

Advocating for Equality

By Wendy Lewington and Caroline Clipson



Independent Advocacy Campaign

The members of the IAC are:

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Understanding learning disability



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1 Executive Summary

The Independent Advocacy Campaign (IAC) was established by Scope in 2001 as a response to the perceived lack of independent advocacy provision available for people with physical, sensory, communication and profound and multiple impairments. The members of the consortium include disability organisations, service providers and advocacy umbrella organisations.

The IAC definition of advocacy is *“taking action to help people say what they want, secure their rights, represent their interests and obtain services they need”*.

The IAC decided to undertake some research to determine whether there is a lack of advocacy provision for adults with physical, sensory, communication and profound and multiple impairments in England, and if so, to provide recommendations to improve this situation. A questionnaire was sent to 754 organisations listed on all known advocacy databases. In all, 155 responses were received.

Aims of the Research

The aims of the research were:-

- to establish the level of advocacy provision for people with physical, sensory, communication and profound and multiple impairments
- to make recommendations to Government, policy-makers and others on how to ensure that people with sensory, physical, communication and profound and multiple impairments are able to access appropriate independent advocacy provision
- to identify what support and resources current advocacy providers would require to develop their schemes to include people with physical, sensory, communication and profound and multiple impairments
- to establish whether local authorities have a local advocacy plan and whether advocacy providers feel this would be beneficial in their area

Main Findings

The main findings from the research were:-

1. Many disabled people with physical, sensory, communication and profound and multiple impairments would benefit from the support of an independent advocate.
2. There is inadequate independent advocacy provision, especially for people with physical, sensory, communication and profound and multiple impairments.

3. The main causes of lack of independent advocacy provision are funding issues and a lack of skills and experience around working with these groups of people.
4. The types of independent advocacy undertaken by advocacy schemes may not always meet the needs of these groups of people.
5. There is very little evidence of advocacy plans at a local level, but overwhelming support for their development among advocacy schemes.

Recommendations

This report has shown that people with physical, sensory, communication and profound and multiple impairments are less likely to be able to access advocacy than other disabled people. If implemented, the recommendations outlined below will lead to an increase in advocacy provision for all disabled people, but particularly those people with profound and multiple impairments and communication impairments who may be among those most in need of this kind of support.

Recommendations include:-

National Government

- Provide greater financial support for advocacy provision, ensuring that all disabled people have access to independent advocacy provision that is suitable for their needs.
- Place a statutory requirement on local authorities to produce a local advocacy plan, which will outline how advocacy provision will be developed in the area, how different groups will be served and how funding dedicated to advocacy will be spent.
- Allocate responsibility for this issue to a single department or body to ensure co-ordination of the Government's strategy on advocacy including the promotion and monitoring of local advocacy plans and the allocation of funding for the development and dissemination of good practice.

Local Government and Health Bodies

- Consider how funding for advocacy can be increased and allocated to ensure the needs of a broad range of people can be met, particularly people with physical, sensory, communication and profound and multiple impairments.
- Develop local advocacy plans in conjunction with advocacy schemes, users of advocacy, disabled people and disability groups.
- Consider nominating one individual to be charged with co-ordinating production, dissemination and monitoring of the plan at a local level.

Funders

- Acknowledge that to develop advocacy for the groups of people discussed in this report can take a considerable amount of time and this needs to be considered in all aspects of funding and commissioning.
- Positively encourage applications from advocacy schemes who provide advocacy for a wide range of people.

Members of Parliament, Councillors and other Key Decision Makers

- Identify what independent advocacy provision exists in their local area, make contact and offer support in fulfilling the recommendations in this report.
- Encourage civil servants, local authority officers, colleagues and others to consider the recommendations relevant to them and explore how they can be taken forward.

Advocacy Schemes and Networks

- Advocacy schemes to consider ways to make their provision meet the needs of a broad range of people by working closely with local authorities and local disability groups to identify unmet advocacy needs and tapping into local and national sources of support and information.
- Advocacy networks to continue to encourage the development of advocacy provision which meets the needs of a broad range of people by facilitating greater development, dissemination and sharing of good practice on advocacy provision for people with physical, sensory, communication and profound and multiple impairments.

Service Providers

- Service providers should actively encourage the use of independent advocacy in their services by identifying and working in partnership with local advocacy schemes; providing training to advocacy schemes on issues that impact on the users of their service and providing training to their staff that will encourage a positive attitude towards advocacy.

Conclusion

The IAC would recommend to Government that following the results of this research, it gives urgent consideration to the advocacy needs of people with physical, sensory, communication and profound and multiple impairments. The evidence from this research suggests that these groups have very limited access to independent advocacy, despite the fact that they may be among the most in need of such support.

The consequences of this are that many people with physical, sensory, communication and profound and multiple impairments are less likely to obtain services they are entitled to, have their voices heard and have maximum involvement in the decisions affecting their lives. By increasing their access to independent advocacy, the Government would enable people with physical, sensory, communication and profound and multiple impairments to have a greater chance of achieving equality of opportunity, choice and control over their lives.

2 Introduction

The Independent Advocacy Campaign (IAC) was established by Scope in 2001 as a response to the perceived lack of independent advocacy provision available for people with physical, sensory, communication and profound and multiple impairments. The members of the consortium include disability organisations, service providers and advocacy umbrella organisations.

The consortium acknowledged the positive impact the White Paper, **Valuing People**, has had on the further development of advocacy provision for people with learning disabilities. However, there were concerns that no plans have been made in relation to the specific advocacy needs of people with physical, sensory, communication and profound and multiple impairments.

All members of the IAC had experienced difficulty trying to support people with physical, sensory, communication and profound and multiple impairments access advocacy provision. The Citizen Advocacy Information and Training (CAIT) List of UK Advocacy Schemes is the only database that identifies which groups of people are served. From their 2002 list, less than 10% of the 571 schemes stated that they provide advocacy for people who did not come under the learning disability, elderly or mental health groups.

The IAC has undertaken this research to determine whether there is a lack of advocacy provision for adults with physical, sensory, communication and profound and multiple impairments in England, and, if so, to provide recommendations to improve this situation.

3 Background

3.1 What is Independent Advocacy?

There are many different definitions of advocacy in existence. In 2002, the Independent Advocacy Campaign adopted the following definition of advocacy:-

“Advocacy is taking action to help people say what they want, secure their rights, represent their interests and obtain services they need.”

Essentially, advocacy is about empowering people, so they may be more actively involved in the decisions that affect their lives. A good advocate will possess the skills not only to assist a person speak up for themselves but also to establish what their preferences are, even when they cannot be communicated in conventional ways. They will also respect the particular needs and values of people from different minority ethnic communities or faith groups.

An advocate is not there to express or impose their own views but to act as a facilitator, supporting the individual to express their views. In addition, the advocate should be independent of the organisation an individual or person is dealing with to ensure there is no conflict of interest.

3.2 Why is Access to Independent Advocacy Important?

Some people with physical, sensory, communication and profound and multiple impairments will be able to deal with all aspects of their lives themselves and will not need to have access to an independent advocate. Others will have friends, family, colleagues and neighbours who can help and support them in dealing with these issues.

However, many people with physical, sensory, communication and profound and multiple impairments may find access to independent advocacy a vital tool in maintaining their independence, obtaining services they are entitled to, getting their voices heard and having control over decisions affecting their lives.

This is partly because people with these impairments are often significant users of statutory services and support, such as domiciliary care and means-tested benefits, which are frequently overstretched and difficult to access. In addition, they are often subject to discrimination and social exclusion and may find access

to an independent advocate an important means of overcoming barriers of prejudice and ignorance which can affect how they are treated by others.

CASE STUDY ONE: OVERCOMING PREJUDICE

Beth is a 47-year-old woman who uses a wheelchair and has a communication impairment.

“Up until three years ago, I had spent my whole life in homes, going from one home to another. For a long time I told social workers and care staff that I wanted my own flat, to live independently, but I was always told ‘Don’t be silly, you can’t manage on your own, you’re better off in a home.’

“At my last home they’d make me get ready for bed at 6.30pm – I’m a grown woman! I’d sit in the garden in my nightie, just so I could be on my own.

“Then an advocate began to visit the home where I lived, and talked about independent living. It sounded really interesting and I started to talk to him.

“I told the advocate I wanted to move out, and he began to help me, getting on at the local Authority and negotiating for me. It took a long time, but now I have my own flat and live independently. I employ four carers through direct payments, and have even been involved in developing the National Care Standards.”

3.3 Recent Policy and Research on Advocacy

Successive governments have highlighted the importance of independent advocacy for adults and showed an appreciation of the valuable role it can play in supporting people to access vital services and ensure their rights are protected. For example, the National Minimum Standards for Care Homes for Younger Adults (December 2001) mentions advocacy in a number of contexts including the use of advocates to support people in drawing up care plans, contracts and being involved in decision making.

However, the Government’s White Paper, **Valuing People** (March 2001), also acknowledged that advocacy provision is patchy. As a result, it announced an allocation of £1.3 million per year for three years to develop citizen advocacy and self-advocacy for people with

learning disabilities. Whilst this was widely welcomed, it did not seek to address the perceived lack of independent advocacy provision for other groups of disabled people.

In the last few years there has also been a growing body of research into the level of provision and effectiveness of advocacy for different groups of people. This has included an evaluation of the Sense advocacy project for deafblind people (Harding, 1996), an assessment of mental health advocacy for black and ethnic minority groups (A Rai-Atkins et al 2002) and research into specialist mental health advocacy (Barnes et al 2002). There has also been research into advocacy provision for the elderly (A. Quinn et al 2003), for those with dementia by Dementia North (Cantley et al 2003) and advocacy and autism (The National Autistic Society, 2003).

More recently, the Disability Rights Commission has also commissioned a report on advocacy. This aims to explore and analyse the current and proposed legal framework for decision-making for disabled people and what legal systems are in place to safeguard the interests of disabled people when there is an issue around capacity to make decisions.

(For a more detailed overview of recent advocacy-related legislation and policy, please see appendix 1.)

4 The Aims and Objectives of the Research

The IAC decided to conduct this research in order to:-

- establish the level of advocacy provision for people with physical, sensory, communication and profound and multiple impairments
- make recommendations to Government, policy-makers and others on how to ensure that people with sensory, physical, communication and profound and multiple impairments are able to access appropriate independent advocacy provision
- identify what support and resources current advocacy providers would require to develop their schemes to include people with physical, sensory, communication and profound and multiple impairments
- establish whether local authorities have a local advocacy plan and whether advocacy providers feel this would be beneficial in their area

5 Methodology

A questionnaire was circulated to all organisations listed on the databases held by the following organisations: Citizen Advocacy Information and Training (CAIT), Advocacy Across London, National Advocacy Network and British Institute of Learning Disabilities (BILD). This amounted to a total of 754 organisations.

The questionnaire was initially piloted with 10 advocacy projects, and various changes were made. It was then emailed to 384 organisations and posted to 370 with a freepost return address. Fifty-two of those who were emailed surveys were then followed up with a paper copy due to people having difficulties accessing the electronic version.

Respondents had four weeks to complete the survey and return it. Follow-up emails and telephone calls were made to non-respondents. A large number of follow-ups revealed that the organisation wasn't a direct advocacy provider, no longer existed or had moved premises with no forwarding address. In total, 155 schemes responded to the survey.

In addition to the main survey, a separate form was sent to 272 local authorities, county councils and district councils asking for information on their advocacy plans. We received 38 responses to this request.

6 Main Findings

The survey asked advocacy schemes about their current advocacy provision, especially for people with physical, sensory, communication and profound and multiple impairments. It also aimed to identify what factors would assist them to provide advocacy for these groups of people. Schemes were also asked about advocacy provision in their local area and whether they felt a local advocacy plan would be beneficial. (For a comprehensive overview of all results please see Appendix 2).

The following were the main findings from the research:

1. Many disabled people with physical, sensory, communication and profound and multiple impairments would benefit from the support of an independent advocate.
2. There is inadequate independent advocacy provision, especially for people with physical, sensory, communication and profound and multiple impairments.
3. The main causes of lack of independent advocacy provision are funding issues and a lack of skills and experience around working with these groups of people.
4. The types of independent advocacy undertaken by advocacy schemes may not always meet the needs of these groups of people.
5. There is very little evidence of advocacy plans at a local level, but there is overwhelming support for their development among advocacy schemes.

CASE STUDY TWO: THE BENEFITS OF ADVOCACY

James, 32, is a wheelchair user and has a communication impairment.

“I live at home with my mum and dad. I was receiving the lower level of Disability Living Allowance. A friend who works at an advocacy project thought I should be on the higher level. I tried to fill out the forms but found it difficult. My mum was scared that I would lose my benefits and tore up the form. My friend became my advocate and helped me talk to my mum and fill out the forms. At first I was turned down so we had to appeal but now I get the higher level. It made me realise how important advocacy is and I have now trained to be a peer advocate.”

6.1 Who is Accessing Advocacy?

The results from the survey revealed that advocacy schemes are far less likely to provide advocacy for people with communication impairments and profound and multiple impairments than any other groups of people.

Table 1. *Who do you see as being your main client groups for advocacy provision?*

Learning disability	52%
Mental health issues	41%
Elderly	28%
Physical impairments	27%
Sensory impairments	18%
Black and ethnic minority	17%
Profound and multiple impairments	11%
Communication impairments	10%

Note: Percentages total more than 100 because respondents could choose more than one option.

However, over half of the respondents stated that they would like to provide advocacy for a wider range of people in the future.

6.2 What are the Key Factors Influencing Provision?

Respondents who don't currently provide advocacy for these groups of people were asked about key factors preventing them from doing so. They were also asked what would enable them to provide advocacy for people with physical, sensory, communication impairments and profound and multiple impairments in the future.

In addition, the schemes that do provide advocacy for people with people with physical sensory, communication and profound and multiple impairments were asked what factors enabled them to provide advocacy for these groups of people.

The key factors that influence a scheme's ability to provide advocacy for these groups of people can be divided into two main areas: funding issues and perceived level of skills and experience.

Funding: Almost half of the respondents stated that lack of funding was preventing them from providing advocacy for these groups of people. However, the issue of funding is more complex than a straightforward lack of money, with almost a third of respondents also stating that service level agreements do not encourage work with these groups of people.

As the majority of schemes stated they were funded by local and health authorities, it is important that these authorities review their current funding criteria to ensure it is encouraging advocacy schemes to be inclusive and work with a broad range of disabled people.

This review of funding criteria should also consider the timeframe that schemes are funded for. The majority of respondents (57%) stated they were funded for up to two years. Developing meaningful advocacy partnerships with people who have communication impairments and profound and multiple impairments is often a very lengthy process. Appropriate staff need to be recruited and trained. The process of getting to know a person and understanding their way of communicating can take months, and may involve a number of different techniques such as shadowing, working with other key staff and developing a communication passport. This process will often take longer than two years and advocacy schemes need to be confident of the longevity of their project, prior to committing to an individual in this situation.

Similarly, it is important that outcomes for monitoring the success of an advocacy project take into account the amount of time it may take to work with one client. In addition, the success of advocacy is always going to be difficult to measure due to the qualitative nature of the work. Funders need to take this into account when negotiating project outcomes with advocacy schemes.

CASE STUDY THREE: TIME TAKEN TO FIND THE RIGHT ADVOCATE

A co-ordinator of one citizen advocacy scheme stated: “We have 50-60 citizen advocates volunteering for our scheme, and yet we still had a young man with very complex communication issues and challenging behaviour on our waiting list for nearly two years. It was vital for him that we matched him with the right advocate who could commit long term to work with him, and had the skills and confidence to develop a partnership with him. It was worth waiting as the partnership is developing well. He has been disappointed many times before; he didn’t need to be let down again.”

Skills and Experience: Lack of specialist skills and experience was also cited as being a significant factor preventing schemes from providing advocacy for people with physical, sensory, communication and profound and multiple impairments.

Groups that do provide advocacy for people with sensory, physical, communication and profound and multiple impairments saw that their knowledge of the issues that affect these groups, as the main factor in enabling them to provide advocacy for these people.

To ensure that these groups of people have access to independent advocacy in the future, advocacy schemes need the opportunity to develop skills and experience to work with them. Advocacy schemes should have the opportunity to access training such as disability awareness training, disability specific training (e.g. working with people with an autistic spectrum disorder) and communication aids training.

There also needs to be greater development and dissemination of good practice guidance around advocacy provision for people with physical, sensory, communication and profound and multiple impairments. Several organisations and schemes have produced information on advocacy provision for these groups of people. For example, BILD has produced guidelines on providing advocacy for people with learning disabilities and high support needs (BILD, 2003). Also, Asist, an advocacy scheme in Staffordshire has produced guidance on the use of 'Watching Brief'. This is an alternative form of advocacy used when an advocate is unable to obtain a view or a consistent view from the person they are working with (Asist, 2002).

It is important that we continue to develop this area of work and funding is made available to organisations and schemes to develop and share good practice.

6.4 What Types of Advocacy Are Being Provided?

Approximately two-thirds of respondents provided more than one type of advocacy. Issue-based/case-work was the most frequent type of advocacy provided, with 77% of respondents involved in this form of advocacy. Some 45% of respondents stated they provide citizen advocacy and 45% self-advocacy.

It is positive to see that the majority of advocacy schemes do provide more than one type of advocacy, and therefore will be able meet a greater range of needs.

When developing advocacy provision for the groups of people discussed in this report, schemes need to be flexible and creative in the approaches they use. There are many issues that need to be considered such as:

- The time it can take to develop an effective partnership with someone, especially if they have communication impairments.
- People's understanding of advocacy and the impact this will have on referrals, both self-referral and third party referrals.
- Difficulty recruiting and retaining advocates, both paid and volunteers, with the appropriate skills and characteristics.

It is important then that other types of advocacy are also considered, such as peer advocacy, and that advocacy schemes have the resources to provide a range of advocacy types to meet the needs of a broad range of people.

CASE STUDY FOUR: THE BENEFITS OF OUTREACH

Barry is 40 years old.

"I use a wheelchair and sometimes people have difficulty understanding me speak. I used to live in a home with a lot of other people. The home was run by a charity.

"When I was at the home an advocate used to come and visit us once a week. At first I didn't know what he did. But he explained that we could talk to him if we had a problem or wanted help to get something sorted.

"One day I was accused by another resident at the home of hitting them. It was awful. I had to speak to the police and everything. I went to the advocate. I knew he could help and support me, as I'd got to know him and what he did.

"The advocate really helped me. I don't know if I would be here today if it wasn't for him. I could not have coped without him."

(For definition of types of advocacy, please refer to Appendix 3.)

6.5 Is There Enough Local Advocacy Provision?

Over 94% of respondents felt there was not enough advocacy in their local area to meet the current need, and 92% felt a local advocacy strategy would be beneficial. At present, local authorities are not required to fund advocacy or have a local advocacy plan, although it is “highly recommended” for Learning Disability Partnership Boards, set up following **Valuing People**, to develop an advocacy plan.

Of the 38 local authorities who responded to our survey, two stated they have an advocacy strategy, two included advocacy in other policy documents and three stated they were currently developing an advocacy strategy.

Whilst there is no system in England to ensure that every local area has an advocacy strategy, this is a requirement in Scotland. In addition, the Advocacy Safeguards Agency (ASA) is funded by the Scottish Executive Health Department to further the Executive’s commitment to advocacy.

The ASA has four main tasks:

- To work with NHS boards and local authority commissioners to facilitate the development of independent advocacy across Scotland
- To evaluate independent advocacy organisations
- To develop policy and good practice in relation to independent advocacy
- To research independent advocacy

The Scottish Executive is also providing three years funding to develop a consortium called the Scottish Independent Advocacy Alliance, which aims to ensure advocacy is available to any vulnerable person that needs it in Scotland.

Adoption of a similar statutory model and mechanisms in England could help to ensure greater advocacy provision for people with physical, sensory, communication and profound and multiple impairments.

7 Recommendations

This report has shown that people with physical, sensory, communication and profound and multiple impairments are less likely to be able to access advocacy than other disabled people. If implemented, the recommendations outlined below will lead to an increase in advocacy provision for all disabled people, but particularly those people with profound and multiple impairments and communication impairments who may be among those most in need of this kind of support.

7.1 National Government

- Provide greater financial support for advocacy provision, ensuring that all disabled people have access to independent advocacy provision that is suitable for their needs.
- Place a statutory requirement on local authorities to produce a local advocacy plan which will outline how advocacy provision will be developed in the area, how different groups will be served and how funding dedicated to advocacy will be spent.
- Set local authorities targets and performance indicators that will encourage the development of independent advocacy.
- Allocate responsibility for this issue to a single department or body to ensure:-
 - co-ordination of the Government's strategy on advocacy
 - support for the promotion and monitoring of the implementation of local advocacy plans
 - allocation of funding for the development, promotion and dissemination of good practice for advocacy, especially for people with physical, sensory, communication impairments and profound and multiple impairments.

7.2 Local Government and Health Bodies

• Local Advocacy Plans

Local authorities should be required to develop local advocacy plans in conjunction with advocacy schemes, users of advocacy, disabled people and disability groups. These plans should:

- promote the development of provision for a wide range of groups, reflecting the particular needs and requirements of the local population. Particular attention should be paid to

the advocacy provision for people with physical, sensory, communication impairments and profound and multiple impairments.

- outline funding for local advocacy development, including how resources allocated to advocacy can be increased, and used to train advocates to meet the needs of a broad range of people.
- consider nominating one individual to be charged with co-ordinating production, dissemination and monitoring of the plan at a local level. This person would liaise with local advocacy providers, and local and national advocacy networks to develop and share good practice.

- **Training and Information**

Ensure commissioners, social workers, health visitors and others whose decisions have a clear impact on disabled people's lives receive disability awareness training, which will include information on the role of independent advocacy, how it can assist their work and the availability of local advocacy provision.

Ensure commissioners are made aware of the issues involved in providing advocacy for a broader range of people, especially people with physical, sensory, communication impairments and profound and multiple impairments. These issues affect the number of people advocacy providers can work with and the time taken to develop meaningful advocacy relationships. This needs to be taken into account when service level agreements are being negotiated with advocacy providers.

7.3 Funders

- Acknowledge that to develop a meaningful advocacy partnership with a person with a communication impairment or a profound and multiple impairment will often take a considerable amount of time and so consider making funding available over longer periods, and ensure project outcomes take this into account.
- Engender a more inclusive approach to advocacy by not imposing arbitrary limitations on the groups of people advocacy schemes can work with.
- Positively encourage applications from advocacy schemes who providing advocacy for a wide range of people, especially people with physical, sensory, communication and profound and multiple impairments.

7.4 Members of Parliament, Councillors and other Key Decision Makers

- Identify what independent advocacy provision exists in their local area, make contact with them and offer support in fulfilling the recommendations in this report.
- Encourage civil servants, local authority officers, colleagues and others to consider the recommendations relevant to them and explore how they can be taken forward.

7.5 Advocacy Schemes and Networks

- Advocacy schemes need to consider ways to make their provision meet the needs of a broad range of people by:-
 - working closely with local authorities to identify the unmet advocacy needs of people with physical, sensory, communication and profound and multiple impairments.
 - tapping into local and national sources of support and information, such as speech therapists, disability networks and community groups to help them to develop the skills and confidence to work with a greater range of people.
 - developing links with local influencers, decision-makers and media and holding events such as open days to promote advocacy schemes and the positive impact they can have on people's lives.
 - talking to local disability groups to find out more about the level of need for advocacy for different groups in the area.
- Advocacy networks should continue to encourage the development of provision which meets the needs of a broad range of people by:-
 - facilitating greater development, dissemination and sharing of good practice on advocacy provision for people with physical, sensory, communication and profound and multiple impairments.
 - informing and educating local authorities, health authorities and funders of the particular issues and complexities of providing advocacy for people with sensory, physical, communication and profound and multiple impairments.

- challenging service level agreements or funding criteria that prevents advocacy schemes from working with certain groups of people.

7.6 Service Providers

- Service providers should actively encourage the use of independent advocacy by their service users. This can be done by:-
 - identifying and working in partnership with local advocacy schemes.
 - providing training to advocacy schemes on issues that will impact on the users of their service.
 - providing training to their staff that will encourage a positive attitude towards advocacy.

8 Appendix 1:

A Review of References to Independent Advocacy in Recent Policy and Legislation

NB This review aims to provide a concise account of the main recent policy and legislative coverage relating to advocacy. It is not intended to be a fully comprehensive assessment of every policy intervention or piece of legislation related to advocacy provision or to provide a comprehensive statement of the law on this issue.

Successive governments have highlighted the importance of independent advocacy for adults and showed an appreciation of the valuable role it can play in supporting people to access vital services and ensure their rights are protected. Numerous White Papers, sets of standards, guidance documents and reports from different government departments, non-departmental public bodies and associated agencies have drawn attention to the benefits advocacy can bring and supported the need for further development and support for such services.

Advocacy References in Policy Documents and Reports

The Department of Health has raised the issue of advocacy or been nominated as a key department in numerous publications. For example, **Valuing People** (March 2001), the Department of Health's major strategy for people with learning difficulties, has a section on advocacy which notes "both citizen advocacy and self-advocacy are unevenly developed across the country... The Government's long-term aim is to have a range of independent advocacy services available in each area so that people with learning disabilities can choose the one which best meets their needs." It goes on: "the Government will work in partnership with the self-advocacy movement to promote the development of a clear national voice for people with learning difficulties."

Valuing People also announced the creation of an Implementation Support Fund of £1.3 million per year for three years to support and develop citizen and self-advocacy projects across the country. It was intended to establish a National Citizen Advocacy Network for Learning Disability working towards at least one citizen advocacy group in each local authority area. It also aimed to increase funding for local self-advocacy groups and strengthen the national infrastructure for self-advocacy. Two voluntary organisations, the British Institute of Learning Disabilities (BILD) and Values Into Action

(VIA), administered the distribution of this money. In April 2003, it was announced in **Making Change Happen** that this fund would continue in some form until March 2006.

More recently, expert advisors on advocacy have been appointed to the Valuing People Team and an advocacy toolkit is being produced. This is designed to help the Learning Disability Partnership Boards, set up in all local authority areas, to ensure there are good advocacy services for people with learning disabilities in their areas. Some Partnership Boards have also chosen to allocate more money to advocacy.

Valuing People also revealed the Government's intention to address the advocacy needs of other groups of disabled people, stating "The Department of Health will also work with the [Disability Rights] Commission to consider the way forward for advocacy for all disabled people."

This was also mentioned in **Towards Inclusion** (March 2001), published by the DfEE (now known as the DFES), as the Government's response to the Disability Rights Task Force report of December 1999. This had made 156 recommendations covering a wide range of policy and practice issues affecting disabled people, including that "The Department of Health should look at improving the arrangements for advocacy support, including whether Sections 1 to 3 of the Disabled Persons (Service, Consultation and Representation) Act 1986 should be implemented."

This piece of legislation charged local authorities with setting up a formal system of authorised representatives who could make representations about disabled people's need for services, get a statement of assessed needs and services to be provided and make representations about this. However, this formal system was never implemented, on the basis that there was a danger of diverting resources into complex administrative arrangements at the expense of services.

The Government's response to this in **Towards Inclusion** did not comment on implementing this right, but stated that they were "considering how best to promote the development of advocacy services for people with learning disabilities in the context of the forthcoming Learning Disability White Paper. The Department of Health has held a preliminary meeting with DRC officials and agreed to work together to consider the most effective ways of developing advocacy services for disabled people generally."

Latest reports from the DRC are that it has commissioned a report on advocacy. In addition, following its comprehensive listening exercise with key stakeholders, the Social Care Institute for Excellence will be starting a review of advocacy services in 2004. Its Code of Conduct for Social Workers and Social Care staff also recognises the value of advocacy.

Other reports published by the Department of Health during 2001 also referred to the issue of advocacy especially in relation to its underprovision. **Making It Work** (September 2001) was a Social Services Inspectorate report about welfare to work provision for disabled people in a sample of eight councils. In chapter 4 on **Helping Make Informed Choices**, it noted:-

“4.6 Half the councils had made arrangements for advocacy for disabled people, often in partnership with health. Advocacy services had been commissioned from voluntary organisations and in many there was a particular emphasis on services for people with a learning disability. In the other council areas advocacy services were either underdeveloped or there was heavy reliance on social services staff to undertake the role.”

Among the key messages of this chapter it was noted that “Independent advocacy services were not universally available.” Similarly, the Issues and Good Practice section noted “underdeveloped independent advocacy services that, where they existed, mainly focused on people with learning disabilities.”

This concentration on particular groups and situations is also reflected in the coverage of independent advocacy in the latest **Annual Report from the Chief Inspector of Social Services**. Mentions of advocacy are limited to sections related to people with learning disability, children and young people and the implementation of direct payments.

Advocacy References in Recent Legislation

There has recently been some movement towards legislative backing for access to advocacy for people in particular situations or issues. For example, the **Health and Social Care Act 2001** (part 1, section 12, clause 19A) empowers the Secretary of State “to arrange, to such extent as he considers necessary, to meet all reasonable requirements, for the provision of independent advocacy services”. This heralded the introduction of the Independent Complaints Advocacy Services (ICAS), aimed at helping individuals pursue complaints about the NHS.

However, it is worth noting that the **interim report of the Transition Advisory Body**, the group putting in place arrangements for this new service, recommended that “ICAS needs to support the development of specialist independent advocacy services and, where appropriate, commission services to supplement the generic ICAS.” Work of this sort has been taken forward, with a feasibility study of a national independent advocacy database commissioned from Citizens Advocacy Information and Training (CAIT).

Similarly, the **draft Mental Health Act** published in June 2002 states that specialist mental health advocacy must be available for all patients being treated under compulsory powers and their nominated person. Research was commissioned by the Department of Health to examine existing mental health advocacy provision (Barnes et al, 2002). This aimed to ensure current practice and experiences informed recommendations for this new independent specialist advocacy service. This research has subsequently recommended a model of a professional, individually focussed, statutorily funded service commissioned by primary care trusts.

More recently in Scotland, the **draft Mental Health (Care and Treatment) (Scotland) Act 2003** includes a section on advocacy (259) which states:

“Every person with a mental disorder shall have a right of access to independent advocacy; and accordingly it is the duty of -

- (a) each local authority, in collaboration with the (or each) relevant Health Board and
- (b) each Health Board, in collaboration with the (or each) local authority,

to secure the availability, to persons in its area who have a mental disorder, of independent advocacy services and to take appropriate steps to ensure that those persons have the opportunity of making use of those services.”

Other groups have noted this tendency and made recommendations influenced by these developments. For example, the Making Decisions Alliance, a group of over 20 voluntary organisations campaigning for legislation around situations when people have limited mental capacity, has recommended that draft legislation gives people a right to independent advocacy in certain situations, such as when major life decisions are being considered.

Advocacy References in Practice Standards

Several documents relating to standards of practices and service produced by the Department of Health have also referred to advocacy. In October 2001, **Building Capacity and Partnership in Care** was produced by the Department of Health and noted in chapter 3, “one of the principal ways of improving services is to involve patients, users and their carers along with independent providers in the planning and design of services through the commissioning process... Independent advocacy arrangements should also be encouraged and supported.”

Later in 2001 the **Domiciliary Care Standards Consultation** was also produced by the Department of Health. This announced minimum quality standards for personal care and support which people receive whilst living in their own homes in the community. Among the proposed outcomes were that prospective service users are informed about independent advocacy/self-advocacy schemes and that service users and their carers or other representatives are informed about independent advocacy services.

Similarly, in December 2001, **The National Minimum Standards for Care Homes for Younger Adults** (which relate to adults under 65 years old) mention advocacy in relation to a number of different standards including the drawing up of the contract or statement of terms and conditions with the home, the development and review of their service user plan, individual decision-making, the maintenance of consistency and continuity of support and raising concerns and complaints. All of these draft standards were adopted and have formed the basis of the new regulatory framework for the conduct of care homes since April 2002.

The National Service Framework for Older People, published in March 2001, also referred to advocacy, noting that “in order to make decisions about their care, older people need: contact points for further information and support, such as local voluntary organisations and independent advocacy services.” It also commented that stroke services should take account of the need for interpreting or advocacy support, especially for patients and carers for whom English is not their first language.

Conclusion

It is clear from this brief review that despite the extensive references to and support for the use of independent advocacy in policy documents, White Papers, inspection reports, standards and legislation, national Government has been less than forthcoming in providing funding for independent advocacy services or in providing a statutory right to independent advocacy. However, more recently there has been some movement towards legislative backing or dedicated resources for particular situations or groups.

The IAC would recommend to Government that following the results of this research, it gives urgent consideration to the advocacy needs of people with physical, sensory, communication and profound and multiple impairments. The evidence from this research suggests that these groups have very limited access to independent advocacy, despite the fact that they may be among the most in need of such support.

9 Appendix 2: Results from Survey

Questions 1-7 were demographic questions. Since this information is confidential, it has not been included.

8 What is your main source of funding for your advocacy work?

Local authority	39%
Health authority/primary care trust	33%
Joint health and local authority	30%
Community Fund	21%
Local charities and trusts	12%
National charities	10%
No reply	9%

Percentages add up to more than 100% as some respondents referred to more than one funding source

9 What period of time does your funding cover?

Less than one year	15%
One-two years	42%
Three years	32%
Over three years	13%
No reply	8%

Percentages add up to more than 100% as some respondents referred to more than one funding source

10 Please tick the main types of advocacy you provide. (Can tick more than one box).

Issue-based/casework	77%
Citizen advocacy	45%
Self-advocacy	45%
Voluntary advocacy	34%
Group support	33%
Peer advocacy	18%
Legal advocacy	6%
No reply	4%

11 Who do you see as being your main client group(s) for advocacy provision? (You can tick up to three boxes.)

Adults with learning disabilities	52%
Adults with mental health issues	41%
Elderly people	28%
Adults with physical impairments	27%
Adults with sensory impairments	18%
Black and ethnic minority adults	17%
Adults with profound and multiple impairments	11%
Adults with communication impairments	10%
No reply	4%

12 Do you provide advocacy on a regular basis for any of the following? (You can tick more than one box.)

Adults with physical impairments	51%
Adults with sensory impairments	41%
Adults with profound and multiple impairments	36%
Adults with communication impairments	33%
No reply	35%

13 In the future would you be interested in working with any of the groups of people you did not tick in question 11?

Yes	54%
No	16%
No reply	30%

14 Which of the following are preventing you from currently working with the groups you didn't tick on question 12? (Tick up to three reasons.)

Lack of funding to provide advocacy for this group of people	47%
Lack of specialist skills (eg signing, using communication aids)	32%
Funding/service provision agreements do not encourage work with these groups	31%
Lack of experience of working with this group of people	17%
Lack of knowledge of the issues affecting this group of people	14%
No reply	33%

15 Do you have difficulty reaching the groups of people you did not tick in question 11?

Yes	15%
No	46%
No reply	38%

16 Which of the following would enable you to provide advocacy for the above groups of people you didn't tick in question 12? (Please tick up to three.)

More funding specifically for these groups of people	53%
Skills training (e.g. using communication aids)	35%
Support to promote your work with these groups of people	27%
Increased knowledge about the difficulties experienced by these groups of people	21%
Disability awareness training	13%
Other	4%
No reply	36%

17 What are the key factors that enable your group to provide advocacy for the groups of people you have ticked in question 12? (Tick up to three main reasons.)

Experience of working with this group of people	59%
Knowledge of the issues affecting this group of people	57%
Funding to provide advocacy for this group of people	46%
Funding/service provision agreements that encourage us to work with these groups of people	25%
Availability of specialist skills	20%
No reply	33%

18 Do you feel there is enough advocacy provision for all people that need it in your location?

Yes	5%
No	94%
No reply	1%

19 Do any of the local authorities in which you provide advocacy have an advocacy strategy?

Yes	18%
No	39%
Don't know	41%
No reply	2%

20 Do you think there should be a local advocacy strategy in each local Authority Area?

Yes	92%
No	2%
No reply	6%

10 Appendix 3: Types of Advocacy

Citizen advocacy

This is a one-to-one ongoing partnership between a volunteer advocate and a person who is not in a strong position to exercise or defend their rights and is at risk of being mistreated or excluded. The citizen advocate should be free from conflicts of interest with those providing services to their partner and should represent the other person's interests as if they were the advocate's own.

Self-advocacy

This essentially means "speaking up for yourself". Self-advocacy involves a person who expresses their own needs and concerns and represents their own interest.

Peer advocacy

Peer advocacy is when one person advocates for another who has experienced or is experiencing similar difficulties or has similar life experiences (eg service users in a residential facility).

Professional advocacy

People that are paid to provide an advocacy service, usually using the casework model, focusing on particular issues, as opposed to a long-term 'befriending' model. However, it can still be long-term, depending on the issue, and the advocate may support their partner on a number of issues.

Legal advocacy

Work done by lawyers on behalf of users of health and social care services (in the form of litigation and judicial reviews) and those investigations carried out by quasi-legal bodies such as ombudsmen.

(A Right Result?, Henderson & Pochin, 2001)

11 Useful Contacts

Advocacy Across London
St Paul's Church
Lorrimore Square
London
SE17 3QU
Tel: 020 7820 7868

Email: info@advocacyacrosslondon.org.uk

www.advocacyacrosslondon.org.uk

A resource and support agency for London's advocacy sector. The AAL website includes a map-based directory of London advocacy schemes. Publications include quarterly magazine 'Planet Advocacy', 'The Advocacy Charter' and 'Advocacy in Focus' awareness training pack.

Asist
Winton House
Stoke Road
Stoke on Trent
ST4 2RW

Tel: 01782 845 584

Email: help@asist.co.uk

www.asist.co.uk

For information on Watching Brief, contact this not for profit organisation supplying advocacy in Staffordshire and Stoke on Trent.

British Institute of Learning Disabilities (BILD)
Campion House
Green St
Kidderminster
Worcestershire
DY10 1JL

Tel: 01562 723 010

Email: enquiries@bild.org.uk

www.bild.org.uk

Information on the Citizen Advocacy Funding Programme, good practice around advocacy for people with high support needs, advice on writing policies for advocacy groups, promoting good practice around advocacy.

Citizen Advocacy information and Training (CAIT)

162 Lee Valley Park

Ashley Road

London

N19 9LN

Tel: 020 8880 4545

Email: cait@teleregion.org.uk

www.citizenadvocacy.org.uk

CAIT produces publications including detailed guidelines and practice concerning the establishment and operation of citizen advocacy schemes for a wide range of beneficiaries, including people with disabilities, users of mental health services, black and minority ethnic communities, children and young people and older people. CAIT's training programme is aimed at those who provide advocacy and the health, social care and inspectorate staff.

Fast Forward

67 Hertford Road

Brighton

East Sussex

BN1 7GG

Tel: 01903 767 070

Fast Forward provides training and consultancy around all issues associated with advocacy.

Mencap

123 Golden Lane

London

EC1Y 0RT

Tel: 020 7454 0454

Email: information@mencap.org.uk

www.mencap.org.uk

Charity working with people with learning disabilities, their family and carers.

National Autistic Society

393 City Road

London

EC1V 1NG

Tel: 020 7833 2299

Email: nas@nas.org.uk

www.nas.org.uk

National charity for people with autistic spectrum disorders and their families. The Society provides a wide range of services to help people with autism and Asperger syndrome live their lives with as much independence as possible.

Royal National institute for the Blind (RNIB)

105 Judd St

London

WC1H 9N

Tel: 020 7388 1266

Email: helpline@rnib.org.uk

www.rnib.org.uk

Charity offering information, support and advice to people with sight problems.

Scope

6 Market Road

London

N7 9PW

Tel: 020 7619 7100

Email: cphelpline@scope.org.uk

www.scope.org.uk

Disability organisation in England and Wales, whose focus is people with cerebral palsy.

Sense

11-13 Clifton Terrace

London

N4 3SR

Tel: 020 7272 7774

Email: enquiries@sense.org.uk

www.sense.org.uk

Charity providing specialist information, advice and services to deafblind people, their families, carers and the professionals who work with them.

12 Useful websites and publications

Disability Rights Commission
www.drc.org.uk

Law Society solicitors online
www.solicitors-online.com

Local Government Ombudsman
www.lgo.org.uk

National Association of Local Societies for Visually Impaired People
www.nalsvi.charityskills.net

National Service Framework for Older People
www.doh.gov.uk/nsf/olderpeople

Rightsnet - the welfare rights website for
older people
www.rightsnet.org.uk

UK Self-Help Groups
www.ukselfhelp.info

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Rai-Atkins A, Ali Jama A, Wright N, Scott V, Perring C, Craig C, Katbamna S. *Best practice in mental health: Advocacy for African, Caribbean and South Asian communities*. The Policy Press, 2002.