The Sounds Good Project (2006) found that advocacy input at transition may mean that young people were more likely to be invited to their review meetings and other forms of transition planning.

### Better quality involvement of young disabled people in transition planning

There was some evidence to suggest that the existence of advocates in transition meetings could lead to better quality involvement of young disabled people in the transition planning process. Findings from the Sounds Good Project (2006) indicated that meetings may be conducted differently when an advocate is present, that young people may feel more involved and there may be improved communication between professionals and the family/young person. Grove and Giraud-Saunders (2003) study of the effectiveness of Connexions PAs in working with young disabled people at transition stressed the advocacy element of the PA's role. They found that young people liked having an independent person to talk to and parents appreciated the neutral status of the PA.

## Positive impact on behaviour and knowledge of professionals at transition

Hoggarth et al (2004) found that the advocacy and awareness raising role of Connexions PAs is of great importance when working with young disabled people in terms of reminding other professionals of their own roles and responsibilities at transition.

They also suggested that this awareness raising role could potentially include other functions such as educating the wider society about the rights of young disabled people. Although their evidence is less robust than Hoggarth et al the Sounds Good Project (2006) also found that advocates may unwittingly act as educators for other professionals in that they may model good practice in involving young people at transition.

## Advocating for better quality provision post-transition

It is well established in the research literature that options and opportunities for young disabled people post-transition are often more limited and of poorer quality than those accessed pre-transition. There was some evidence to suggest that providers of advocacy at transition may be acting as 'change agents' (Sounds Good Project 2006), as 'campaigners' (Hoggarth et al 2004), or as 'instigators of change, mediators and advocates' (Balcazar et al 2004). Balcazar et al (2004) set up and evaluated a school intervention programme designed to develop the advocacy skills of minority ethnic young disabled people in the USA. This programme involved an 'advocacy' component, where young people were linked with a case manager to support them through the transition process and beyond. The researchers found that case managers became 'mediators and advocates' in that they were often included in efforts to resolve conflicts between students, teachers, family members, and service providers, which often involved resource allocation issues.

## 2.4.2  Outcome benefits

We found six pieces of research literature reporting outcome benefits as a result of advocacy input (two of these were reported in a systematic review). All but one of these studies involved appropriately sized samples, gave adequate methodological details and produced results that appear to be generalisable. However, the relative paucity of research in this area means that limited outcomes have, to date, been described and reported. Existing data can be grouped into two main areas: impact on the personal development of young disabled people and access to employment. There are many more areas where we might potentially expect to see positive outcomes as a result of advocacy input. For example:

● impact on access to healthcare, social care, and individual budgets

● impact on personal relationships

● impact on well-being, and so on.

However, the literature to date shows no evidence of these.

### Impact on personal development

Several studies reported a significant positive impact from advocacy input at transition on the personal development of young disabled people. The Sounds Good Project (2006) found that young disabled people reported increased confidence about taking part in transition planning when an advocate was involved. The advocate also supported them to change small things in their lives and have some new experiences. Interestingly, the researchers also found that advocacy enabled young disabled people to better understand their own reasons for certain stated wishes or life choices, particularly where these might be difficult to achieve. One project gave the example of a young person with learning disabilities who said he wanted to learn to drive. Once this was explored through advocacy, it emerged that his reason for wanting to learn to drive was because he wanted to be able to visit his friends, not learn to drive per se. The young man was then supported to achieve his real goal, of meeting up with friends.

Advocacy may also support young disabled people to raise their expectations of what is possible, thus increasing feelings of self-esteem, independence and self-reliance, 'key indicators' of successful transition (Community Living Project 2006). The Trans-Active project (Pennington 2001) set up a buddying scheme pairing young people with learning disabilities from special schools with mainstream peer advocates. The project wanted young people to be able to make more informed choices about their future through sharing experiences with non-disabled youngsters. The project provided support for the initial bonding process via a residential weekend. The teenagers then worked together on different topics relating to transition, such as advocacy, education, living skills, working, leisure and friendship. By using photos, video clips and other multi-media techniques each young person was able to create a CD Rom (or 'transition passport') to express their views and spell out their own choices. The project found that mixing with non-disabled peers in this way broadened the horizons of young people with learning difficulties and encouraged them to aim 'higher' in terms of their future goals than they would otherwise have done. The project also highlights the importance of peer support as a form of independent advocacy.

The benefits of peer advocacy and support are backed up by research from the USA which looked at the sorts of learning support young disabled people might need as they go through transition to adulthood (Corrigan et al 2001). This study concluded that for some young people with physical impairments, group work alongside disabled peers can be very effective in supporting them through transition, particularly in terms of developing a positive self-identity and setting career and life goals.

## Impact on access to employment

The two pieces of research reported below, relating to impact on employment, show significant findings and are of good quality.

They push the boundaries, however, of 'what counts' as independent advocacy. Nonetheless, we feel that they suggest outcomes that may be achieved as a result of input that is very similar to that which might be provided by an independent advocate, and so are worthy of inclusion in this review.

The Community Living Research Project (2006) has produced a systematic review of tools, approaches and programmes designed specifically to support young disabled people at transition. The report originates from Canada, but the review took an international perspective. This report was identified through the grey literature search and did not specifically use the phrase 'independent advocacy'. However, many of the programmes and projects described appear to have worked with young disabled people in a way that is consistent with an independent advocacy approach. For the purposes of this section, two studies are highlighted which report an impact on access to employment as a result of some form of advocacy-type input.

Firstly, the Transition Services Integration Model (TSIM) sought to combine the services, supports and resources of the USA special education system, the rehabilitation system and the disability support system to maximise employment opportunities for young disabled people (Certo et al 2003, reviewed by the Community Living Research Project 2006). Young people with physical impairments got focused support on the transition from high school to employment from 'aides' (playing a similar role to advocates[9]) from adult services and met, in a group, to discuss options and strategies. Strategic work was also undertaken by the project team to improve policy, practice and employment options for young people. The TSIM was piloted in 14 school districts, over four years and, in 2003, had worked with 234 young disabled people. Results showed that 71 per cent of young people included in the TSIM were competitively employed three years post rogramme, and that on average, their wages exceeded the minimum wage, with an average of 14.4 hours worked per week. Although these results appear positive, given what is known more widely about the difficulties experienced by disabled people in accessing employment, the lack of a control group makes it difficult to judge whether the TSIM intervention actually led to an improvement in access for those involved.

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[9]  This role involved acting as a point of co-ordination, providing information, taking a neutral stance and supporting young people to consider their options and make decisions.

Another employment programme based in the USA, Project Corporate Support, supported young disabled people in their last year of high school (West et al 2001, reviewed by the Community Living Research Project 2006). Employment specialists (playing what appeared to be an advocacy role[10]) worked with students to create an Individualised Written Rehabilitation Plan which followed person-centred planning principles and focused on work and career planning. They also supported students to get training to work in their desired setting, which involved extensive liaison work with employers. The study reports that 43 of the young people worked with moved onto the employment setting of their choice, but the total number of those included in the programme is unclear.

We recognise that these studies do not provide direct evidence of the impact of independent advocacy in this context, but we feel it is useful to highlight their findings as indicative of the potential impact that could be achieved in terms of access to employment if independent advocates were to support young disabled people at transition in a similar way.

## 2.5    Advocacy input at transition – what helps?

We now draw out the evidence relating to the role of advocacy at transition and what factors appear to promote the process and outcome benefits listed above. In doing so, this section provides evidence relating to the nature of advocacy input that might be needed at transition.

[10] Ibid.

### 2.5.1  A relationship built on trust and developed over time

Hoggarth et al's (2004) primarily qualitative study explored the impact of the Connexions Service on young people (including young people with learning disabilities and young people with physical and sensory impairments). This extensive and in-depth study (which included 855 interviews with young people) examined the work carried out by Connexions PAs with young people and how this was viewed. This included both direct one-to-one transition support work with young people, and wider work such as brokerage or advocacy. The study concluded that despite, at that point, being a relatively new service, Connexions was already achieving a positive impact. The researchers suggested that the primary mechanism of impact was the development of a trusting relationship between PAs and young people. They also highlighted the importance of working with young people as early as possible to provide the time to build up trust.

The importance of building up a strong and trusting relationship between advocate and client may also be central to the question of how best to advocate for young disabled people who have no verbal communication. A qualitative, well-designed study by Knight and Oliver (2007), which looked at the experience of advocacy for 12 disabled children and young people (out of a total sample of 48 children and young people using advocacy), found that the quality of the relationship was key to providing advocacy for young people with no verbal communication. Being able to spend time with a young person and establish rapport over time may mean that many severely young disabled people are able to 'direct' the advocate to represent their views in ways that would be impossible to achieve with short-term, issue-based advocacy.

### 2.5.2 Credibility and 'clout' with other professionals

Grove and Giraud-Saunders (2003) also suggest that the success of the Connexions PA role depends on building trust with parents and professionals. Their research indicated that to be effective, PAs must have credibility that enables young disabled people, families and other professionals to view them as 'insiders', but does not completely identify them with the systems that maintain discipline or allocate resources. PAs must also have 'clout' in terms of a formal status with other agencies involved in the transition process.

### 2.5.3 What sort of advocacy is needed by young disabled people at transition?

Research into the effectiveness of Connexions PAs in working with young disabled people may provide some useful pointers for the elements that might be incorporated into the role of an independent advocate at transition.

Research in this area has shown that providing effective support and advocacy to young disabled people at transition can involve a vast range of skills, knowledge and experience. As Grove and Giraud-Saunders (2003, page 16) put it: 'these young people and their families need someone to metaphorically 'walk alongside' them during the period of transition, who can act as map maker, bridge builder, encouragement provider, truth teller and developer of the education, social and employment network they need.' They go on to suggest that people undertaking this sort of role at transition with young disabled people will need the following experience, knowledge and professional support:

- previous experience of working with young disabled people

- understanding of the education system as it applies to this group

- awareness of child protection issues and legislation

- training in basic counselling skills and group work – listening skills, feedback techniques, management of boundaries, facilitation and mediation

- professional supervision and peer support and learning.

The question is, would an independent advocate be able, or willing, to meet this challenge? Moreover, could this role really be played successfully by someone who is completely unconnected with service structures if a degree of professional influence is required to bring about change in the lives of young disabled people and their peers? There are also certain 'tools' central to transition planning that would need to be shared with and developed by an independent advocate, such as the young person's transition plan, and for young people with learning disabilities, their person-centred plan and health action plan. It is not clear how this might work in practice. Significant extra consultation and discussion might be needed to clarify the role of independent advocacy at transition and to understand how it would be integrated into existing support and service structures for young disabled people.

## 2.6 Evidence of costs of independent advocacy for young disabled people at transition

Our searches have revealed no published research evidence of costs (or cost-benefits) of advocacy at transition.

Work in progress at the Social Policy Research Unit (University of York) may provide some costs data towards the end of 2009. A project is underway which is looking at models of multi-agency services for transition to adult services for young disabled people and those with complex health needs. Part of this work involves assessing outcomes for parents and young people of provision of different models of transition services (including models which involve transition key workers, who may be taking on an advocacy role) and investigating sources of funding and costs of these different models of transition services.

## 2.7    Overview of gaps in the evidence

The systematic review has shown that the evidence base in this area is lacking in terms of quantity and quality of research specifically relating to independent advocacy at transition for young disabled people. We found just one report (Sounds Good Project 2006) that covered this topic and although useful in terms of highlighting some salient points, the findings were limited by a small sample (see 2.4.1). The gaps in the evidence are therefore rather basic at present:

- primary research is needed to explore the extent and nature of existing input from independent advocacy at transition

- primary qualitative and quantitative research is needed to explore and define process and outcome benefits of advocacy input at transition

- primary research is needed to quantify the costs of independent advocacy at transition and to assess the cost-benefits of this type of input.

# 03

## Independent advocacy for disabled parents whose children are subject to safeguarding procedures

# 03 Independent advocacy for disabled parents whose children are subject to safeguarding procedures

This chapter presents evidence relating to the need for, and benefits and costs of, independent advocacy for disabled parents whose children are subject to safeguarding procedures. A total of 27 items of research literature were critically reviewed (for further details see Annex 1).

● There is currently no reliable national data set relating to the number of disabled parents involved in child protection proceedings. Thus the extent of potential need for independent advocacy in this context is not wholly clear, although fragmentary findings from good quality research suggest the need is likely to be high.

● There is a limited amount of published work which describes the nature of advocacy services which disabled parents involved in child protection proceedings may be able to access. However, this is an area that requires some systematic mapping and research across all impairment groups.

● The reasons why disabled parents involved in child protection proceedings need advocacy include:

  ○ the over-representation of some groups of disabled parents in the child protection system

  ○ the need to educate and inform other professionals working with disabled parents

  ○ parents' need for support to understand and to speak up throughout the child protection process

  ○ the need to reduce institutional discrimination

  ○ evidence that independent advocacy is wanted by disabled parents.

- There is a paucity of evidence relating to process benefits of advocacy for disabled parents, particularly parents with mental health support needs and parents with physical/sensory impairments. The evidence that exists shows that process benefits of advocacy input for disabled parents include:

  ○ increased and better quality involvement of parents throughout the child protection process, including increased understanding of the process by parents

  ○ increased knowledge and understanding among other professionals of the needs of disabled parents

  ○ better communication and decreased antagonism between parents and professionals.

- The evidence base for outcome benefits is also limited in size and scope and to date has focused solely on the outcomes of advocacy for parents with learning disabilities. Findings relate to two key areas.

  ○ Positive impact on empowerment and personal development of parents involved in child protection proceedings – in terms of an increased understanding of the reasons for loss of custody of their child, where this was an outcome.

  ○ Impact on maintaining child custody – there is not, as yet, conclusive evidence of a causal link between providing the context and resources for a positive process and bringing about a positive outcome for the parents in terms of maintaining their child at home. However, research is lacking in terms of quantity and quality so current evidence is contradictory and incomplete.

- The evidence shows that there are certain factors which appear to promote the process and outcome benefits listed above:

  ○ a relationship built on trust and developed over time

  ○ credibility and 'clout' with other providers

  ○ a clearly defined role which includes a number of key components relating to specific skills, knowledge and experience, specifically including an understanding of both child and family services, and services supporting disabled adults.

- In terms of evidence relating to costs and cost-benefits, one study, using hypothetical scenario analysis, suggests that for parents with learning disabilities, the provision of advocacy and support to care for their child at home is cheaper than the costs of adoption.

- The evidence base in this area is lacking in terms of quantity, quality and scope. Further primary qualitative and quantitative research, with larger and broader samples, is needed to explore and define process and outcome benefits of advocacy input for disabled parents. Primary research is needed to quantify the costs of such independent advocacy and to assess the cost-benefits of this type of work.

## 3.1 What does independent advocacy look like for disabled parents whose children are subject to safeguarding procedures?

Safeguarding procedures are instigated when there is concern about a child's safety or well-being, and extend from first contact with child protection professionals through to any legal proceedings that may result. Any parent (disabled and non disabled) who is subject to public child care proceedings is entitled to non-means tested legal aid for their representation. If the parent lacks capacity, the Official Solicitor can also act as their guardian ad litem if there is no one else available to fulfil this role. There is a range of possible outcomes for families as a result of legal proceedings:

- the child may remain with the family

- the child may be placed in foster care

- the child may be adopted by another family

- the child may end up in the care of the local authority.

If child custody is lost, ongoing contact between disabled parents and their birth children may also be negotiated through the courts and may involve a range of contact from regular, face-to-face contact, to postal contact only (letters and cards). The nature of the

procedures involved when children's social care services act on concerns about children's welfare necessitates a particular need for independent advocacy, as section 3.3 will explain in more detail.

The role of advocates working with parents with learning disabilities had been investigated and discussed in some detail by Mencap (2006), Tarleton et al (2006) and Ward (in press). The advocates involved in Tarleton et al's (2006) study (summarised by Ward, in press) used a range of strategies to support parents whose children were subject to safeguarding procedures, including:

- ensuring everyone involved used accessible language

- making sure issues were clearly explained

- helping parents to speak or speaking on their behalf as required

- making sure parents had access to reports and time to understand their contents and put forward their own views on them

- keeping a diary of meetings, phone calls and conversations for the parents

- engaging solicitors where necessary and supporting parents to meet them

- reinforcing to parents important messages from the legal team

- visiting the court with parents before the hearing to help them familiarise themselves with it

- attending court during the hearing and explaining what was going on

- explaining the advocate's role to the court, and seeking any special measures that may be helpful to the parents in question: for example, a break in sessions or permission for parents to only enter court when their presence is explicitly required

- providing parents with emotional support.

# The story of Michelle and Becky

Michelle is a parent with learning disabilities. She has two children, both of whom are in foster care placements, and she is pregnant with her third child, who is already the subject of a child in need plan. Her advocate, Becky, works for the North West Parents Advocacy Project which has been set up to provide crisis advocacy and ongoing support for disabled parents involved in child protection proceedings.

### Michelle's story

Becky helps me. She comes to my looked after reviews…she helped when my social worker wouldn't help me about housing. She'll talk to me about things, about anything…She's upfront honest...if something is gonna hurt you she'll explain in another way, never had things explained like that before. She is a tower of strength, a godsend. If I am looking strange in meetings she'll say 'did you understand that?' or afterwards will go through the meeting again explaining. The other day I was so angry and she spoke to me and told me to take a big deep breath and calm down, not to do anything stupid. You feel safe with her there, and if I walk out she'll follow me. Once I've talked to her I feel a lot better.

### Becky's story

I started working with Michelle when she was going through the courts about her second child. It was a terrible time for her, having already had her first child put into foster care, and the same about to happen with her second. She didn't understand what she was doing wrong as a mum, and was really confused about why her children were taken away so we've done a lot of talking and thinking about this, which is obviously very painful for her… and I do believe that she now has a good understanding of what child neglect means and what she has to do to be a good-enough mum to her new baby. I meet her every week or so to talk about her situation and how she is feeling. Also the contact agreement is quite complicated so I do remind her about what this means for her quite often, so she can keep in touch with her kids. Now she

is pregnant again, there are child in need meetings [arranged by children's social services] and I spend time with her beforehand and support her to speak up, and keep calm in the meetings. We are working towards her keeping the baby, but this will mean considerable input from child and adult social work teams and right now I can't be completely sure that the support and coordination will be there.

Adapted from Mencap (2007)

## 3.2    Policy and guidance relating to independent advocacy for disabled parents

Parents whose children are subject to safeguarding procedures (disabled and non disabled) do not currently have a statutory right to involve an advocate on their behalf[11]. However, there is a strong presumption that local authorities should allow this as it is in the spirit of various guidance, legislation and case law, including Working Together to Safeguard Children (HM Government 2006), the Review of Child Care Proceedings (Department for Constitutional Affairs and Department for Education and Skills 2006), and the Human Rights Act 1998. The Family Rights Group (2008) has produced a useful fact sheet on advocacy for any family in local authority decision-making. It sets out families' legal position in relation to their 'moral right' to advocacy.

With regard to parents with learning disabilities, recent guidance documents make a clearer statement about the desirability of access to independent advocacy. The 'Good Practice Guidance on Working with Parents with a Learning Disability' aimed at professionals and others working in this area in England (Department of Health/ Department for Education and Skills 2007), identifies three different kinds of advocacy to which parents need access if their chances of parenting successfully are to be maximised:

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[11] As stated previously, any parent involved in public child care proceedings is entitled to non-means tested legal aid and if they lack capacity, can use the services of the Official Solicitor as guardian ad litem.

- self-advocacy – to help parents build confidence and self esteem

- advocacy and self-advocacy – to help parents access and engage with services

- independent advocacy – where children are the subject of a child protection plan and/or care proceedings are instituted.

'Valuing People Now', the three-year strategy for people with learning disabilities in England (Department of Health 2009) reiterates the need for services to support parents with learning disabilities and their children, pointing out that '…such parents are at disproportionate risk of losing their children into care' (paragraph 3.55). More specifically, the associated 'Valuing People Now: The Delivery Plan' contains a commitment to 'work to develop advocacy services which include support for parents with a learning disability' (paragraph 39). This reflects the recommendation of 'A Life like Any Other?' (Parliamentary Joint Committee on Human Rights 2008) on the human rights of adults with learning disabilities, that: '… parents with learning disabilities should have access to independent advocacy when subject to safeguarding procedures.' (page 65)

## 3.3 Evidence of the need for independent advocacy by disabled parents whose children are subject to safeguarding procedures

The material reviewed shows some published evidence of a stated need for independent advocacy by all disabled parents at risk of, or already involved in, child protection proceedings. The vast majority of this literature focuses on parents with learning disabilities, with a smaller number of outputs relating to parents with mental health support needs, and only scant mention of disabled parents with physical/sensory impairments in this context.

### 3.3.1  How many disabled parents are involved with the child protection system?

There is currently no reliable national data relating to the number of disabled parents involved in child protection proceedings. More general statistics relating to disabled parents per se are not precise, but may highlight the potential scale of the issue:

● the 2004 Labour Force Survey calculated that 12 per cent (1.7 million) of Britain's 14.1 million parents were disabled and 1.1 million households with dependent children had at least one disabled parent (Strickland and Olsen 2005)

● the 2005 National Survey of adults with learning disabilities in England found that 1 in 15 of the nearly 3,000 people interviewed had a child (Emerson et al 2005). There are an estimated 796,000 adults with learning disabilities over the age of 20 in England (Institute for Health Service Research 2004), which suggests there may be around 53,000 parents with learning disabilities in England alone

● the 2006 Social Care Institute for Excellence (SCIE) Knowledge Review on supporting disabled parents (Morris and Wates 2006) uses figures from the 2004 Labour Force Survey and Family and Child Study to estimate that there may be a total of about 450,000 parents with mental health support needs in Britain.

Of course, only a proportion of disabled parents are likely to be subject to safeguarding procedures regarding their children, and this proportion is likely to vary across impairment groups. Data relating to the involvement of parents with mental health support needs in the child protection system (Cleaver et al 1999) indicates that 'the prevalence of identified mental illness increases with the level of enquiry' (page 13). Cleaver et al's report for the Department of Health synthesised the findings from a number of research studies (although full details of these were not given in the report's bibliography). Taken together, these studies showed that:

- thirteen per cent of all child protection referrals recorded parental mental illness

- twenty five per cent of all child protection conferences record parental mental illness

- forty two per cent of all care proceedings involved parents with mental illness.

There are some studies which give limited data relating to disabled parents and custody loss, but currently this data lacks sufficient detail to fully describe and explain the current situation. Research in one English local authority area by Booth et al (2005) found that a sixth of all family court care proceedings concerned children with at least one parent with learning disabilities and, in about three quarters of these cases, children were removed from their family. This small-sample evidence is corroborated by evidence from a much larger sample of people with learning disabilities who responded to the English National Survey (Emerson et al 2005). Of the mothers with learning disabilities in the English National Survey, who were living on their own, or with a partner or husband, 60 per cent did not have their children under 18 living at home with them. It is unclear, however, whether these children had been removed into care placements, or whether they were living with the mother's partner or another family member. However, findings from research by Cleaver and Nicholson (2007), involving 64 cases where a child of a parent with learning disabilities had been referred to child protective services, suggest that 11 of these children (17 per cent) had been removed from their family.

There is some evidence to suggest that a very high proportion of parents with mental health support needs are not living with their children. A North American study of parents with mental health support needs found that three quarters did not have full custody of their children. However, the small sample (just 20 participants) limits the generalisability of this data (Sands et al 2004).

## 3.3.2 The nature of independent advocacy services for disabled parents

As part of the grey literature search strategy for this review, the research team made contact with networks of professionals and others interested in improving support to disabled parents. While these contacts were anecdotal and not systematic, they provided a general overview of the context in which independent advocacy services are operating for disabled parents in Britain currently. It appears that parents are accessing advocacy (not always 'independent') via the following routes:

- from groups or via one-to-one support from workers involved with parenting support programmes/projects, aimed at supporting 'at risk' families

- from contact with health or social services professionals (for example, health visitor, community nurse, adult social worker)

- from independent advocates connected with generic advocacy schemes

- from specialist advocates, and/or via parents' support groups, connected with advocacy schemes aimed at parents involved in child protection proceedings.

Moreover, it appears that the input provided in these situations is often 'crisis advocacy', where urgent advocacy support is needed by families who are already at risk of losing their children. This indicates a need for earlier intervention in supporting disabled parents.

Clearly, this is an area that requires some systematic mapping and research across all impairment groups. All of the published work accessed by the research team at the time of writing related to evaluations of specialist advocacy services for parents with learning disabilities. Some of this evidence (Mencap 2007, MacIntyre and Stewart 2008) indicates that many generic advocacy services are finding their case loads are over-represented by parents with learning disabilities, and that referrals to more specialist advocacy

services aimed specifically at parents with learning disabilities appear to be increasing. MacIntyre and Stewart's (2008) evaluation for Equal Say, a provider of independent advocacy for parents with learning disabilities in Glasgow, highlighted an increase in the number of referrals to the service involving child protection issues, demonstrating the growing need for this type of advocacy by this group of parents.

### 3.3.3 Why is advocacy needed by disabled parents whose children are subject to safeguarding procedures?

The nature of the procedures involved, when social services and the courts act on concerns about children's welfare, means that there is a risk of parents losing choice and control for many reasons. To counter this risk, there is a particular need for independent advocacy as the following sections show.

**Need for early intervention to prevent over-representation of some groups of disabled parents in the child protection system**

Some groups of disabled parents, namely parents with learning disabilities and BME parents with mental health needs, may be over-represented in the child protection system (Booth, 2000, Green et al 2008). However, the evidence also shows that this is likely to be due more to a lack of support with parenting, or a reluctance to ask for help from professionals, than to issues of abuse or neglect per se. There is no clear relationship between IQ and parenting, unless IQ is less than 60 (McGaw and Newman, 2005). Most concerns about children's welfare where parents have learning disabilities relate to inadequate levels of childcare, often as a result of lack of parental education and lack of support from health and social services (Cleaver and Nicholson, 2007).

A review by Booth (2000) presents evidence, mainly from Australia and North America, showing that parents with learning disabilities are disproportionately represented in child care proceedings and are less likely to have received support in their parenting, or to have received inadequate support, before care proceedings are initiated.

A research review by Greene et al (2008) found that BME parents with mental health support needs are often reluctant to seek help from services and may delay contact until a crisis point arises. Consequently, children of BME parents with mental health support needs are over-represented in the child care system. Lindley and Richards' (2002) qualitative study sought the views of (disabled and non disabled) parents drawn into the child protection system and their involvement with advocates. They state that the profile of parents who came forward to take part in the research was distinctive in that the majority were white and very articulate. The authors believe that this sample was not necessarily representative of all those likely to be drawn into child protection services and that it was likely there was under-representation of BME families and advocates, again indicating their reluctance to speak about their situation.

These studies indicate that careful work is needed to engage with families who may be understandably fearful and unwilling to make contact with services, including advocacy services. Service providers will need to find creative ways to ensure that early intervention and early advocacy input are available, accessible and acceptable to these groups of families, who are potentially at higher risk of child custody loss.

## Need to educate and inform other professionals working with disabled parents

There is some compelling evidence from two good quality, qualitative and well researched studies that child welfare professionals, such as children's social workers, lack experience of working with parents with learning disabilities, lack understanding of their needs, and may hold stereotypical attitudes about their parenting ability (Booth and Booth 2005, Tarleton et al 2006).

Similarly, various studies have highlighted the inadequate or negligible involvement of mental health professionals in the child protection system when parents with mental health support needs come to court (Sheenan and Levine 2005, Sheenan 2004). In such cases the court does not have all the necessary information about the needs of, and likely outcomes for, such parents and their children. For these reasons, Fish (2005) explains why it is important

for solicitors representing parents with mental health support needs to have a basic knowledge of the terminology used by psychiatrists in the diagnosis and treatment of mental health issues. Where such knowledge is lacking, there is an important role to be played by independent advocacy in educating other professionals and raising awareness of the needs of disabled parents involved in child protection proceedings.

## Need for support to speak up and to understand the child protection process

Research focusing on parents with mental health issues has also highlighted a need for advocacy if involvement in child protection arises. Sands et al's (2004) study of 20 mothers with 'severe mental illness' in the USA found that three quarters did not have full custody of their children. Most of these mothers were genuinely confused and bewildered about the custody loss, which demonstrates a clear need for advocacy and a sense of the scale of the issue. Baum and Burns' (2007) study of the experience of custody loss of eight mothers with learning disabilities also found that many of the women appeared not to understand the process of their children's removal and said they felt bullied or victimised by it.

Other evidence shows that parents with learning disabilities feel that, among other things, children and families services do not listen to them, expect them to fail, treat them differently from other parents with support needs, and use their need for support against them as evidence of poor parenting (Tarleton et al 2006). Once in court, parents with learning disabilities have reported feeling embarrassed, confused, excluded and humiliated by the legal system (Booth and Booth 2005). They also have difficulty in instructing a solicitor and are often not advised to do so by children's services (McConnell and Llewellyn 2000).

## Need for support to fight against institutional discrimination

Several key pieces of primary research have specified the particular ways in which parents with learning disabilities are discriminated against and disadvantaged by the child protection and legal system, amounting to a form of 'institutional abuse' (Booth and Booth 1998, Booth 2000, Tarleton 2007, Tarleton et al 2006). A review by Booth (2000) presents evidence, from Australia and North America, showing that parents with learning disabilities are:

- at risk of having their parental responsibility terminated on the basis of evidence that would not hold up against non-disabled parents

- likely to have their competence as parents judged against stricter criteria or harsher standards than other parents

- more likely to have their children removed and their parental rights terminated

- disadvantaged in the child protection and court process by rules of evidence and procedure, their own limitations and inadequacies in services.

These findings have been confirmed by more recent primary research in the UK by Tarleton et al (2006) and in England by Tarleton (2007).

## Independent advocacy is wanted by disabled parents

There is less evidence relating to the need for child protection focused independent advocacy for parents with physical/sensory impairments. However, Wates' (2002a) review gives two examples where she believes the provision of independent advocacy was crucial in parents with physical impairments maintaining custody of their children. Similarly, research by Olsen and Tyers (2004) found that support from advocates was considered by disabled parents to be an important way to reduce barriers to fair treatment and helped parents to access a fair hearing in court. Both of these pieces of work, and research by Wates (2002b), show that consultation with disabled parents has revealed a desire for advocacy services to support them in their parenting role.

## 3.4 Evidence of process and outcome benefits relating to independent advocacy for disabled parents

There is a small, but growing, research base assessing the impact of independent advocacy for disabled parents. Studies have predominantly focused on parents with learning disabilities (LeMieux 2001, Booth and Booth 1998, 2001). They include three, recent, small-scale evaluations of independent advocacy services for parents with learning disabilities (Mencap 2006, MacIntyre and Stewart 2008, Greenwich Citizen Advocacy Project 2008). Only one study was located which looked at outcomes of advocacy for people with mental health support needs (Hinden et al 2005), while another focused more generally on families involved in child protection proceedings, including disabled parents (Lindley and Richards 2002).

### 3.4.1 Process benefits of independent advocacy for disabled parents

**Increased and better quality involvement of parents throughout the child protection process**

Several studies have presented evidence indicating that the provision of independent advocacy had led to disabled parents being heard and participating more actively in the child protection process when their child is subject to safeguarding procedures. This includes advocacy input, both to enable parents to understand what is happening and to speak up as active participants in the process in which they are involved.

Mencap (2006) carried out a review of two specialist parents' advocacy services supporting parents with learning disabilities during child protection proceedings in England. In both services parents could access one to one support to prepare for, attend, understand and contribute to child protection meetings. The advocates helped parents understand often lengthy and complex reports about their parenting, and to articulate their views. They also supported them when they met with their solicitors. In one of the services, parents were also able to access a peer-support group of other parents.

This research highlighted various benefits relating to the increased
and better involvement of parents.

- Parents reported that they were treated with greater respect.

- Parents said they got more information about the child protection
  process in general and about the perceived issues with their
  parenting in particular.

- For parents, having an advocate meant their voices were heard,
  with the result that a number of parents reported feeling more
  confident about speaking up for themselves when their advocate
  was alongside them.

- Parents were grateful for the emotional support their advocates
  gave them outside meetings and court appearances.

- Being part of a peer support group boosted parents' morale.

A similar study conducted in Scotland by MacIntyre and Stewart
(2008), evaluated the work of Equal Say, a provider of independent
advocacy to parents with learning disabilities. All the parents who
participated in this study were able to identify a range of process
benefits from their involvement in the advocacy service. These
included feelings of empowerment, being heard, understanding child
protection processes and improved access to support in relation
to daily living. The authors hypothesise that it is likely that without
the support of an advocate, the parents who took part in the study
would have continued to find themselves being excluded from the
processes and procedures within the child protection system that
concerned them. The report recommended an increase in focused
professional advocacy available on a long-term basis for parents
with a learning disability.

## Increased knowledge and understanding of the needs of disabled parents

Mencap's (2006) research found that advocates appeared to have a
significant impact on the practice of local professionals. Advocates
acted as 'overseers' during child protection meetings, checking that
procedures were followed appropriately. This appeared to have a
positive impact on the practice of child protection social workers,

particularly in terms of their communication and interaction with parents. The advocacy services were also credited with increasing the awareness of other local professionals about the needs of parents with learning disabilities: for example, by raising their consciousness of the need to follow guidelines on the involvement of parents in child protection proceedings.

## Better communication between parents and professionals

Several studies have highlighted the role of advocates in supporting and developing better communication between parents and professionals and this action, in itself, appears to have a significant impact on other areas of advocacy process and outcome.

Lindley and Richards (2002) examined the role of both professional advocates and solicitor advocates in supporting (disabled and non disabled) parents involved in the child protection process. This qualitative research found that advocacy input had a positive impact on the partnership process between parents and child protection professionals, provided it was specialist, independent, and non-confrontational, and was instigated at an early stage in the child protection process.

Hinden et al (2005) evaluated targeted input to parents with mental health issues in the USA who were in contact with child welfare services and potentially at risk of losing custody of their children. The intervention, the 'Invisible Children's Project', included four essential service components, one of which was liaison and advocacy services between parents and child welfare providers. This involved translating providers' concerns and intentions to parents, and in turn parents' perspectives to providers. This was reported to be directly linked to decreased antagonism between parents and child welfare workers, enhanced communication and more effective parent-provider collaboration towards mutually desired goals.

Finally, Tarleton (2007) found that many of the parents involved with the advocacy services in her study were aware that they were at risk of becoming upset and angry in a way that could work against them. Consequently, they were happy to let their advocate speak up and ask questions on their behalf, often with the positive result that they were more appropriately involved in the child protection process.

## 3.4.2 Outcome benefits of independent advocacy for disabled parents

### Positive impact on empowerment and personal development of parents

Several studies have reported significant positive impact, as a result of advocacy input, on the personal development and empowerment of disabled parents involved in child protection proceedings (Booth and Booth 1998, 2001, LeMieux 2001). This is particularly in terms of an increased understanding of the reasons for loss of custody of their child, where this was an outcome.

LeMieux's (2001) case study describes in detail the process of developing a relationship with Molly, a mother with learning disabilities in the USA, to advocate for her in her dealings with child welfare professionals and the court. The author concludes that empowerment and advocacy activities, while inherently valuable, are time-consuming and can conflict with the expectations, time frames and expected outcomes of child protection services. Relationship building was a lengthy process and the priority in the early part of the relationship was establishing trust and collaboration. In her evaluation of the practice she undertook with Molly, the author suggests that while the outcomes of her work might be considered unsuccessful by some (since the child was placed with a foster family and subsequently adopted), on the other hand, Molly was enabled to explore, understand, and eventually admit her abilities and limitations in caring for her son. This, felt the author, constituted a highly successful outcome in terms of Molly's self-awareness and empowerment.

### Impact on maintaining custody of children

The evidence on the impact of advocacy on maintaining child custody is contradictory and incomplete. Evidence from Booth and Booth (1998, 2001) reinforces LeMieux's case study findings cited above. Their action research provided advocates to work with 25 families, where one or more parents had learning disabilities. It suggested that provision of independent advocacy might improve the process of supporting parents with learning disabilities, but outcomes (including potential loss of custody of children) were not necessarily affected, although they might be better understood.

The advocates supported parents in a number of general ways, not just during child protection proceedings. Although the roles played by the advocates were varied in nature and extensive in time and commitment, the overall impact on parents' lives was not conclusive. The authors concluded that:

- parents felt better for having an advocate, but the advocates could do little to change their situation

- without adequate support from services, advocacy alone was unable to relieve the environmental pressures that undermined parents' abilities to cope

- advocates, like parents, were worn down by the system. This could lead to overwork and stress.

Greenwich Citizen Advocacy Project (2008) evaluated the outcomes of a project offering advocacy to parents with a learning disability in the London Borough of Greenwich, the majority of whom were either going through court proceedings or child protection procedures. Services offered involved providing one to one advocacy, work at a strategic level, and awareness raising with professionals about the needs of parents with learning disabilities. A 'pre-intervention' and 'post-intervention' survey of professionals indicated that over the period of time the project had been operating, the number of parents involved in the project who had their children living at home had increased from 35 per cent (2002-05) to 63 per cent in 2007. The number of parents involved in the project where lon-term plans included either the child/ren remaining with birth parents or birth parents maintaining parental responsibility and regular contact with children had increased from 50-75 per cent over the same time span. These are interesting and potentially significant findings, although the generalisability of the research is limited by the small sample size overall: the sample on which the percentages are based for the period 2002-05 was 23 parents, the sample for 2007 was 44 parents.

## Is there a link between input from independent advocacy and maintaining child custody?

Overall, the evidence suggests that the benefits of independent advocacy for parents in this situation relate more to process than to outcomes. Indeed, a focus on process benefits, such as better

involvement in the court process, is all the more important where the outcome for a parent may still involve losing custody of a child.

At present, there is not conclusive evidence of a causal link between providing the context and resources for a positive process (in terms of support throughout child protection and legal proceedings) and bringing about a positive outcome for the parents in terms of maintaining their child at home. However, this may be due to lack of quality research in this area as the evidence available to date has been based on small samples and a very low number of available, reported studies.

This review found no research which considered the longer term question of whether provision of advocacy at an earlier stage (ie pre-conception or during pregnancy) would reduce the number of children of disabled parents subsequently being identified by children's services as being 'at risk'.

## 3.5 Advocacy input for disabled parents – what helps?

It is helpful to draw out the evidence relating to the role of advocacy for disabled parents and to examine what factors appear to promote the process and outcome benefits outlined above. Evidence from Mencap's (2007) study suggested that successful advocacy for supporting parents with learning disabilities during child protection proceedings should:

- be independent of services

- have a person-centred, open style

- be honest with families about what they might expect out of the process

- have an understanding of both child and family services and services supporting adults with learning disabilities

- be able to explain the role clearly.

These findings appear to relate to a need for independence, professional 'clout', specialist knowledge and credibility of advocates, as also found in the evidence review relating to transition.

Several other studies (Booth and Booth 1998, 2001, LeMieux 2001) stress the importance of also developing a trusted relationship, over time, as the basis for successful advocacy. This echoes the findings presented on transition, and is something that may need to be borne in mind when developing advocacy services for these groups of disabled people.

## 3.6 Evidence of costs of independent advocacy for disabled parents

Hurstfield, Parashar and Schofield et al (2007) carried out research on the costs and benefits of independent living for the Office for Disability Issues (ODI). This included estimating the costs of several hypothetical case studies contrasting the cost of conventional support with the cost of an 'independent living' alternative. One case study looked at two alternative scenarios when a woman with learning disabilities becomes pregnant:

1. the conventional support scenario – the removal of the baby into care, followed by adoption

2. the independent living scenario – support is provided to enable the parents to keep the child.

Detailed costs data for the case study was put together on the basis of a brief literature review, followed by discussion with a series of stakeholders in Stockport, England, including parents with learning disabilities, an advocate, a solicitor and local authority workers and managers.

The scenario where the baby was removed into care assumed that a short-term foster family would be quickly identified, a straightforward court case would follow that did not involve the High Court, with the outcome of permanent adoption. The total cost of this scenario was estimated to be £113,582.

The independent living scenario involved advocacy support pre-birth, and social work and advocacy input during an initial period of short-term fostering. It also included a residential assessment and at-home support over several years to enable the parents to keep their child. The total cost of this scenario was estimated at £106,614.

This study did not set out to look at the costs and benefits of providing advocacy input to disabled parents whose children are the subject of safeguarding procedures. However, in contrasting the perceived costs of a scenario which involved advocacy support, with one that did not, it found that advocacy and support for parents to care for their child at home is cheaper than the costs of adoption.

## 3.7   Overview of gaps in the evidence

There is some fragmentary data from good quality research relating to the number of disabled parents involved in the child protection system and the extent of child custody loss experienced by parents with learning disabilities and parents with mental health support needs. But this data lacks sufficient detail to fully describe and explain the current situation.

The systematic and grey literature review has shown that there is some evidence relating to reasons why independent advocacy might be important for such parents. However, the vast majority of this literature focuses on parents with learning disabilities, with a smaller number of outputs relating to parents with mental health support needs, and only scant mention of disabled parents with physical/ sensory impairments in this context. More thorough research is needed to explore the experiences of all disabled parents in this context and reasons why advocacy is important.

It is unclear how many generic or specialist advocacy services are currently offering a service to disabled parents in this situation, and whether this group comprises a small or large part of their overall caseload. The overall extent, and nature, of current input from independent advocates to support disabled parents through child protection proceedings is not known. Although there is some evidence relating to the nature of advocacy services aimed at parents with learning disabilities, more systematic service mapping is needed to identify and describe services aimed at other groups of disabled parents.

A handful of publications have focused on evaluating the process and outcomes of independent advocacy for parents whose children might be subject to safeguarding procedures. Overall, these studies are characterised by a qualitative (often case study) approach, with small/limited samples, and single service settings.

There is not, as yet, conclusive evidence of a causal link between providing the context and resources for a positive process and bringing about a positive outcome for the parents in terms of maintaining their child at home. However, research is lacking in terms of quantity and quality, so current evidence is contradictory and incomplete. Moreover, this review found no research which considered the longer term question of whether provision of advocacy at an earlier stage (ie pre-conception or during pregnancy) would reduce the number of children of disabled parents subsequently being identified by children's services as being 'at risk'. The link, if one exists, between positive process (ie: provision of good quality independent advocacy) and positive outcomes (for example, reduction in the identification of children 'at risk', maintaining child custody) awaits further careful research.

Very little is known about the costs of independent advocacy services for disabled parents in this situation. We found just one study that estimated the costs of providing advocacy input to parents with learning disabilities and contrasted this with the costs of adoption. However, its focus was parents with learning disabilities and the scenarios associated with other groups of parents are likely to involve different sets of costs. Moreover, this study only looked at the costs and did not evaluate the benefits of each scenario for those involved. Evaluating the cost effectiveness of such services may prove to be more complex, given the likely difficulty of identifying outcomes that both professionals and parents agree constitute 'success'.

# 04

Independent advocacy for disabled people when entry to residential care is a possibility
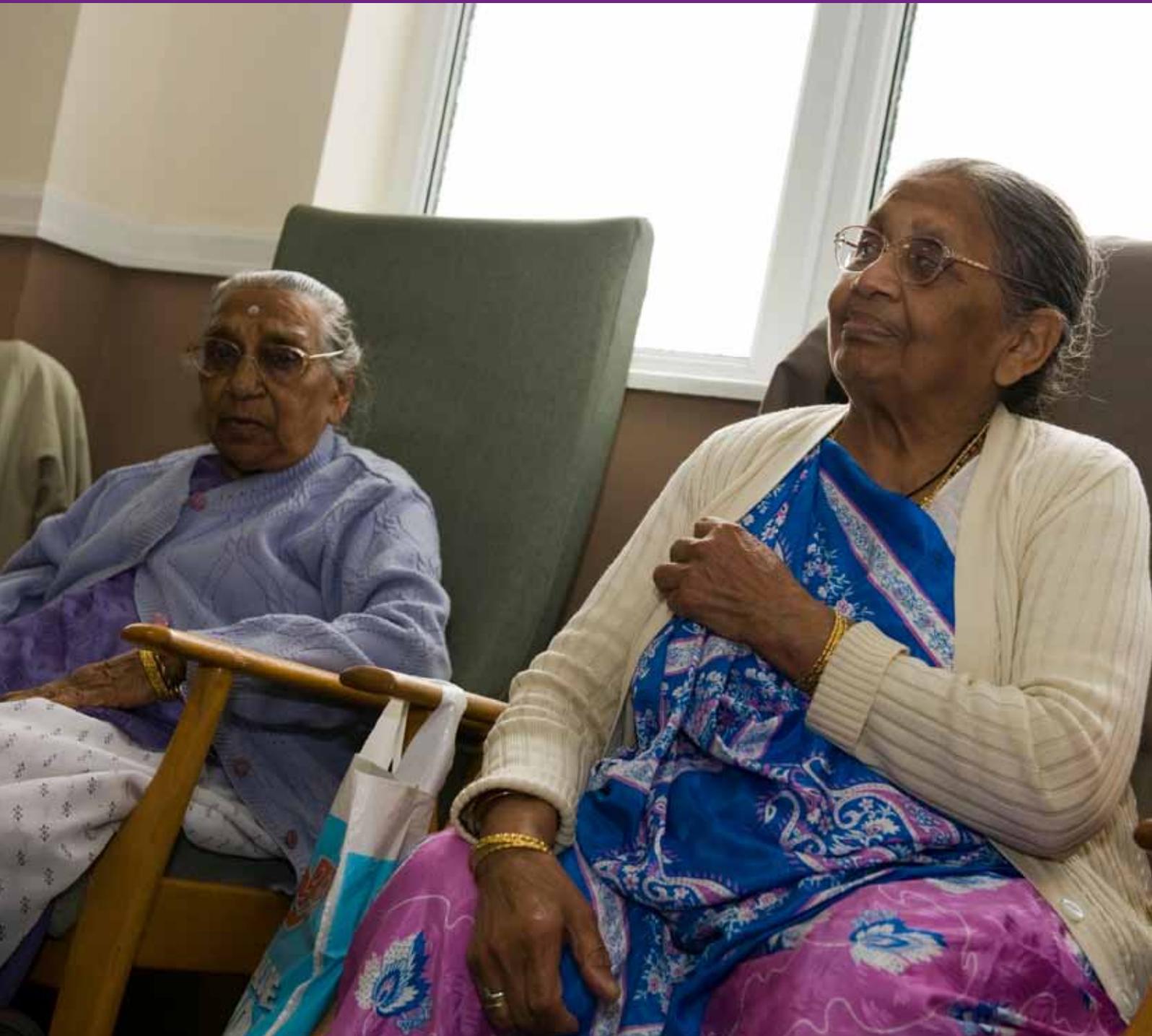
# 04 Independent advocacy for disabled people when entry to residential care is a possibility

This chapter presents evidence relating to the need, benefits and costs of independent advocacy for disabled people when entry to residential care is a possibility. The systematic literature search did not identify any research specifically relating to independent advocacy for disabled people when entry to residential care is a possibility. In addition to the systematic search of formal literature, we also searched for grey material, held in reports or unpublished form. This included searching specialist databases, such as the AgeInfo database and searching relevant websites, such as The Older People's Advocacy Alliance (OPAAL). Not all of this research met the criteria for inclusion in the critical appraisal, but it was all read for background and context, and any relevant issues were noted along with any further references to retrieve.

A total of 18 items of research literature were critically reviewed (for further details see Annex 1).

- There is a paucity of research relating to independent advocacy for disabled people when entry to residential care is a possibility, even though this is a situation where people are at risk of losing choice and control. Both policy and older peoples' organisations have called for more, and improved, advocacy services for older people.

- The proportion of referrals to generic advocacy services relating to a change of accommodation suggests a need for advocacy services to provide support in this area. However, the evidence base is limited due to a lack of research exploring the number of people in this situation and the current levels of independent advocacy available for them.

- It is likely that a large proportion of disabled people, for whom entry to residential care is a possibility, will be older people. Research with older people has shown a low level of awareness of advocacy services and a lack of understanding of the concept of independent advocacy.

- There were no studies that specifically researched the benefits of independent advocacy for disabled people when entry to residential care is a possibility. However, there was a small body of work exploring the benefits of advocacy services for older people, which are often used by disabled people when entry to residential care is a possibility. This identified some process benefits of advocacy services for individuals, such as increased confidence and improved emotional well-being. Benefits to services, carers and the wider community have also been identified, such as a reduction in the burden of caring and cost savings to statutory services.

- There was only one study reviewed which specifically explored if the independent advocacy had met service users' expectations (Murphy 2001). This showed that most of the respondents felt their expectation had been met, but the advocacy was not solely provided for disabled people when entry to residential care was a possibility. There is more research of generic advocacy services exploring if expectations have been met and some of this identifies other outcome benefits including physical adaptations to a home to increase independence.

- This review has found no research evidence of costs or cost-benefits in relation to advocacy services for disabled people when entry to residential care is a possibility. There is only very basic data exploring the costs of a general advocacy service for older people.

## 4.1 What does independent advocacy look like for disabled people when entry to residential care is a possibility?

Disabled people who may enter residential care are not a homogenous group. Those who may need independent advocacy in this situation include:

- disabled people whose care needs cannot be met in their current accommodation (who could be any age, but the largest group is likely to be aged over 80)

- disabled people who are discharged from hospital (who could be any age, but the largest group is likely to be aged over 80)

- younger disabled people with 'profound and multiple learning disabilities'

- younger disabled people with significant mental health problems and/or autistic spectrum disorders, attention deficit hyperactivity disorder (ADHD) etc.

### The story of Sally and Kate

Sally first came into contact with mental health services when she was 17. At this point she lost contact with all her family and friends. When she was discharged from hospital she had no money and nowhere to go. She was homeless. For nine years she battled her problems, got herself onto her feet, into a flat, and got her life back. But things started to slip away again and she had to go back into the hospital. This was an extremely daunting thing to happen to someone who had had such a bad experience the last time she was in hospital. Luckily, this time, Sally met Kate. Kate is a professional advocate based in Stobhill hospital. She works with people with mental health problems on specific issues that affect their lives. She attended review meetings with Sally, making the

process more bearable and understandable...For three years, on and off, Kate and Sally have been working together on specific problems that Sally has come up against...Until Sally met Kate she felt that she was always facing things alone. Having Kate there helped Sally to stand up for herself and empowered her to self-advocate…

…For one particular review meeting, Sally's social worker wanted all of Sally's health professionals to be present, which was around 10 people, all knowing about Sally and talking about her. Sally told the social worker that she would rather have lots of smaller meetings. Sally felt this was an overwhelming situation to be put in and she felt that she wouldn't be able to act naturally and give an accurate impression of her recovery. Sally called Kate and asked for help, a meeting with the social worker was arranged and together they convinced the social worker that this would not be beneficial for Sally's case and eventually the social worker agreed…

Sally feels this is a very typical example of how having an advocate present has helped change people's minds and decisions that are made about her without her input…

…A further upheaval came to Sally's life when she learnt, on the day of her being discharged from hospital, that the building she had been living in for nine years was being condemned and that she had to move. Various things were not made clear, like: how? when? where?...for this, Kate set up meetings with the housing officer, took notes for Sally to refer back to, made sure that all Sally's points and concerns were addressed and acted as a witness to what was said and agreed.

Adapted from a case study presented in Scottish Independent Advocacy Alliance (2008).

## 4.2 Policy and guidance supporting the concept of independent advocacy for disabled people when entry to residential care is a possibility

The Independent Living Strategy (ODI 2008) emphasised the need to improve access to better information, advocacy and support for disabled people to facilitate their choice and control over any support needed to go about their daily lives.

Similarly, the English White Paper 'Valuing People' (DH 2001) emphasised the need for people with learning disabilities to have as much choice and control as possible over all aspects of their lives, including their housing. 'Valuing People Now' (DH 2009) reiterated this message while noting that the number of advocacy organisations has increased since 2001, although it did not clarify what proportion of these were independent advocacy organisations, as distinct from self-advocacy groups.

Other policy documents have noted the need for access to independent advocacy schemes for older people (DH 2001, 2003, Home Office and DH 2000, Welsh Assembly Government 2004).

## 4.3 Evidence of the need for independent advocacy for disabled people when entry into residential care is a possibility

Our search did not identify any studies that specifically researched the need for advocacy for disabled people when entry to residential care is a possibility. This is supported by a recent review (Manthorpe and Martineau 2009) which concluded 'there is a lack of research in the area of advocacy and entry into care homes' (page 7). We have not been able to identify any advocacy services that explicitly target the provision of advocacy in this situation and this makes it difficult to research. This does not mean there is not a need for advocacy

when residential care may be a possibility for disabled people and our search did identify some research which adds to the evidence base for this need, even if it does not meet all the inclusion criteria for the study.

Since a large proportion of people, when entry to residential care is a possibility, will be disabled older people, we have included research that focuses on general advocacy services for older people. This literature was identified through our expert advisors and key advocacy organisations. Findings from such research are relevant, as it is this type of service that could provide independent advocacy in cases relating to disabled older people's housing and other needs.

## 4.3.1 Levels of need for independent advocacy for disabled people when entry to residential care is a possibility

We were unable to find any research that specifically explored the need for independent advocacy for disabled people when entry into residential care is a possibility. However, a large proportion of disabled people for whom entry to residential care is likely to be older people and there is a body of research exploring advocacy services for older people. This work raises some issues that are relevant here. For example, there is consensus from experts working in this area and from policy and strategy documents that there is an unmet need for independent advocacy when older disabled people could enter residential care. However, the evidence for this consensus is unclear as this search retrieved no studies which directly explored the need for independent advocacy in this situation.

### Existing advocacy services

Research exploring the existing provision of advocacy services for older people suggests that this is currently insufficient. The Older People's Advocacy Alliance (OPAAL) identified the lack of information about existing independent advocacy schemes as a major barrier to the use, and development, of advocacy services and commissioned work by Robinson around this. Robinson (2005)

attempted to identify all advocacy schemes for older people across England and this mapping exercise identified 80 such schemes. She argued that this represents 'vast gaps' (page 10) in the provision of adequate advocacy as these services clearly could not address the existing needs of older people (though the mapping exercise may not have identified all existing schemes). She noted that some of the schemes had kept records of unmet needs and enquiries which they had been unable to pursue due to service limitations, reflecting their inability to meet the current level of need for their service. Therefore, she contended that if the Government recommendations for provision of advocacy services are to be implemented, there needs to be improved resourcing to enable sufficient access for older people.

Subsequently, Kitchen (2006) identified 136 services providing some form of advocacy services to older people. Coverage appears unevenly distributed across Strategic Health Authorities and he argued it 'is clearly very far from comprehensive in any of the regions' (Kitchen 2006, page 4). For example, he identified 15 services in the South East and noted that this region has 1.5 million people over State Pension age. He also found that, on average, each service was working with an average of 41 people. Extrapolation of this data suggests that the advocacy services in the South East region in 2006 were able to offer service provision to less than 0.05 per cent of older people in the area.

Despite the policy recommendations for independent advocacy and the arguments for the need for such services when changes of accommodation are being discussed, the Social Care Institute for Excellence found that users of adult placement schemes for people with learning disabilities rarely had independent advocates. Advocacy services were limited in all four schemes they reviewed, with only one service user being actively supported by an advocate (SCIE 2005).

## Relevant referrals to advocacy services

The proportion of referrals to advocacy services that are related to accommodation needs reflects the need for advocacy for disabled people when entry to residential care is a possibility.

Our review identified evidence that specifically highlights the demand for independent advocacy in relation to housing. For example, Bright (2008) evaluated a pilot advocacy service providing advocacy for vulnerable people over the age of 18 with complex health, social care and accommodation support needs due to physical and/or sensory disability. More than half of the cases that were referred to this service related to housing needs. The exact nature of these referrals was varied and included the need to find alternative accommodation that was more suitable due to changing circumstances. The report concluded that housing needs had a disproportionately large impact on the service. Bright found that housing issues caused a lot of anxiety for individuals and identified a need for independent, non-professional advisors who understand the problems and issues involved and were in a position to give advice and to explore solutions. It was suggested that this role could be a 'housing advocate' or 'barefoot adviser'.

Murphy (2001) evaluated an advocacy and dementia service and found that of the 39 referrals examined in detail in the research, 24 of these were related to accommodation issues. This highlights the need for advocacy in relation to accommodation changes.

Further evidence comes from the referral patterns to the Independent Mental Capacity Advocate (IMCA) service. The aim of this service is

> to help vulnerable people who lack capacity who are facing important decisions made by the NHS and local authorities about serious medical treatment and changes of residence - for example, moving to a hospital or care home.[12]

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[12] Background to the IMCA service – Department of Health website www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/MentalCapacity/ IMCA/DH_4134876

The research on the pilot IMCA project (Redley et al 2006) and the DH (2008) analysis of the first year of the service have shown that the majority of representations made were for decisions on accommodation moves. From April 2007-March 2008 there were 3,047 such representations made out of a total of 5,175 to the IMCA service generally (DH 2008). The largest proportion of these decisions involved people who were in hospital at the time (1,165 cases), followed by 859 people looking to move from a care home and 679 people who were at risk of moving from their own homes. The data showed that most people moving from their own home or from hospital were moved to residential care (69.5 per cent and 65.6 per cent respectively). Such statistics arguably demonstrate the need for advocacy when changes in accommodation are being proposed. Luke et al (2008) provided further support for the need for independent advocacy in these circumstances. They found that in the cases referred to the IMCA service, even where there was a relative/friend available, over half did not want/could not be involved in the decision making process. There was also a significant number of cases where an IMCA was involved because of a perceived conflict of interest. This finding confirms the importance of advocacy services being independent.

The lack of evidence relating to unmet need is likely to be due to the fact that there are no statistics relating to the number of disabled people for whom entry to residential care is a possibility, and that there do not appear to be any specialist advocacy services for this group. This does not mean, however, that there is no need for independent advocacy – simply that need is currently difficult, if not impossible to measure, without the availability of this basic data.

### 4.3.2 Why is advocacy needed when entry to residential care is a possibility for disabled people?

## Older disabled people

The arguments for the need for more, and improved, general advocacy services for older people seem to be based on policy, personal experience and general demographic information rather than hard evidence that has specifically explored this need. However, there is widespread agreement among the experts working in the field of independent advocacy and older people that there is a demonstrated need for more advocacy services for older people (for example, Dunning 2005, Quinn et al 2003, Margiotta et al 2003). Such research cites existing policy (for example, DH 2001, 2003, Home Office and DH 2003) as evidence for this need. These policy documents do not cite any research evidence to support their recommendation for the need for independent advocacy services for older people. This is not to say that such recommendations are misguided, merely that they are based on expert knowledge of the problems faced by older people and on wider evidence.

## Generational differences

There may be a particular need for independent advocacy services for older disabled people as they may have a tendency to accept their current situation, with generational differences resulting in older disabled people being less likely to complain than younger disabled people (Robinson 2005). According to Kane and Kane (2001) they are less likely to use legislation to protect their rights than younger people are, with the result that improvements in their rights are dependent upon better advocacy.

## Complaints about residential care

Independent advocacy may be necessary to address any complaints individuals have about their current or future accommodation.

A consultation exercise with users of long-term care, their family carers and advocates reported that generally people were satisfied with their long-term care (Brody et al 1997). Problems that were reported, however, included couples being unable to stay together in a residential home and individuals being relocated out of their community. Both these situations highlight a role where independent advocacy could potentially be useful.

## Groups of disabled people at risk of exclusion

There are specific groups of disabled people who may have additional needs in accessing advocacy services.

Demographic changes mean increasingly larger numbers of older people in the future. Taken together with the insufficient coverage of advocacy services for older people, this results in a 'post code lottery' of support rather than equitable access to appropriate services (Kitchen 2006). Kitchen's study also found a greater need for specialist work. For example there is very little provision in place to address the needs of different ethnic communities.

Other groups requiring specialist services include adults with dementia, as there are specific challenges involved when trying to advocate for people who struggle to express their choices and preferences. Jones (1998) argued that the voice of older people with mental health needs is heard less than that of younger people and that this reflects the need for independent advocacy, especially for those with dementia. However, the evidence base for dementia advocacy is not well developed, despite existing services having recognised the importance of monitoring and self-evaluation (Cantley et al 2003).

## Addressing the needs and wishes of residents

Existing evidence shows that the wishes of disabled people are not always considered when a change of accommodation is being proposed. There is a role for independent advocacy in ensuring their voices are heard.

A qualitative study in Northern Ireland sought the views of people with learning disabilities and their relatives following resettlement from a long-stay hospital (McConkey et al 2003). Following the move, 85 per cent of those interviewed were happy to have left the hospital, even though not all of them had requested the move originally. Although some of the relatives had initially been unhappy about the resettlement, after the move they all felt the new residence was at least as good as the hospital and most rated it as much better. The resettlement scheme was thought to have a number of weaknesses, for example, only one-third of the relatives reported that their family member had been offered an alternative to the present placement. Another shortcoming was the failure to enable people to move on from their community placement. Despite a number of individuals being identified as suitable for more independent living arrangements, all but one were still living in residential or nursing homes over a year after they had left the hospital. It was these findings that led the authors to conclude it is crucial that residents have access to independent advocacy services to ensure their needs are addressed when resettlement is an issue. However, it could also be argued from the data that the majority of those who were moved ended up happy with their new placement despite a lack of advocacy.

A body of work has identified the ongoing problem of people with learning disabilities being inappropriately placed in residential homes for the elderly (Thompson and Wright 2001, Bigby 1998). Informal advocates have highlighted the tendency of providers to move disabled people as they age, rather than to assist them to remain at home and live as independently as possible (Bigby 1998, Kane et al 2007). This suggests a role for independent advocates in challenging such moves, if they conflict with the wishes of the individual, and helping them explore viable alternatives.

## 4.4 Evidence of benefits/outcomes of independent advocacy for disabled people when entry to residential care is a possibility

Despite thoroughly searching academic databases and the grey literature via websites, and requests for information through relevant fora and contact with specialists working in the field, no studies were located that explored the benefits of independent advocacy when entry to residential care is a possibility. However, three evaluations of specific advocacy services were retrieved which contribute relevant evidence and which are discussed below (Murphy 2001, Jones 2004, Bright 2008). Another piece of relevant work was a UK wide consultation exercise which collected data via one-to-one interviews and focus group discussions with 35 older people who had used various advocacy services (Wright 2006).

Wright's (2006) participants were from a wide geographical area and were a representative group in terms of age, gender, ethnicity and disability. There were no concerns about the methodology of this research, although limited information was given about the data analysis. This consultation showed that participants found the **process** of advocacy was as important as the **outcome**. There was evidence that the advocacy service itself was valued, even if the desired outcome of the particular situation was not achieved.

### 4.4.1 Process benefits

**Positive effects on the service user**

The effect of advocacy on the service user was one of the measures of effectiveness used by Murphy (2001) in an evaluation of an advocacy service for people with dementia. This found that 72 per cent of respondents (most of whom were professionals) felt that advocacy had had a positive effect on the service user. Only 1 of the 13 service users interviewed had anything that could be construed as negative to say about the service.

Interviews with service users in two other relevant studies reported positive outcomes for them, including an increased sense of self-worth, self-esteem, self-confidence and emotional well-being (Wright 2006, Bright 2008), although the robustness of the Bright study is limited by its small sample size.

> They encourage, help to find a solution.
> They make you confident.
>
> (Wright 2006, page 12)

Other research has shown that older people using advocacy services can still feel better following advocacy, irrespective of the outcome. 'Even on the few occasions when there is little or no concrete outcome, clients feel they have been listened to.' (Jones 2004, page 17). Moreover, advocates can help service users to understand and accept the outcomes of the intervention, even if these were not the outcomes originally desired (Murphy 2001).

## Benefits to others

Jones' evaluation of an advocacy service for older people suggested that the process of advocacy does not only benefit the service user, but can have positive impacts for professionals, carers, volunteers and the wider community (Jones 2004). However, only professionals were interviewed in the study, so the findings reported in relation to other groups need to be treated with appropriate caution.

The majority of clients who used this service were referred by professionals working in the statutory sector. These workers valued the work of this advocacy service highly:

> It is invaluable and essential.
>
> (Jones 2004, page 23)

> We are constrained by practicalities and the complexity of the network of agencies. WASSR (Westminster Advocacy Service for Senior Residents) can cut through this and provide a simple, focused service of help to the client.
>
> (Jones 2004, page 23)

> Professionals felt that statutory services benefited in various ways from the local advocacy service, including:
> - reduction in workload
> - training and education
> - improved understanding for their staff
> - cost savings to statutory services.
>
> (Jones 2004)

Professionals also felt that the advocacy service could help carers to feel less isolated and could reduce the 'burden' of caring. They also felt volunteers could benefit from working with advocacy services, by accessing training and gaining experience and new skills.

Jones argues that the existence of an effective and well-known advocacy service can benefit the wider community (even if they currently have no need of the service), simply through the comforting knowledge that it is there if needed. She found that the work of the advocacy service in relation to local strategic planning had resulted in more effective, high-quality services for older people. The service had also improved partnership working between agencies, while their work with local minority ethnic support groups had helped to bridge communities and improve integration (Jones 2004).

## 4.4.2  Outcome benefits

### Achieving expectations

Individuals usually approach, or are referred to, an independent advocacy service about a specific issue and successfully addressing this is the aim of the advocacy intervention. However, there have been very few studies evaluating the outcome of cases where the advocacy service was used in relation to the issue of moving into residential care.

Analysis of referrals for IMCA services (see section 4.3.1. for further information) showed that the IMCAs involved believed they were able to discern the views of the service-user in 1,417 of the 3,047 accommodation cases reviewed, and that the decision made reflected the individual's choice in 1,071 of these cases (DH 2008.) Given that advocacy is about enabling the views of the individual to be heard, this is a crucial benefit. Moreover, if it were possible to achieve the desired move for over a third of these individuals (who had been deemed not to have the capacity to make this decision themselves), this suggests that advocacy could be even more effective in the case of residential moves where the individuals involved do not lack capacity, but perhaps just lack the confidence or information for decision making. This study concluded that the outcome achieved was significantly affected by the IMCAs' involvement in 1,149 of the accommodation cases. However, the findings are based on the IMCAs' own perceptions of whether they had been able to determine the individual's choice and if their involvement had made a difference. A more robust research design would be needed to provide stronger support for this claim.

The pilot advocacy service evaluated by Bright (2008) had been in operation for less than two months when the evaluation began (see section 4.1). Therefore it was too early to report conclusively on its effectiveness in terms of the outcomes attributable to the service. However, the research was able to identify some positive changes in the lives of individuals who had used the service, through a small number of case studies. For example, one disabled older man was no longer able to live in his own home following an admission to hospital. With the help of the advocacy service, his family were able to challenge the council on what they saw as an inappropriate placement. Eventually his needs and wishes prevailed and more suitable accommodation was found for him. Bright (2008) concluded: 'It is clear to me from the evidence I have collected over a relatively short period of time that some excellent work is underway and that for some individuals critical changes have occurred in their lives as a result of interventions made on their behalf by staff of this service' (page 26). Ideally, a longer term study would assess the effectiveness of this pilot service and include more participants. (The sample size was small, with only three service users interviewed – factors which also limit the quality of this evidence.)

This search identified only one study which specifically asked service users if their expectations of the advocacy service they had used had been met (Murphy 2001). In this evaluation of a dementia advocacy service, the majority (but not all) of the referrals related to accommodation issues. Not all the respondents were able to remember and therefore reflect upon their expectations. Of those who could, four of the six felt that their expectations had been met. The professionals involved were also asked their opinion, the majority felt that the advocacy had successfully met their expectations. The difficulty with this type of outcome measure, however, is its dependence upon the initial expectation of the service. For example, one service user was disappointed as he had expected the advocate to be a financial expert. Unrealistic expectations could also be seen in the professionals. One staff nurse, for instance, had wanted the advocacy service to persuade the service user concerned that she could not return home, even though she wanted to. Such an expectation is clearly at odds with the overriding aim of advocacy, namely to empower the individual and give them more choice and control in their life. This raises the question of who is best placed to judge if an advocacy intervention has been successful – an issue which will be critical to any future cost effectiveness evaluation of advocacy services.

## Material outcomes

Another measure of the success of independent advocacy relates to the attainment of material outcomes for the individual.

Research exploring the benefits of generic advocacy services for older people has shown that it can result in increased income through improved access to entitlements (Wright 2006, Jones 2004). It can also enable people to obtain equipment that may help them maintain their independence within their home for longer, thus improving their choice and control over where they live. Examples include improved access to physical adaptations to increase independence (Wright 2006) and a specialist mattress (Bright 2008).

### Resolution of complaints

Disabled people already living in residential care may also have
need of independent advocacy services if they have any complaints
about the quality of care they are receiving or the appropriateness of
their placement.

One case study, described by Bright (2008), highlighted a number
of concerns about a residential placement, such as dehydration and
problems with the changing of catheters. Independent advocacy can
help individuals challenge such issues and a family member is being
supported to pursue the complaints in this case, even though their
relative has since died.

## 4.5    Advocacy input when entry to residential care is a possibility for a disabled person – what helps?

Due to the paucity of evidence specifically relating to the role of
advocacy for disabled people when entry to residential care is a
possibility, it is difficult to clarify what factors promote the process
and outcome benefits listed above. However, as the majority of
disabled people, for whom entry to residential care is a possibility,
are likely to be older disabled people, there is some relevant
evidence from the research relating to advocacy services for older
people generally and for older people already in residential care.

### 4.5.1  Promotion of the advocacy service

If people are not aware of advocacy services and the role they can
play, then they will be unable to benefit from them.

One of the highest quality, and most relevant, pieces of research
reviewed used a mixed methodology to explore the use of advocacy
and its impact on the lives of older people living in residential care
(Northway et al 2004). This demonstrated that family members
and care staff are the primary source of information, advice and
support for older disabled people in residential homes. There was

no mention by older people, their families or care staff of a role for independent advocacy, leading the report to conclude the need for independent advocates to promote their services, as all the homes in the study already had some type of provision for independent advocacy.

This finding was further supported by a critical review of current practices in advocacy services for older people (Margiotta et al 2003). As part of this work, a series of focus groups were conducted. They found none of the participants had used an independent advocate, or even heard of this type of service. They concluded there was a need for more information about advocacy for older people and how to access it. The difficulties experienced in the research process of exploring what older people want from an advocacy service, reflected some of the problems of service provision (Quinn et al 2003). For example, the researchers struggled to identify relevant advocacy services and found it particularly difficult to engage the older members of the South Asian communities in the area.

Overall, much of the relevant research has identified not only a need for advocacy services, but also more information about it (Wright 2006, Quinn et al 2003, Northway et al 2004, Dunning 2005 Robinson 2005). For example, Northway et al (2004) and Margiotta et al (2003) revealed a general lack of understanding about advocacy, with older people tending to associate the term with legal systems (Kerr and Kerr 2003). Therefore, it is insufficient simply to offer independent advocacy, the service must also be clearly explained to ensure appropriate take-up. This low level of awareness has also been found in residential care staff, reflecting the need for the topic of advocacy to be included in staff training (Northway et al 2004). This study of advocacy input for older people living in residential care suggested that independent advocacy services should visit residential homes regularly to promote their work.

The above studies relate to advocacy services for older people, but Bright's (2008) evaluation of an advocacy service for disabled adults also found that there was insufficient awareness of the service. Similarly, the joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS

Trust (Healthcare Commission 2006) found that some of the staff
did not know what advocacy was and most of those interviewed
were generally unaware of available local advocacy services.
This demonstrates the futility of providing advocacy services for
vulnerable people in residential care if staff are unaware of them.

## 4.5.2  Involvement of service users

Dunning (2005) argued that advocacy services must actively engage
with their potential users if they are to ensure that the service
works effectively in practice and meets people's varying, individual
needs. Such involvement may take place at three levels: personal,
organisational and policy.

## 4.5.3  The relationship between the advocate and the service user

The quality of the relationship between the advocate and the service
user appears to be related to the process benefits of advocacy, but
the search did not find any research exploring the impact of the
relationship on outcome benefits.

Factors shown to be important in strengthening the relationship
between the advocate and the service user were:

● the advocate building up trust

● making the individual feel valued

● being there for the individual. (Murphy 2001)

It has also been shown that an advocacy service was more likely
to have been judged as having had a positive effect on the service
user when they had received input from paid advocates as opposed
to volunteers (Murphy 2001). However, the number of cases
explored in this study was small and further exploration is needed
to determine the moderating effect of advocates being paid.

### 4.5.4 What sort of advocacy is needed by disabled people when entry to residential care is a possibility?

This search has retrieved no evidence of any research exploring the sort of advocacy needed by disabled people when entry to residential care is a possibility.

## 4.6 Evidence of costs of independent advocacy for disabled people when entry to residential care is a possibility

There is no evidence of the costs of providing independent advocacy for disabled people when entry to residential care is a possibility. The search identified one study which explored the costs of a generic advocacy service for older people (Jones 2004).

Jones analysed data from a review of 150 cases between 2003 and 2004. Cases which the advocates judged would have needed the involvement of statutory services, if the advocacy service did not exist, were categorised into two groups:

1. cases which were likely to result in litigation, a tribunal hearing or a formal complaint

2. cases involving the statutory authorities in significant use of staff time.

Using an estimate of the average amount of time spent on each type of case, it was calculated that the advocacy service had spent 2,248 hours on this work. This is equivalent to 1.5 full-time posts and estimated as equating to costs of about £50,000 per year. It is impossible to ascertain if statutory services providers would have had to have spent this money to work on these cases, if advocacy had not been provided by WASSR. However, the design did attempt to identify the cases where statutory services would have needed to give input. Moreover, Jones argues that as referrals were often made on the basis that WASSR has access to skills and information not easily available to the referrer, it is likely that the costs to the statutory services may have been higher.

These costs related to data collected from 2003-04. Fifty of the cases reviewed related to housing needs. Detailed information is given in the study about how the costs were calculated, although they were based on average figures and extrapolations. Therefore they may not be completely accurate. Moreover this estimate of the savings to statutory services is based on assumptions which may not be valid. Even where independent advocacy services do reduce the need for involvement of statutory services, it is unlikely that they eliminate the need altogether, since often the advocacy is provided in the context of accessing statutory services. Nevertheless, these cost data are of some interest, as they are the only attempt we have found to place a monetary value on an advocacy service for older people.

Two studies were reviewed on the new IMCA service, both with data relating to the time taken for this work (DH 2008, Redley et al 2006). The majority of the cases in which an IMCA was used were related to a change of accommodation decision. The pilot study of the IMCA service noted that the average time spent on completed cases was just over seven hours, with an additional two hours spent travelling (Redley et al 2006). The later DH (2008) report of the first year of the service reported on over 3,000 cases where decisions on accommodation moves were required and found these cases took an average of 9.5 hours to complete. These figures therefore seem stable over a period of time, but they were not equated to a financial cost.

## 4.7    Overview of gaps in the evidence

The review of the literature identified through the search of academic databases and the grey literature has shown that there is no real evidence base specifically relating to independent advocacy for disabled people when entry to residential care is a possibility. Importantly, there has been research that contributes relevant findings. For example, there is a body of research around general advocacy for older people, which shows that housing issues are paramount for this group.

- To establish the need for independent advocacy when entry to residential care is a possibility, there needs to be some focused research. This needs to include disabled people of all ages in this situation and not just focus on older disabled people. Specifically, such research needs to provide further information about the number of disabled people for whom entry to residential care is a possibility, the current availability of independent advocacy for these people and the level of unmet need.

- There is a need to explore if there are benefits from the provision of independent advocacy when entry to residential care is a possibility. These may be process benefits, such as a feeling of empowerment or they could be related to the outcome of the advocacy, such as finding a suitable residential placement.

- Further research needs to identify how to make advocacy services work in practice and how they can meet the needs of individual disabled people when entry to residential care is a possibility.

- It is important that there is research to explore the costs of providing independent advocacy to an individual when they are facing a move into residential care.

# 05

Independent advocacy when disabled people are victims or alleged perpetrators of anti-social behaviour
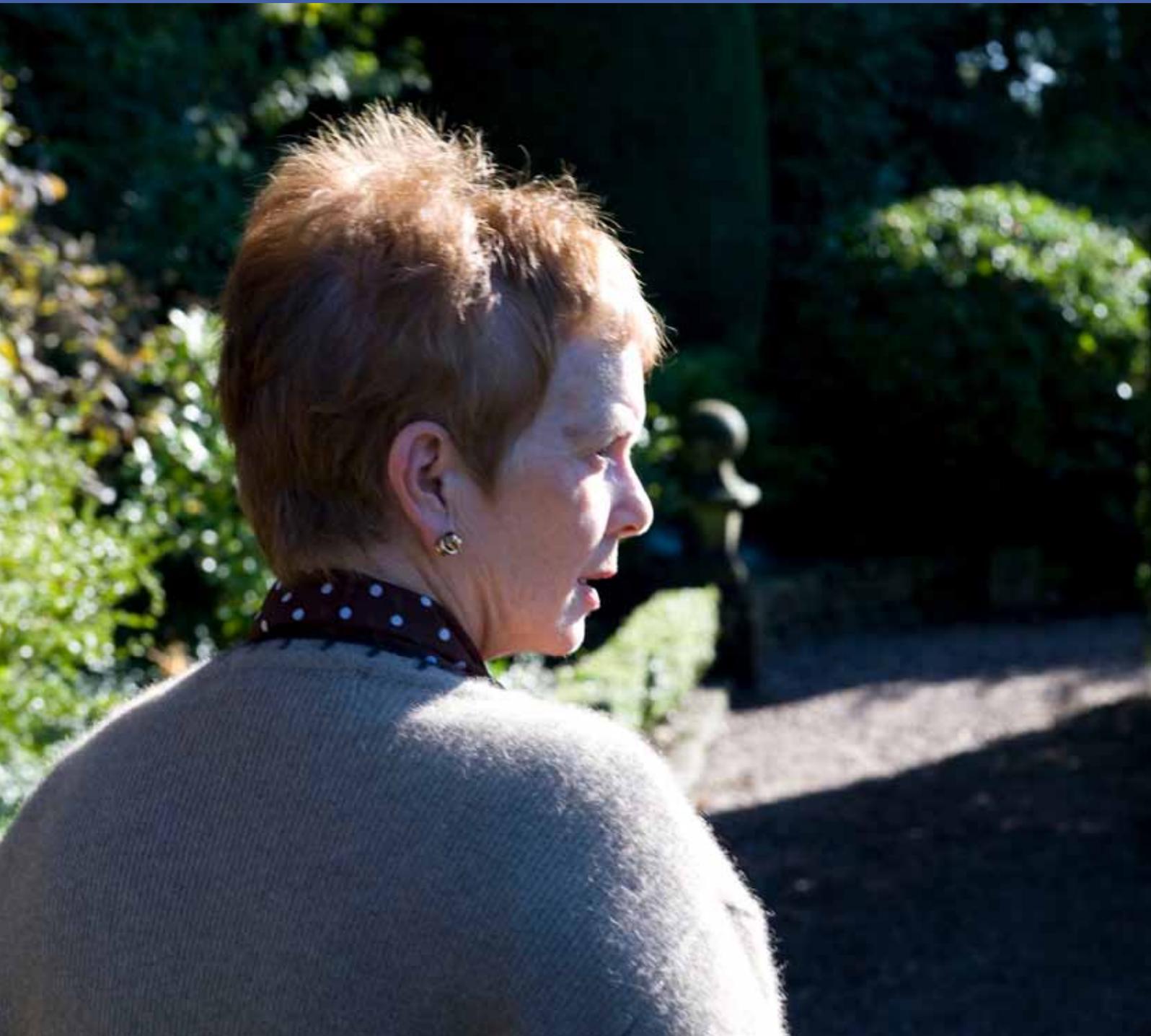
# 05 Independent advocacy when disabled people are victims or alleged perpetrators of anti-social behaviour

This chapter presents evidence relating to the need, benefits and costs of independent advocacy for disabled people who are involved, as victims or alleged perpetrators of anti-social behaviour. For the purpose of this review, anti-social behaviour has been viewed as a continuum of experiences from bullying and harassment through to murder. A total of 22 items of research literature were critically reviewed (for further details see Annex 1).

## Disabled victims of crime

- There is a strong evidence base, from a number of large studies, of high levels of anti-social behaviour towards disabled people. This review has found a range of studies that show that all groups of disabled people are more likely to be physically or verbally abused than the general population. A series of studies has shown the extent and severity of the problem of bullying faced by young people with learning disabilities both in school and out in the community. The research has shown the impact of bullying on this group and also the difficulties in stopping it.

- Disabled people are less likely to report crime against them in comparison to the general population. Research has identified factors that affect this under-reporting. These include people not knowing how to report a crime, or not having the appropriate support to do so. The research suggests that disabled people feel the police do not take their claims seriously and do not always investigate them appropriately. There is a role for independent advocacy in addressing these barriers.

- There is a failure within the criminal justice system to recognise and prosecute disability hate crime. Data about disability-related hate crime is now collected but the evidence suggests that only a small proportion of disability hate crimes are prosecuted as such.

- This review identified some research exploring the benefits of advocacy for vulnerable adults who had been victims of abuse. This showed that in majority of the cases reviewed the goals of the advocacy were met and the abuse was stopped. However, this research did not directly involve the service users.

- This review did not identify any research exploring the related costs of independent advocacy services for disabled victims of crime.

## Disabled perpetrators of anti-social behaviour

- This review found high-quality evidence concerning the high rates of prisoners with learning disabilities or mental health problems. Many of these prisoners are inappropriately placed and do not have appropriate support or access to advocacy. There is evidence that over a fifth of prisoners with learning disabilities did not understand what was going on during their court case and they identified the need for someone to explain difficult words to them. Once in prison they needed help with filling in written forms.

- There are high costs involved with prison placements, but there is no research around the cost-benefits of schemes that work to divert disabled offenders from prison.

- One high-quality piece of research demonstrated the need for an independent advocacy service in a high-security hospital. This study also identified benefits and outcomes of the service and found it was viewed positively by patients and staff. Both patients and staff felt there were benefits from the process of the advocacy service even when desired outcomes were not possible. The process benefits included getting rid of anger and the outcome benefits included access to useful information. This study collected data in relation to the time spent by advocates, but there was no cost analysis performed.

## 5.1 What does independent advocacy look like for disabled people who are victims or alleged perpetrators of anti-social behaviour

There are many potential roles that an independent advocate could fulfil when working with disabled victims or perpetrators of anti-social behaviour. Victims of alleged anti-social behaviour may need support in reporting incidents and then, if the case is prosecuted, they may subsequently need support during this process. Alleged perpetrators of anti-social behaviour may need support during police interviews and at all stages of the court process. Those who receive a prison sentence or are sent to a high-security hospital may need advocacy in this setting.

### The story of Peter and Jim

Peter works at an advocacy service and he received a phone message from Criminal Justice Social Work at the local prison saying that Jim, who has mental health issues, had been released and told to access help from their service.

**Peter**

Sure enough, Jim turned up at our office at 3pm with many urgent needs. He was having serious difficulties sorting these out because he was prevented by interdict from attending the local housing, benefits, social work and criminal justice offices. These interdicts were based on the fact that Jim represented a threat to females, through his intimidating and aggressive behaviour. No mention of these facts were made to us by the referring social worker, and we were fortunate that I was in the office as well as our (female) office manager. He therefore had very little cash, no way of accessing benefits, no accommodation, no social work support, and no food. He was still adamant that he was affected by mental health problems, but had received no support in prison, no referral to GP or other services upon his discharge…As I attempted to access services for Jim, it became apparent from responses that he was not allowed access to any of the services he needed because of the perceived threat he posed…The irony of this situation was not

lost on us, as the very service (criminal justice) who had referred him to us, without warning and without concern for our female staff, were denying him their own support, even though their own offices and reception are protected by strengthened glass and security systems...Nevertheless, we found Jim to be calm and polite and through a series of assertive phone calls and discussions were able to secure Jim emergency accommodation for the weekend, a food parcel from another voluntary organisation and an appointment with myself for the Monday morning.

Jim kept this appointment and turned up on time…We were unable to organise appointments with any of the statutory services because of the interdicts, and neither would these services accept a visit from him with myself accompanying him. The Benefits Agency agreed to post him an emergency payment, but as he had no address asked if they could use our address for him, and post a giro which he could pick up from our office. Mental health services were equally reluctant to accept a referral from us…It was at this point that I suggested that he actually contact the police to request that they accompany him to benefits and housing offices. Although initially surprised at the idea, Jim agreed to give it a go. It had never occurred to him (or me!) that the police could actually help him. After negotiating these arrangements, Jim then did manage to access these services, and I was able to write to mental health services, requesting an assessment from the Community Mental Health Team…

…The corollary is that society and services 'process' thousands of Jims as 'criminal' despite their appeals for mental health support…At one point, Jim said to me that unless he got the help he needed, he might have to really hurt someone, so that at least he would not have to keep leaving prison…This case emphasised to me how individuals fall between stools and enter terrifying freefall into negative spirals. All other services had abandoned or antagonised Jim, yet we found him to be frightened, courteous and non-threatening. His story showed me, yet again, the value of advocacy in very demanding situations. Although we did not solve all his problems, we were able to help him to be heard and to begin to rebuild a life.

Adapted from a case study presented in Scottish Independent Advocacy Alliance (2008).

## 5.2 Evidence of the need for independent advocacy for disabled people who are victims of anti-social behaviour

This search has not identified any research directly exploring the need for independent advocacy when disabled people are involved as victims in anti-social behaviour. There is, however, a robust evidence base showing that disabled people are at a higher risk of being victims of anti-social behaviour than the general population, with people with learning disabilities and/or mental health conditions being at a particularly high risk. Moreover, they have problems reporting such incidents and in resolving the situation. There is a need for independent advocacy to help them in overcoming the barriers that make it difficult to obtain justice in this situation.

### 5.2.1 Levels of anti-social behaviour towards disabled people

Between a fifth and a third of disabled people do not feel safe in their own homes and local community and this figure rises for adults who have a mental health problem (MORI 2007, Scope 2008). Anti-social behaviour can affect all groups of disabled people, irrespective of their impairment and age. Moreover, disabled people can be victims of anti-social behaviour at school or work, while out in the community or even in their own homes. Some of the evidence reviewed relates to specific groups of disabled people, for example, children with learning disabilities, but many of the issues raised will be pertinent to the general evidence base in this area.

**Bullying towards disabled children**

The National Autistic Society (NAS) used a large-scale survey in conjunction with more detailed interviews to explore bullying towards children with autism within school (NAS 2006). The figures showed that 54 per cent of children with autism in mainstream schools experienced bullying. This robust research explored the impact of the bullying and showed that self-esteem, development of social skills and the mental health of the victims were all negatively affected. Over half the children had missed school or had to change

schools as a consequence of the bullying. The wide-ranging negative effects and the severity of these demonstrate the gravity of such behaviour and that it cannot merely be dismissed as harmless name-calling.

Mencap (2007) used an accessible questionnaire with workshops run for school children with learning disabilities, aged 8-19 years old, to find out more about their experiences of being bullied. This study also provided evidence of high levels of bullying, with 80 per cent having been bullied at school. Additionally, 60 per cent reported being physically hurt and many were too scared to leave their home.

## Anti-social behaviour towards adults with learning disabilities

There is some evidence of a disturbing level of anti-social behaviour directed at people with a learning disability. Eighty eight per cent of people who responded to a questionnaire run by Mencap reporting being bullied within the last year (2000). The questionnaire was sent to group homes, leisure clubs, disability employment services and self-advocacy groups across the UK. The most common type of abuse was verbal (47 per cent), but a significant amount of participants (23 per cent) reported a physical assault. The frequency of such incidents was high, with almost a third of the respondents being a victim of bullying on an almost daily basis. The survey also explored the context of the behaviour and found that most of it takes place in public, although 26 per cent of respondents reported being bullied within their homes. However, it must be noted that these findings may overstate the situation as it is possible people who have experienced verbal or physical abuse are more likely to respond to this kind of survey than those who have not.

## Anti-social behaviour towards adults with sensory impairments

Verbal and physical abuse towards blind and partially sighted people was recently investigated using a survey and focus groups (Action for Blind People 2008). Comparisons between visually impaired people and people without a visual impairment showed that those who were visually impaired were more likely to have been

verbally or physically abused, and on a more frequent basis. This study used the data collected from their sample to extrapolate the findings to the UK population of people with visual impairments. This may not be appropriate as there was no attempt to explore the representativeness of the sample. Therefore, some of the claims made in the report should be viewed with caution.

## Anti-social behaviour towards adults with mental health problems

A recent study explored the extent of crime and victimisation to which people with mental health problems are exposed (Mind 2007). The survey was available online and 5,000 questionnaires were sent to their networks. The data also showed a high level of crime against the respondents, with 71 per cent of them having been a victim of crime, which they believed was related to their mental health history, within the last two years.

## Hate crime against disabled people

Mencap (2000, 2007) argued that if perpetrators of bullying are not stopped at an early stage then it is likely that the behaviour will escalate into more serious hate crime.

Several studies have conducted research into the prevalence of hate crime against disabled people (Hoong Sin et al 2009, SCOPE 2008, DRC 2004). The evidence from this body of research suggests that disabled people are at a higher risk of targeted violence than the general population. The DRC (2004) study undertaken in Scotland and employing questionnaires and focus groups found that disabled people living in urban areas are at a higher risk of being attacked than those in rural areas. They concluded that hate crime is a significant issue for disabled people and noted that 31 per cent of those who are victims of hate crimes, experience attacks at least once a month. Such ongoing abuse has a major impact on peoples' lives, with a quarter of participants having moved home as a result.

The annual British Crime Survey suggests that disabled people are not at a higher risk of being a victim of a crime, which may conflict with the evidence reviewed above. SCOPE (2008) argue that there are many reasons for this under-representation of disabled people in

the British Crime Survey, including the fact that this does not cover residential homes where many disabled people live, that no accessible information is available for those with difficulties reading and they do not use sign-language interpreters, affecting responses by Deaf people. For these reasons it is likely that the British Crime Survey underestimates the level of crime directed at disabled people.

## 5.2.2 Why is advocacy needed for disabled people who are victims of anti-social behaviour?

The studies reviewed above report data that suggests disabled people are subjected to high levels of anti-social behaviour and hate crime. Yet disabled people are less likely than the general population to report such behaviour to the police and therefore the behaviour is unlikely to be stopped or punished.

### Empowering people to report crime

If crime against disabled people is not reported to the police then we do not have official figures to provide evidence of the scale of the problem.

There is some evidence showing that disabled people are much less likely to report the offending behaviour than their non-disabled peers (Mind 2007, Action for Blind People 2008). Recent research which involved interviews with 15 people with learning disabilities who had been victims of crime found that a small proportion told the police (4 people) or their family (3 people), but the majority told a third party such as an advocate (12 people) (Hoong Sin et al 2009). The researchers concluded that there is a disparity between the under-reporting to the police which is well documented in the literature and actual levels of informal reporting. They found that reporting to a third-party is quite common, but this may not lead to a formal report to the police. Such reporting is under-researched and therefore the level of need for independent advocacy for disabled people who have been the victims of anti-social behaviour is being masked. They argued there is a need for more detailed research to explore this further.

Three studies specifically investigated the reasons for this under-reporting by disabled people (Cunningham and Drury 2002, Action for Blind People 2008, Hoong Sin et al 2009). They identified these as:

- confusion as to what constitutes a criminal offence

- fear of not being taken seriously

- not knowing how to report

- being too scared to report an incident

- past experience of a lack of support following the reporting of abuse

- lack of access to police stations and inaccessible reporting systems

- difficulty in verbalising experiences.

A specific issue for people with visual impairment was the added difficulty of not being able to visually identify the attacker.

Similarly, Mencap's (2000) report highlighted the need for support services for victims and better information about how to report a complaint to the police. There is a clear role for independent advocacy in helping address all of these barriers and empowering victims to report crime. Despite this, the studies reviewed made very few explicit references to the role advocacy could play in the provision of information and support in reporting crime. One study which specifically explored the role of advocacy found that it was only accessed by a quarter of people with mental health problems when they reported a crime. Moreover, the support workers who participated in this research believed that the scarcity of independent advocacy schemes was a significant factor in the low reporting rates of disability-related crime (Mind 2007). More recently, research commissioned by the Equality and Human Rights Commission (Hoong Sin et al 2009) also identified lack of access to an advocate as a barrier to reporting crime. They argued that an important role of an advocate is to identify appropriate support needs while the victim is at the police station.

## Supporting disabled victims to be taken seriously

Fear of not being taken seriously by the police is a contributing factor to the under-reporting of crime against disabled people. Statistics presented by SCOPE (2008) indicate that disabled people show a lack of confidence in the justice system in comparison to the general population. There is evidence that this is a justified concern.

Even if disabled people were empowered to report a crime they often found that this did not have any effect as the police were either uninterested in the problem or unable to help due to a lack of evidence (Mencap 2000, DRC 2004, Scope 2008). Mind (2007) found that of those who did make a report, only 6 per cent were satisfied with the outcome of their case.

It is only recently that the Crown Prosecution Service has officially acknowledged disability-related hate crime and collected performance information on it. Their data shows that 183 defendants were prosecuted for crimes involving disability incidents in 2007-08. The majority of these (77 per cent) resulted in a conviction. This report notes reasons for unsuccessful prosecutions. It showed that 15 per cent of these were due to unreliability of a witness and 21 per cent were due to 'victim issues' (which include retraction and the failure of a witness to attend court). There was no mention of advocacy support in the disability hate crime section of this report (CPS 2008). We speculate that it is possible that with appropriate support from an independent advocate, some of these abandoned cases might have been able to proceed with a prosecution.

## To protect vulnerable adults

There is a small body of research that has explored the needs of vulnerable adults who are victims of abuse.

Recent research which explored the impact of advocacy when working with victims of elder abuse concluded that reported figures of the prevalence of abuse of older people are likely to be under-estimated (OPAAL 2009). However, there is an ongoing programme of research into the abuse and neglect of older people, funded by Comic Relief and the Department of Health, which should provide

more accurate data about the scale of the problem in 2011. In the first year of the Independent Mental Capacity Advocate (IMCA) service, 706 referrals (out of 5,268 referrals) were made in relation to adult protection procedures, which is only a minority of IMCA referrals, but shows that there are a significant number of adults who have needed independent advocacy on their behalf where they have been victims of abuse (Redley et al 2008). Financial abuse tended to be the most prevalent form of abuse, but many vulnerable adults had experienced multiple forms of abuse (OPAAL 2009, Redley et al 2008).

The perceptions of vulnerable adults who were alleged victims of abuse were explored through interviews and this research found that only a small proportion had been offered advocacy services (Darwin and Pickering 2007). Even when advocacy was offered, there were difficulties in securing services and over time some of the advocacy input had stopped due to funding issues. The interviewees felt that if they had been offered advocacy this would have been beneficial: 'someone neutral could have sat and spent some time with me' (Darwin and Pickering 2007, page 91)

The majority of the people for whom IMCA referrals were made were female and the most common reasons for lack of capacity were dementia and learning disability. In 57 per cent of the cases family members were the alleged offenders, reinforcing the need for independent advocacy. The qualitative data from the IMCAs indicate that the practice of the police in regard to adult protection cases varies across the country. There were suggestions that the police were reluctant to get involved in cases where the complainant lacked capacity or in cases they perceived to be 'domestic abuse'. This is further evidence of the need for independent advocacy to support vulnerable adults who have been victims of abuse.

## 5.3 Evidence of the need for independent advocacy for disabled people who are alleged perpetrators of anti-social behaviour

Disabled people accused of anti-social behaviour may need independent advocacy to ensure they are treated fairly at all stages of the criminal justice process. It has been argued that such an advocacy service needs to be independent, user-led and clearly distinct from the forensic service (Edwards 2004).

## 5.3.1 Levels of need for independent advocacy for disabled perpetrators of anti-social behaviour

### Pre-conviction

It is difficult to estimate the level of need for independent advocacy as the precise number of people with mental health needs or learning disabilities that come into contact with the criminal justice system are not known. There is no national requirement for such statistics to be noted and this limits accurate estimates of the scale of the problem and the need for services (Bradley 2009).

### Post-conviction

An evaluation of the first advocacy service in a high-security hospital in Britain showed that 98 per cent of patients and staff interviewed felt there was a need for the service (Barnes and Tate 2000).

> The majority of patients in high-security hospitals have been convicted of a serious criminal offence and are subject to restriction orders (Sections 41 & 49) under the Mental Health Act 1983.
>
> (Barnes and Tate 2000, page 6)

The high proportion of patients (65 per cent of all the patient population) that had used the service is a reflection of the need for it. It was not just the patients that saw the advocacy service as important. Managers felt there was a greater need for advocacy in high-security hospitals than in general psychiatric hospitals. In general, the nurses were also positive about the service, acknowledging the need for it because it covered issues they did not have time to address, although there were some concerns about advocates supporting patients to make unrealistic complaints.

Prisoners with learning disabilities are over-represented in the UK prison population (Hayes et al 2007). As there is no routine screening it has traditionally been difficult to provide estimates as to the exact prevalence, but research in 2007 suggested that almost 6,000 people with learning disabilities were in prison (Prison Reform Trust website). A major piece of research has recently been undertaken by the Prison Reform Trust to explore the experiences of these prisoners of the criminal justice system (Talbot 2008). This high-quality study identified 154 prisoners with learning disabilities/difficulties in a sample of prisons across England, Wales and Scotland and employed a comparison group. This research identified a number of areas for which these prisoners need support. These included help with filling in forms and the need for someone to explain difficult words to them in court. These are functions that advocates could assist with.

There is a high level of mental health problems in prisons, with over 70 per cent of prisoners suffering from two or more mental health disorders (Talbot 2008). The Bradley Report (Bradley 2009) has recently confirmed that there are now more people with mental health problems in prison than ever before. The Prison Reform Trust has conducted further research into this issue, which collected evidence from 57 Independent Monitoring Boards (Edgar and Rickford 2009). The majority of these boards reported that they frequently saw prisoners who were too ill to be in prison. There was an urgent need for such offenders to be diverted away from prison and into appropriate health and social care. Independent advocacy services could help to facilitate this, although this report did not explicitly recommend this role for independent advocacy. Some of the prisons in this study stated that the prison nurses acted as

'advocates', but this would not meet the definition of independent advocacy used in this study. There were some examples of good practice, but only two of the prisons had independent advocacy regularly available.

## 5.3.2 Why is independent advocacy needed for alleged disabled perpetrators of anti-social behaviour?

Independent advocacy has the potential to offer support to disabled people at all stages of their contact with the criminal justice system. The role could include advocating for people throughout their court case. There is also a role for disabled people who have been convicted and are subsequently in prison or in a high-security hospital.

### Support to understand the process

Talbot (2008) found that most prisoners with learning disabilities/ difficulties had not received any support during their police interview and in the minority of cases where support was provided it tended to come from friends and family. It was therefore more likely to be emotional support and did not necessarily help people in understanding the legal process. It was apparent that the legal language used was often difficult for people to understand and this contributed towards individuals finding the court process frightening and incomprehensible. Over a fifth of the prisoners interviewed said they did not understand what was going on in court. Everyone, but particularly people with cognitive impairments, needs support and information they can understand about the process as they proceed through the criminal justice system (Barnes and Tate 2000).

### Protection of rights

Talbot's study (2008) found some indication that prisoners with learning disabilities/difficulties were at a higher risk of being mistreated by the police than those in the comparison group and furthermore, some reported being denied access to their medication (Talbot 2008).

There is evidence that prisoners are not always able to have a say in their treatment or access to advocacy to assist with this (Edgar and Rickford 2009). This was also highlighted in the evaluation of the advocacy service in the Ashworth hospital (Barnes and Tate 2000). In this research it was found that many nurses did not feel happy about advocates being involved in issues around clinical care. In these cases, the nurses thought it was appropriate that advocates worked with patients to help them accept any treatment decisions, rather than challenge them. Edgar and Rickford (2009) found there were some attempts to enable patients to be involved in decisions about their treatment, but these were limited. The boards at two prisons stated there was no need for an advocacy service because patients were not forced to undergo any treatment. This suggests that the extent to which prisoners are involved in their own treatment is limited to being able to consent to or reject the treatment being offered.

There are many ways in which independent advocacy can help to protect the rights of disabled people once they have been convicted of an offence. The patients in Ashworth hospital used the independent advocacy service to help them to resolve problems and for support in reviews and tribunals and when lodging a formal complaint (Barnes and Tate 2000).

## 5.4   Evidence of benefits/outcomes of independent advocacy for disabled victims of anti-social behaviour

We have documented from various sources the high level of anti-social behaviour towards disabled people, but there appears to have been little research evaluating recommendations for action to reduce it. We are unable to find a robust evidence base of the benefits of independent advocacy for disabled victims of crime. However, there has been some research that provides some preliminary information. It has not been possible to separate this evidence into process and outcome benefits due to the nature of the data collected.

In their study of the work of IMCAs in adult protection cases, Redley et al (2008) found a general consensus among IMCAs, their managers and other professionals involved in the process, that the

service did benefit adults subject to adult protection procedures. Despite the fact that the clients have been assessed as lacking capacity, in the majority of cases the IMCAs believed they had ascertained the person's wishes. In 15 per cent of the cases reported in this study the investigations resulted in an arrest.

The qualitative research conducted with vulnerable adults who had been alleged victims of abuse found that those who did receive input from advocacy services felt supported by this and reported that the standards were excellent (Darwin and Pickering 2007).

OPAAL (2009) specifically explored the impact of advocacy for victims of elder abuse. Despite the fact that not all of the data was from disabled older people, the findings are presented as they represent one of the few attempts to research the impact of advocacy for vulnerable adults who have been abused. Data was gathered in relation to 98 cases, but there were some non-responses to specific questions. They found that 38 older people reported being fully satisfied with their advocacy support, 21 were partially satisfied and only one was unsatisfied. More specifically, they explored the level of empowerment felt by the older people who had used advocacy services. The results showed that 39 respondents felt informed during the process, 29 felt they had been empowered and 18 felt involved. However, 15 respondents reported they were not informed, empowered or involved. Although this was a minority of respondents, there must be concerns about the effectiveness of an advocacy service where the recipients did not even feel involved.

The outcomes of the advocacy were also measured in relation to its ability to meet identified goals. Both the older person and the advocate had set goals and it was noted that the older people were more likely to set goals that related to feeling supported and listened to than the advocate was. The advocates tended to set goals which focused on practical outcomes such as stopping the abuse. This data showed that the advocacy schemes believed the goals identified by the older person were fully achieved in 33 cases, partially achieved in 33 cases and not achieved in 12 cases. The goals identified by the advocate were fully achieved in 49 cases, partially achieved in 36 cases and not achieved in two cases. The author of the report acknowledges that there were some

qualifications around the achievement of goals and that there needs to be further consideration of this, but there is no further information in regard to these qualifications. In the judgement of the advocacy schemes, the abuse had been stopped in 44 of the cases, reduced in 11 of the cases, been prevented in 17 of the cases, was ongoing in 6 cases and remained unsubstantiated in 18 cases[13].

In the above study, the views of the service-user were reported via their advocates. Future work should also directly include the people using the advocacy service when exploring if the goals of the advocacy have been met and if the abuse has been stopped.

There are some services available which do not describe themselves as independent advocacy, yet they fulfil many of the same roles. One example is the pioneering Liverpool Investigations Support Unit. Their data suggests that the provision of witness support and preparation can help people with learning disabilities, who have been the victims of serious crimes, obtain justice. By 2006, the unit had worked to support 30 people with learning disabilities who had alleged serious sexual or physical assault against them, through the court process. Of the 21 cases that were brought, 18 resulted in a successful prosecution. The results have been so successful that it has been recommended to the Crown Prosecution Service that the model is adopted nationally (Fareed 2006). However, there has been no formal evaluation of this service.

## 5.5 Evidence of benefits/outcomes of independent advocacy for disabled people who are alleged perpetrators of anti-social behaviour

NACRO's (2007) report argued that increased use of independent advocates trained in criminal justice issues is an effective support mechanism and can help ensure the needs of disabled offenders are met and they are able to access suitable services. However, there appears to be a paucity of evaluations of such advocacy services.

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[13] It should be noted that there was no control group used as a comparison in this research.

## 5.5.1   Evidence from UK research

Barnes and Tate's (2000) study of the Ashworth hospital advocacy
service is the only evaluation of an advocacy service for disabled
offenders retrieved in this search. Over the five years the service
had been running it was clear that general attitudes towards the
advocates had become much more positive. This research drew
a distinction between the process and the outcome benefits of the
advocacy service. Eighty per cent of patients and staff agreed that
there was a benefit in seeing an advocate, although the benefit
could be limited as the desired outcome might not always be
achieved.

### Process benefits

The majority of the benefits of the service articulated by the patients
were process benefits. These included being listened to by someone
who understood and, ultimately, feeling more confident. Many
patients found the advocacy service provided an opportunity to
offload and some acknowledged that talking to an advocate could
help them get rid of their anger.

The majority of participants agreed that the advocacy service did
provide the patients with a voice, but this was qualified by some,
who described it as a 'quiet voice' (part 3, page 19).

Three-quarters of the patients believed that the advocacy service
made staff more aware of patients' rights.

The staff viewed the **process** of advocacy as a benefit and thought
that support and reassurance was helpful, regardless of the
outcomes. They felt that an independent avenue for the patients was
beneficial.

### Outcome benefits

One of the main benefits of the service identified by the patients
was access to useful information. Patients used the service to help
support them in making formal complaints, transfer requests and
also for support at tribunals and review meetings.

The research found that the advocacy service had helped patients materially by sorting out benefits and enabling patients to buy goods.

The service also provided a route for assistance in making contact with others including staff, patients and others outside the hospital.

## 5.5.2 Evidence from US research

Three studies conducted in the US contribute relevant evidence in relation to appropriate sentencing and access to services.

A study evaluating the benefits of an advocacy programme for young offenders in the US (the majority of whom were described as having a mental health or special educational need) found that the advocacy programme resulted in significantly reduced sentences although there was no significant decrease in the number of young offenders detained (Mallet and Julian 2008).

Another study comparing three different models of police responses to calls relating to people with mental health problems concluded that collaborations between advocacy services, the criminal justice system and the mental health system could reduce the number of people with mental health problems inappropriately imprisoned (Steadman et al 2000). This research only focused on immediate outcomes and did not consider the longer term impact of the services for individuals.

Norrbin et al (2004) undertook a study of the effectiveness of two separate programmes which were developed to improve access to education programmes, mental health services and family services for young offenders. Although this was not specifically a programme for disabled people, one of their findings was that the majority of their clients had significant mental health problems. They found that the programmes were not effective in reducing reoffending rates, but they did decrease the arrest rate. This suggests that the young offenders were diverted to more appropriate services. The authors argue that the success of such programmes should not be judged solely on a reduction in recidivism, as this client group has serious problems, such as learning disabilities and mental health needs.

## 5.6    Advocacy input for disabled people who are victims of anti-social behaviour – what helps?

There is limited evidence of the factors that promote the effectiveness of independent advocacy services for disabled victims in allegations of anti-social behaviour[14].

The only evidence relating to an existing independent advocacy service for disabled victims comes from the IMCA data (Redley et al 2008), but this did not explore what factors appear to promote the effectiveness of advocacy. Nevertheless, this search did review some evidence that suggests a role for independent advocacy in supporting disabled people who have been the victims of anti-social behaviour.

## 5.7    Advocacy input for disabled people who are alleged perpetrators of anti-social behaviour – what helps?

As there are very few independent advocacy services that directly target alleged disabled perpetrators of anti-social behaviour, there is limited evidence of the factors that promote the effectiveness of such a service.

### 5.7.1  Access to, and understanding of, the service

The interviews with the patients at Ashworth hospital suggested that the service was effective in promoting its work, as only one of the participants was unaware of its existence. The general consensus was that the service was easy to access, although many were keen for improved access at evenings and weekends. Although the response time varied, most participants agreed that response to emergency situations was prompt and that calls were returned

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[14] Although searches were looking since 1997, the term anti-social behaviour has not been in circulation for all this time.

and appointments kept. Despite the fact that the vast majority of the patients were aware of the advocacy service and how to access it, they were not all clear about the role of the advocates. It is important that the role of the advocacy service is clearly understood by both staff and patients. Barnes and Tate's evaluation (2000) suggested that there was still work to be done on clarifying the role of the advocates, as staff and patients viewed the advocates as being there for them both, partially to ease tensions. It was only the advocates themselves that were clear that they were there solely to represent the patients.

### 5.7.2  Independence and representativeness of service

One aspect of the Ashworth hospital service that was most highly valued by both staff and patients was its perceived independence. The importance of the independence of an advocacy service is highlighted by the finding that one of the negative aspects of the service raised by some participants was the close association between the service and the management team of the hospital.

## 5.8  Evidence of costs of independent advocacy for disabled victims of anti-social behaviour

None of the relevant studies retrieved in this search investigated related costs, although Redley et al (2008) found that the mean number of hours spent by an IMCA on an adult protection referral was 13 hours.

The interviewees in this study reported that adult protection cases consumed proportionately more time than other types of IMCA referrals.

## 5.9 Evidence of costs of independent advocacy for disabled people who are alleged perpetrators of anti-social behaviour

Our search has found minimal evidence of the costs of providing independent advocacy services for disabled offenders. Barnes and Tate's (2000) evaluation of the advocacy service for patients detained at Ashworth Hospital included an analysis of advocates' workload over a 12 month period. The data showed that the advocates had worked with 274 patients, with an average of 6.1 each. The mean length of time of each contact was 31 minutes.

A few studies have discussed the cost implications of not providing an effective advocacy service for disabled offenders. NACRO (2007) identified these costs as including:

- doctors' fees

- administration

- prison places (estimated as £40,992 per person per annum, Prison Reform Trust 2008)

- transfers

- hospital beds.

They argue that the financial consequences of not coordinating community services should be sufficient motivation for addressing this. Equally, the high number of people with mental health problems inappropriately placed in prison has led to considerable strain on prison services and related costs (Edgar and Rickford 2009). Such costs should be included in future research that explores the costs and benefits of providing independent advocacy.

Mallet and Julian (2008) included some cost data in their study. They calculated that the reduced sentences resulting from their intervention represented substantial savings in the time period of the study. Specifically, they estimated that the fewer placement days represented a total of $625,898 over a 21 month period. However, no costs of the advocacy provided were taken into account and therefore the overall cost benefit of the programme is not clear.

## 5.10   Ongoing research

It is worth highlighting several pieces of ongoing research, where reports/evidence may be forthcoming in the next one to two years:

● The Ministry of Justice has recently commissioned the British Market Research Bureau to undertake research into the court experiences of adults with mental health problems, learning disabilities and limited mental capacity.

● Research in the USA is undertaking a randomised trial of 'Critical Time Intervention (CTI) for Men with Mental Illness Leaving Prison'. CTI has two components. The first is to grow and strengthen the individual's long-term ties to services, family, and friends. The second component of CTI is to provide emotional and practical support, and advocacy, during the critical time of transition. The goal of this study is to test the effectiveness of CTI for men with mental illness and substance abuse problems leaving prison.

## 5.11   Overview of gaps in the evidence

● There is a body of large-scale robust research that has demonstrated that disabled people are more likely to be victims of crime and yet less likely to report this. This evidence supports the need for independent advocacy for disabled people who are subject to anti-social behaviour, even if the research does not specifically explore the contribution independent advocacy could make. There is minimal evidence of independent advocacy being used for disabled people with capacity and the potential benefits and related costs of this.

- The prevalence of disabled people in prison has been established by robust research and this has also identified their needs. Independent advocacy could be used to address these, but there is no evidence relating to independent advocacy for disabled people in prison. There has been an evaluation of an independent advocacy service for patients in a high-security prison but this did not include cost-benefit analysis and this research was conducted 10 years ago. Therefore, there is a need for further evaluative work of current independent advocacy services to establish a firm evidence base of the benefits of such schemes.

# 06

## Conclusions

# 06 Conclusions

This review set out to investigate the nature and extent of evidence relating to independent advocacy for disabled people at risk of losing choice and control in four specific 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.

In doing so, it described and evaluated evidence about the need, costs and benefits associated with independent advocacy. This final section summarises the state of the evidence base currently available, the gaps therein, and suggests what additional research is needed to further our knowledge in this field.

## 6.1 Quantifying and describing the need for independent advocacy

This review has demonstrated there is a limited evidence base relating to the extent of need for advocacy for disabled people in relation to the four areas considered (transition, parents, residential care and anti-social behaviour/crime). However, a lack of robust data relating to numerical indicators of need does not mean that there is not a need for advocacy. In fact, the qualitative evidence that does exist, and which gives reasons for why advocacy might be needed, presents a very persuasive case for the necessity of advocacy for disabled people.

More information is needed about the number of people at risk of losing choice and control in these situations who may be able to benefit from independent advocacy. More information is needed about what services exist to meet this need and, where such services are available, about the levels of unmet need. Primary research is needed to define and describe the extent and nature of need in each of the four situations. In particular, we need to know, from disabled people themselves, why they seek independent advocacy input and what they hope such input will achieve.

## 6.2     Describing and evaluating the benefits of independent advocacy

Overall, this review has demonstrated that there is a paucity of robust research which has investigated the benefits of independent advocacy for disabled people. However, it has highlighted that there is an important distinction to be drawn between benefits associated with the **process** of independent advocacy and benefits resulting from the **outcomes** of this process. The research reported in this review also found that outcomes from advocacy may not always be perceived as benefits, even where the process of advocacy is perceived as positive by those involved. This distinction, and the lack of a clear causal relationship between a positive process and a positive outcome, is a key finding of this review and one which warrants further research attention. In particular, we need to know more about the other confounding factors that intervene to affect the outcomes of independent advocacy.

Evidence of the effectiveness of independent advocacy for disabled people at **transition to adulthood** is limited. There are some good quality studies, but further work is required in this area to establish a solid evidence base. To date, these studies suggest that advocacy input at transition may lead to:

- increased involvement and better quality involvement of young disabled people in transition planning

- a positive impact on the behaviour and knowledge of other professionals

- advocating for better quality provision post-transition

- benefits in terms of personal development (ie increased confidence and self-esteem, raised expectations about what is possible, and a more positive self-identity as a disabled person).

There is a stronger evidence base in relation to advocacy input for **disabled parents whose children are subject to safeguarding procedures**, but this is still limited in size and scope, particularly for parents with physical/sensory impairments. Further research is needed to explore how independent advocacy can benefit these parents. The evidence that exists shows that benefits of advocacy input for disabled parents in this situation include:

- increased and better quality involvement of parents throughout the child protection process, including increased understanding of the process by parents

- increased knowledge and understanding among other professionals of the needs of disabled parents

- better communication between parents and professionals

- positive impact on empowerment and personal development of parents involved in child protection proceedings (in terms of an increased understanding of the reasons for loss of custody of their child, where this was an outcome).

There were no studies retrieved that specifically explored the benefits of independent advocacy for **disabled people at risk of entering residential care**. There were evaluations of services which might be used by people in this situation but, in general, the evidence base in this area is lacking in terms of quantity, quality and scope. More primary research is needed to explore the potential process and outcome benefits of independent advocacy for this group.

There is very little research exploring the benefits of independent advocacy for **disabled victims of crime** particularly from their own perspective. There is very limited evidence relating solely to professionals' views of the impact of advocacy input for vulnerable adults who have been victims of abuse. More primary research is needed, from the perspective of disabled victims themselves, to explore process and outcome benefits of advocacy for those in this situation.

We found just one study exploring the benefits of advocacy for **disabled offenders**, both from the perspective of disabled people themselves and professionals working with them in a high-security hospital. Benefits of advocacy input included getting rid of anger and improved access to useful information. This research needs to be built on to establish a solid evidence base of the benefits of an independent advocacy service in this type of setting and other types of custodial setting. Further primary research is also needed to explore the impact of advocacy input at other stages of the criminal justice process, from first contact with police, through court and post sentencing.

To sum up, across all four areas, the review has highlighted a need for larger scale studies, with larger samples, and multiple service settings, using comparative approaches, as opposed to small-scale, case studies which have previously characterised research in this domain. There is a need for research to explore the longer term outcomes of independent advocacy. Future research will also need to investigate the variables that affect both the process and outcome benefits of independent advocacy, so that the factors determining the effectiveness of advocacy intervention are clearly understood.

## 6.3 Quantifying the costs of independent advocacy and assessing cost effectiveness

We found just one study that estimated the costs of providing advocacy input to parents with learning disabilities involved in child protection proceedings, and contrasted this with the costs of adoption. It suggested that advocacy and support to enable parents with learning disabilities to maintain custody of their child at home is cheaper than the costs of adoption. However, its focus was solely parents with learning disabilities and the scenarios associated with other groups of parents are likely to involve different sets of costs. Moreover, this study only looked at the costs, it did not evaluate the benefits of each scenario for those involved. Evaluating the cost effectiveness of such services may prove to be more complex, given the likely difficulty of identifying outcomes that both professionals and parents agree constitute 'success'.

The research related to the Independent Mental Capacity Advocate (IMCA) service contains data about time spent working on referrals and this includes change of accommodation referrals and adult protection cases. Similarly, there is some data about time spent on providing advocacy within a high-security hospital.

One of the studies reviewed in relation to the need for independent advocacy for disabled people at risk of entry to residential care provided some estimates of the cost of the service. However, this was a general advocacy service for older people and it was not cost-benefit analysis. One US study explored the savings of an advocacy intervention, but did not consider the costs of the service.

There is, therefore, a need for cost-effectiveness analysis in all four areas considered in this review. These would need to accurately explore the costs involved in providing independent advocacy in each of the situations and quantify both the process and outcome benefits related to the advocacy intervention.

## 6.4    Researching the need, benefits and costs of independent advocacy: next steps

The purpose of this review was to systematically identify, evaluate and synthesise the evidence relating to the need, the benefits and the costs associated with independent advocacy for disabled people at risk of losing choice and control in four specific situations. The report has summarised key themes from the UK and international research literature and highlighted the extent and nature of gaps in the current evidence base.

What is now needed is further exploratory research, designed to fill some of the gaps identified in this report, specifically in terms of costs, outcomes and cost-effectiveness. Such research would need to collect detailed information about the costs, benefits and impact of independent advocacy for disabled people in each of the four situations, and an assessment of the overall cost-effectiveness of

independent advocacy input across and within each setting. This is likely to include detailed service mapping, costs collection (of service unit costs and costs of independent advocacy use by disabled people), and an examination of the experiences of disabled people before and after advocacy input to assess the perceived benefits.

We have developed a 'framework paper' which sets out a proposed framework for future research to investigate the cost-effectiveness of independent advocacy in the four areas considered in this report. This is now available from the Office for Disability Issues website.

# Glossary and References
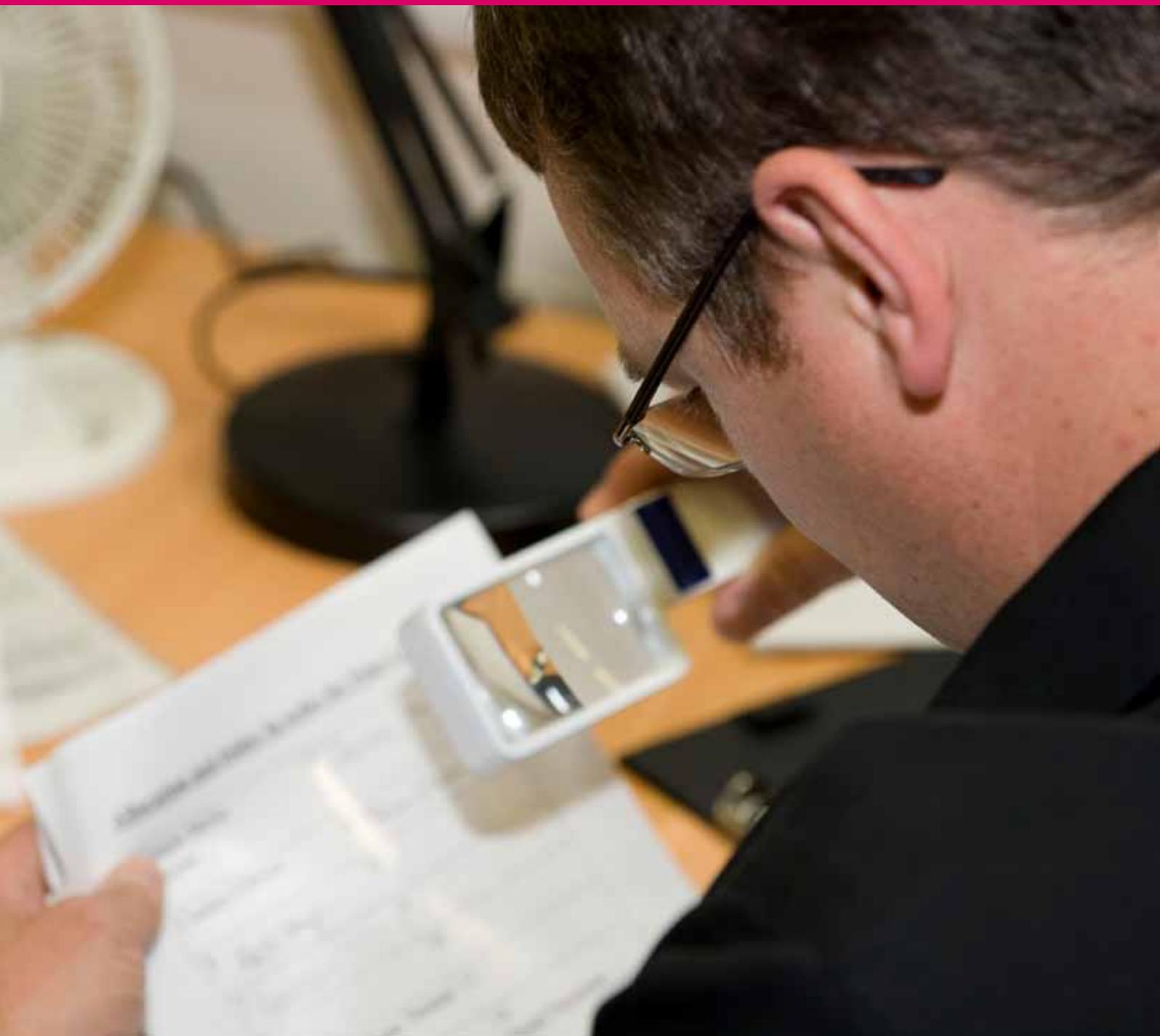
# Glossary and References

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|---|---|
| ACUK | Advocacy Consortium UK |
| AHDC | Aiming High for Disabled Children |
| ADHD | Attention deficit hyperactivity disorder |
| BME | Black and minority ethnic |
| DH | Department of Health |
| DRC | Disability Rights Commission |
| EHRC | Equality and Human Rights Commission |
| IMCA | Independent Mental Capacity Advocate |
| ODI | Office for Disability Issues |
| OPAAL | Older People's Advocacy Alliance |
| PAs | Personal Assistants |
| SEN | Special Educational Needs |
| TSIM | Transition Services Integration Model |
| WASSR | Westminster Advocacy Service for Senior Residents |

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# Annexes
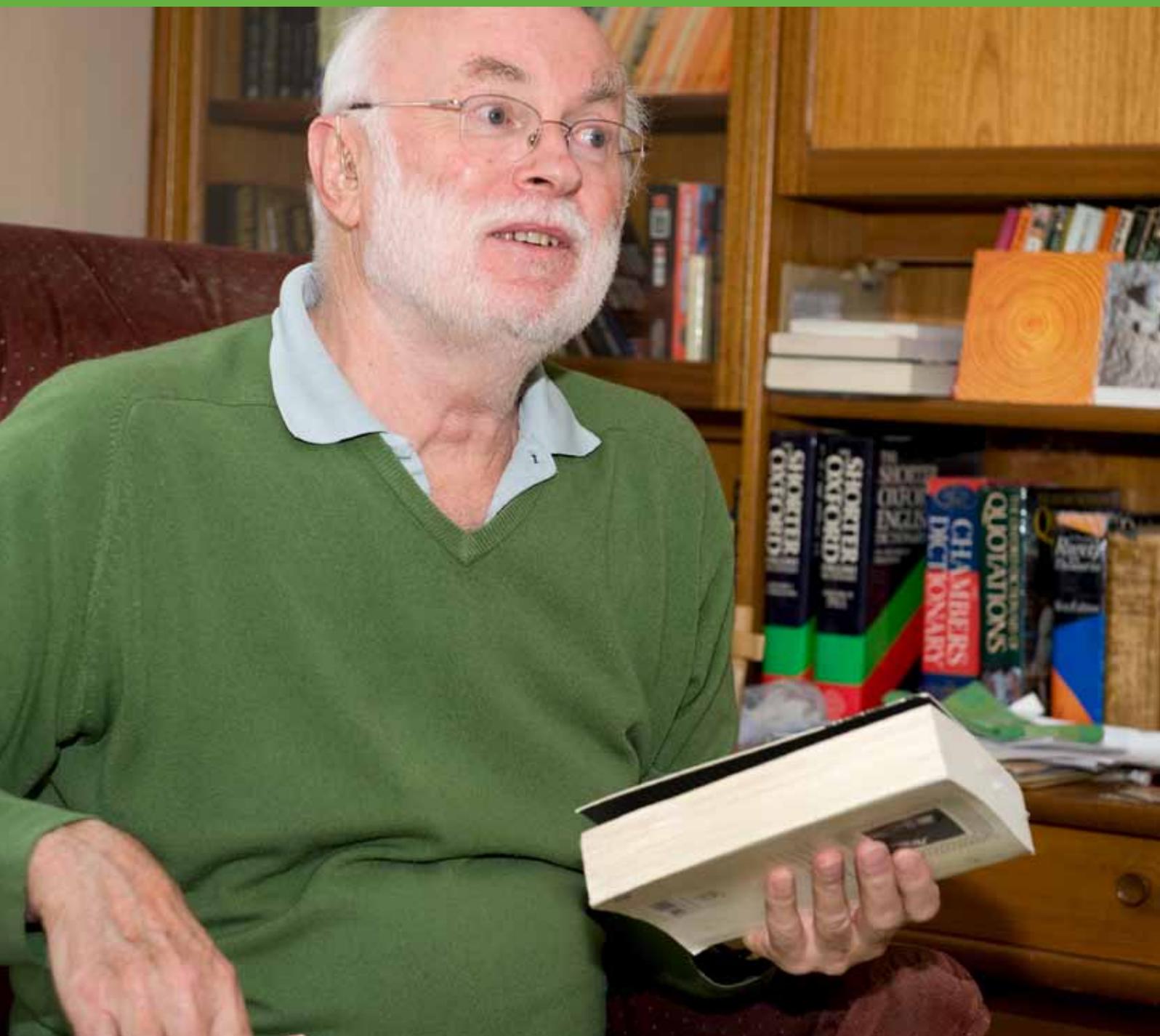
# Annexes

## Annex 1 – Systematic search of bibliographic databases

### Databases used

Our primary search strategy was to conduct a systematic search, using the following databases:

- CSA Illumina (includes Sociological Abstracts, Social Services Abstracts, Applied Social Sciences Index and Abstracts)

- CINAHL/IBSS

- Social Care Online (via Social Care Institute for Excellence and including former CareData)

- Social Sciences Citation Index (SSCI) via Web of Science.

We ran searches for all publications since 1997 and in English only (to include all English using countries, not just the UK). These databases were chosen to reflect the widest range of literature available, and because they were available via the University of Bristol's e-library portal.

### Search terms and inclusion criteria

We used free text terms and Boolean operators as specified by the database used to conduct systematic searches in each of the four topic areas. All database searches involved choosing the 'advanced' function to limit the number of documents retrieved. If available, we chose the option 'search abstract only' to avoid including reference lists in the search.

The key terms used for the systematic search were as follows:

## Primary search terms (PSTs)

learning dif* OR mental retardation OR mental handicap OR mental health OR mental illness OR mental disease OR mental disorder OR schizophreni* OR psychosis OR psychotic OR bipolar disorder OR depression OR depressive OR autis* OR aspergers OR ADHD OR ADD OR disab* OR impairment OR high support needs OR PMLD OR challenging behaviour OR blind* OR deaf* OR down's syndrome

## Secondary search terms (by theme)

#1    Transition

#2    Parent*

#3    Residential care – residential* OR nursing care OR care homes OR extra care housing OR special hospitals OR older people OR high support needs OR dementia OR elderly OR complex

#4    Anti-social behaviour – offend* OR forensic OR anti social behaviour OR bullying OR harassment OR abuse OR ASBO OR appropriate adults OR intermediar* OR crime OR victim OR courts OR criminal justice system OR police

The following searches were run, using the databases specified above:

- PSTs + #1 + advoca*

- PSTs + #2 + advoca*

- PSTs + #3 + advoca*

- PSTs + #4 + advoca*

Inclusion criteria for tagging included:

- English language version available.

- Reference dated between 1997 and 2008.

- Record was specifically related to chosen definition of advocacy and/or each of the four main topic areas as explained in Chapter 1.

- Record related to quantitative or qualitative research (not commentary material).

Abstracts, where available online, were then sought for the tagged references. These were scanned in respect of the above inclusion criteria, and a decision made about whether or not to obtain a copy of the full article or reference. Where items were excluded, the reasons for this were noted. Full copies of papers which met the inclusion criteria were downloaded or ordered, this also happened where it was not possible to judge from the abstract if the inclusion criteria were met or not.

## Systematic search records by topic area

| Topic Area | Number of hits | Number tagged | Number reviewed |
|---|---|---|---|
| Transition PSTs + #1 + advoca* | 88 | 15 | 10 |
| Disabled parents PSTs + #2 + advoca* | 561 | 22 | 11 |
| Residential care PSTs + #3 + advoca* | 596 | 18 | 5 |
| Anti-social behaviour PSTs + #4 + advoca* | 436 | 43 | 8 |

## Transition:

A total of 15 items (from 88 hits) were identified and obtained via systematic review. Five of these were subsequently excluded at the review stage (not research, not relevant) and the remaining 10 were critically reviewed. Additional items were located via other sources/contacts, grey materials review and hand-searching of specific journals. Of these, 13 were included for critical review, and the remainder were read for background and context, but not critically reviewed. Thus a total of 23 items were critically reviewed for Chapter 2.

## Disabled parents:

A total of 22 items (from 561 hits) were identified and obtained via systematic review of electronic databases. Of these, 11 were included for critical review, and 11 were excluded as not relevant or not meeting the criteria for inclusion. Twenty one additional items were located via other sources/contacts, grey materials review and hand-searching of specific journals. Of these, 16 were included for critical review, and 11 were read for background and context, but not critically reviewed. Thus a total of 27 items were reviewed for Chapter 3.

## Residential care:

A total of 18 items (from 596 hits) were identified and obtained via systematic review of electronic databases. Of these, five were critically reviewed, eight were read for background and context and five were excluded as not relevant or not meeting criteria for inclusion. The search of the AgeInfo database identified nine documents which were critically reviewed. Four additional items were located via other sources/contacts, website searches, grey materials review and hand-searching of specific journals and were included for critical review. Three more were read for background and context, but not critically reviewed. Thus a total of 18 items were reviewed for Chapter 4.

## Anti-social behaviour:

A total of 43 items (from 436 hits) were identified as potentially relevant to this study. Thirty five of these were subsequently excluded at the review stage (not research, or research but findings not relevant or not relating to advocacy as we define it). Eight of those met the criteria for inclusion in the critical review. Additional items were located via other sources/contacts, grey materials review and hand-searching of specific journals. Of these, 14 were included for critical review, and the remainder were read for background and context, but not critically reviewed. Therefore, a total of 22 items were reviewed for Chapter 5.

# Annex 2 – Grey literature search

In addition to the systematic search of formal literature, the research team also searched for grey material, held in reports or unpublished form.

The nature and robustness of the grey material collected was varied and included:

- Research-related literature such as student theses and dissertations, evaluation reports of single services, or small number of linked services, research reports for single services which report on the needs of specific client populations

- Service data – for example, details of time/costs of providing advocacy in different situations to specific clients

- Service background information (booklets, handbooks)

- Training packs

- Information packs (for those wanting to set up advocacy services).

The grey literature search involved the following actions:

- Direct requests to project advisers.

- Searching of specialist databases/libraries: AgeInfo database, BILD library catalogue.

- Postings and requests for information on relevant websites/email lists/discussion fora:

  - CHOICE forum

  - UK advocacy groups (via BILD)

  - UK Learning Disability Lecturers network

  - Right-support list (parents with learning disabilities)

  - The Parental Mental Health and Child Welfare Network (via Family Action)

- International Association for the Scientific Study of Intellectual Disabilities (IASSID) special interest group on parents with intellectual disabilities

  - IASSID special interest group on ageing

  - Transition Information Network

  - Transition Partnership

  - UK forensic and learning disability network.

- Direct contact with key informants overseas, via email and international 'special interest groups' and organisations, already known to the project team or suggested by advisers.

- Searching the websites of relevant voluntary groups and networks and Google searches using free-text search terms. Fifty five websites of relevant organisations that were either primarily advocacy-based or work within one of our four areas were searched for relevant resources and links (see table below). This search led to the retrieval of more than 25 documents. Not all of these met the criteria for inclusion in the critical appraisal, but they were all read for background and context and any relevant issues noted along with any further references to retrieve.

Following web and email postings, individuals circulated requests for information among their own networks and contacts. As a result of this work we have had contact with 15 different advocacy services, primarily based in the UK, some of whom have provided material of different types, such as basic costs data relating to their service provision.

# Websites or links

## Topic area: Transition

www.aje-dc.org
www.communitylivingresearch.swfs.ubc.ca
www.nyas.net (National Youth Advocacy Service)
www.oneforus.com
www.trans-active.org.uk

www.transitionsupportprogramme.org.uk

www.voiceyp.org (Voice – an advocacy organisation for young people in public care)

## Topic area: Parents

www.afdsrc.org

www.barnados.org.uk

www.disabledparentsnetwork.org.uk

www.dppi.org.uk – and hand searched on-line all back issues of DPPI Journal (back to 1992).

www.frg.org.uk

www.healthystart.net.au

www.idrs.org.au

www.mentalhealth.org.uk (Mental Health Foundation)

www.mind.org.uk

www.pmhcwn.org.uk – parental mental health and child welfare network

www.right-support.org.uk

www.supported-parenting.com

## Topic area: Residential

www.ageconcern.org.uk

www.alzheimers.org.

www.bjf.org.uk

www.dh.gov.uk/imca

www.helptheaged.org.uk

www.housingoptions.org.uk

www.opaal.org.uk

www.wassr.org

## Topic area: Antisocial behaviour

www.actionforblindpeople.org.uk

www.anncrafttrust.org

www.appropriateadult.org.uk

www.capability-scotland.org.uk/hatecrime

Disability Rights Commission – see www.equalityhumanrights.com

www.nacro.org.uk

www.respond.org.uk

www.scope.org.uk

## Topic area: Advocacy

www.actionforadvocacy.org.uk

www.advocacyforinclusion.org

www.advocacyresource.org.uk

www.equalsay.org

www.independentadvocacy.co.uk

www.u-kan.co.uk (UK advocacy network)

## Topic area: All[16]

www.arcuk.org.uk

www.bild.org.uk

www.bris.ac.uk/Depts/NorahFry

www.cassinfo.org.uk

www.csip.org.uk

www.equalityhumanrights.com

www.jrf.org.uk

www.mencap.org.uk

www.nas.org.uk

www.rip.org.uk

www.together-uk.org

www.valuingpeople.org.uk

www.viauk.org

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[16] This covers searches relating to all four areas, plus advocacy.

# Annex 3 – Reading tool and scoring criteria

| | |
|---|---|
| First reviewer | |
| Date of first review | |
| Second reviewer | |
| Date of second review | |

## (1) Overview of research

| | |
|---|---|
| Author, year | |
| Type of research | |
| Topic area | |
| Aims of the research | |

## (2) Research setting, sample and ethics

| | |
|---|---|
| Country/geographical spread | |
| Date research conducted | |
| Sample – size and who included? (prompt re: older people, younger people, BME groups, men, women) | |
| Sample – who excluded? | |
| How was the sample selected? | |

| Any ethical issues to note? (for example, evidence of ethical approval, consent, etc) State if no ethical information given, or not relevant | |
|---|---|

## (3) Methodology

| Methods – data collection | |
|---|---|
| Methods – data analysis | |
| Involvement of disabled people? | |

## (4) Key findings and relevance of research

| Key findings (esp: evidence of need, costs and benefits of advocacy in this particular setting) | |
|---|---|
| Gaps in the evidence noted by the authors | |
| Other gaps noted by reviewer | |
| If non-UK are findings applicable to UK setting? | |

## (5) Quality appraisal of evidence presented

| | |
|---|---|
| Score up to 13 based on consideration of following factors.<br><br>● Clear explanation of and rationale for methodology? (1-5)<br><br>● Appropriate sample type and size? (1-5)<br><br>● Reliability of conclusions? (1-3) | |

# Annex 4 – Quality appraisal scoring criteria

## Methodology:

1) Unclear – we don't know what was done exactly or why it was done.

2) Clear explanation, but inappropriate method for research question.

3) Reasonable method, but not very well written, not clearly explained.

4) Clear explanation and appropriate method.

5) Clear explanation of method, method totally appropriate to research question, thorough discussion of methodological issues and shortcomings.

## Sample size:

### Quantitative

1) Underpowered and making claims beyond what the data can show.

2) Small sample, but doesn't make unnecessary claims.

3) Reasonable sample but non-stratified.

4) Stratified sample.

5) Good sized stratified sample, acceptable power (explicit) and explicit about stratification.

## Qualitative

1)    Sample is too small and affects the depth of the analysis.

2)    Clearly biased sample, for example, excludes groups such as people with high support needs.

3)    Reasonable sized sample, but could still be biased.

4)    Adequate sample, fit for purpose.

5)    There is enough data for saturation point to have been reached (ie saturation of themes).

## Reliability of conclusions:

1)    Conclusions not justified – making claims well beyond data presented, evidence not trustworthy.

2)    Limited reliability – questions about quality of evidence for example, sample size, analysis not clear or elements missing.

3)    Conclusions well argued and appropriate to methods/sample – good quality evidence.

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