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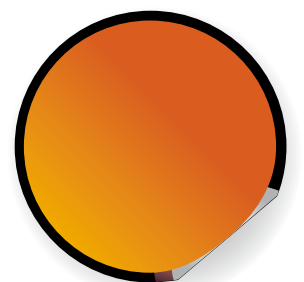


# Access to independent advocacy: an evidence review

## **Executive summary**

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## Introduction

The Independent Living Strategy committed the government to investigate the effectiveness and costs and benefits of advocacy support for disabled people in situations where they are particularly at risk of losing choice and control.

This review delivers on that commitment by systematically identifying, evaluating and summarising key themes in the evidence relating to the needs, costs and benefits associated with 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.

The searches for evidence related to people with mental health support needs, people with learning disabilities and people with physical or sensory impairments.

This report summarises the key themes and highlights gaps in the current evidence base.

## Defining independent advocacy

Independent advocacy<sup>1</sup> involves 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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<sup>1</sup>The following definition is adapted from [www.ageconcerncheshire.org.uk](http://www.ageconcerncheshire.org.uk)

According to leading voluntary sector organisations, core elements of independent advocacy include:

- separation from other forms of direct service provision, such as those provided by the public sector or local authorities
- independent governance
- independent funding arrangements (ie services are not directly funded by public bodies, but via other indirect means, such as pooled budgets).

This set of criteria may be seen as the ‘gold standard’ for defining advocacy services that are truly independent. However, in practice, few independent advocacy services meet this standard and therefore a wider range of independent advocacy services were considered in this review.

## **Current evidence**

The review demonstrated there is a very limited evidence base relating to the extent of the need for advocacy for disabled people in relation to all the areas considered. The existing evidence is mainly from small-scale qualitative studies making it difficult to generalise findings. This evidence is summarised in this booklet.

## **Levels of benefit**

The literature revealed an important distinction between the process of independent advocacy, and the outcome of this process. There were several studies where the outcomes were not always those desired by the disabled person, yet the support provided by the advocate during the associated processes was still regarded as positive by those involved.

## Independent advocacy for young disabled people during transition to adulthood

Reasons why independent advocacy may be needed during transition include:

- to ensure young disabled people's views are heard, while maintaining family involvement
- to support young disabled people who are looked after by the local authority or who are living away from their home area (eg in residential special schools or colleges)
- to promote better involvement of young disabled people in decision making
- to provide emotional support.

A limited evidence base suggests advocacy at transition may lead to:

- increased and better quality involvement of young disabled people in transition planning
- a positive impact on the behaviour and knowledge of professionals
- better quality service provision post-transition.

A small number of more robust studies suggest that advocacy during transition may lead to benefits in terms of personal development. For example:

- increased confidence and self-esteem
- raised expectations about what is possible
- a more positive self-identity as a disabled person.

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

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

The extent of potential need for independent advocacy in this context is not clear as there is no reliable data outlining numbers of disabled parents involved in safeguarding procedures. However, fragmentary findings from good quality research suggest need is likely to be high.

Reasons why disabled parents involved in safeguarding procedures need advocacy include:

- over-representation of certain groups in the child protection system, including 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 speak up throughout the child protection process
- the need to reduce institutional discrimination
- evidence that disabled parents want independent advocacy.

Small-scale, qualitative evaluations of services for parents with learning disabilities suggest advocacy can lead to:

- increased and better quality involvement of parents throughout the child protection process, including increased understanding of the process
- increased understanding of disabled parents' needs by professionals
- better communication between parents and professionals.
- a positive impact on the personal development of parents involved in child protection proceedings. This is primarily in terms of an increased understanding of the reasons for the loss of custody of their child, where this is an outcome.

There is not, as yet, conclusive evidence of a link between providing the context and resources for a positive process, and positive outcomes for the parents in terms of maintaining custody of their child. However, the research is lacking in terms of quantity and quality, so clear conclusions cannot be drawn.

Only one study was identified that looked at the costs of advocacy in this context. This suggested that advocacy and support, enabling parents with learning disabilities to maintain custody of their child, is cheaper than adoption.

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

No studies specifically researched the benefits of independent advocacy when entry to residential care is a possibility.

The high proportion of referrals to generic advocacy services, relating to a change of accommodation, suggests a need for advocacy in this area.

It is likely a large proportion of disabled people that enter residential care are 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.

The review found no research evidence of costs or cost-benefits of advocacy services for disabled people in this scenario.

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

### **Disabled victims of anti-social behaviour**

Disabled people are more likely to be victims of anti-social behaviour than the general population. However, they are less likely to report crime. Independent advocacy could play a role in addressing the barriers which have been shown to contribute to the under-reporting of crime. These include:

- not knowing how to report a crime, or having appropriate support to do so
- a feeling that the police do not take claims seriously and do not always investigate these appropriately.

One study with vulnerable adults who had been victims of abuse showed that in the majority of the cases reviewed, the advocate felt the goals of the advocacy were met and the abuse was stopped.

This review did not identify any research exploring the costs of independent advocacy services for disabled people who are victims of crime.

## Disabled perpetrators of anti-social behaviour

High-quality evidence shows high rates of prisoners with learning disabilities or mental health problems. Many of these are inappropriately placed and do not have appropriate support. One study showed over a fifth of prisoners with learning disabilities did not understand proceedings during their court case. They identified the need for someone to explain difficult words to them. Once in prison they also 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 more access to useful information.

High costs are involved with prison placements. There is no research about the costs and benefits of schemes aiming to divert disabled offenders from prison.

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

Primary research is needed to define and describe the extent and nature of the need for independent advocacy in the four situations. More information is also needed about:

- the numbers of people at risk of losing choice and control in these situations who may benefit from independent advocacy
- what services exist to meet this need and
- where such services are available, the levels of unmet need.

There is a need for larger scale studies, with larger samples and multiple service settings, using comparative approaches. These would increase the extent to which any findings can be generalised to different locations and services. There is also a need for research to explore the longer term outcomes of independent advocacy.

Future research should identify the factors determining the effectiveness of advocacy intervention. For example, the evidence showed certain factors which appeared to improve the level of process benefits and outcome benefits described above. These included:

- a relationship built on trust and developed over time
- credibility and ‘clout’ with other providers
- the advocate acting as an educator, mediator and campaigner
- a clearly defined role for the advocate, which includes a number of key components relating to specific and specialist skills, knowledge and experience.

There is an urgent need for cost-effectiveness analysis in the four areas considered. This 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.

### Further reading

The full report of this evidence review is available from the Office for Disability Issues (ODI).

Alongside this review the ODI has published ‘A framework for research on costs and benefits of independent advocacy’. Its purpose is to describe how evidence can be collected to fill the information gaps identified in this review. The framework document suggests a research methodology to investigate the costs, outcomes and cost-effectiveness of independent advocacy for disabled people, in each of the four situations covered by this review.

Both of these documents are available on the ODI website:

[www.odi.gov.uk/research/research-reports.php](http://www.odi.gov.uk/research/research-reports.php)



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