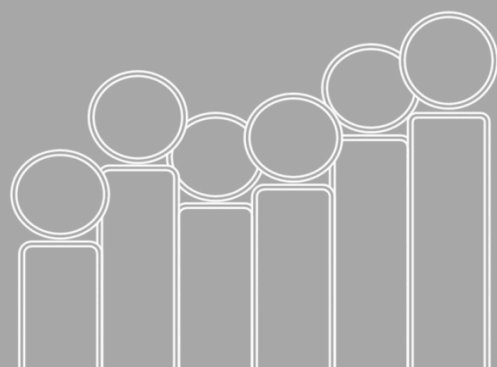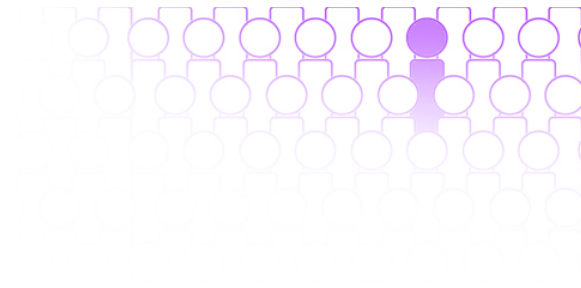# Advocacy by and for adults with learning disabilities in England

Evidence into practice report no. 5

Sue Turner

# Contents
# Page

Improving Health and Lives:
Learning Disabilities Observatory

## About the author

**Sue Turner** initially trained as a nurse for people with learning disabilities in Bristol. She has worked within training, as a Nurse Advisor in Gloucestershire, and has managed a variety of services for people with learning disabilities in Gloucestershire and Bristol including community learning disability teams. Sue was the Valuing People Lead for the South West Region for four and a half years, initially job sharing the role with Carol Robinson. During this time, Sue developed the health network in the South West and introduced the health self-assessment framework to the region. She later worked closely with the Strategic Health Authority on its implementation. Sue also worked closely with the regional self-advocacy network as well as individual self-advocacy groups in the South West. Sue is now leading on the Learning Disability Public Health Observatory (LDPHO) Improving Health and Lives project for the National Development Team for Inclusion.

## Introduction

The Learning Disabilities Public Health Observatory (LDPHO: www.ihal.org.uk) is one of the small number of specialist public health observatories that cover England. It was established by the Department of Health in April 2010 in response to a recommendation made by Sir Jonathan Michael's 2008 inquiry into access to health care for people with learning disabilities.[1] The LDPHO aims to provide better, easier to understand information on the health and wellbeing of people with learning disabilities, and to help commissioners and others make use of existing information whilst working towards improving the quality and relevance of data in the future. This paper is the fifth in a series that aims to translate the key messages from research into advice for commissioners and providers, and is based on the *Advocacy by and for adults with learning disabilities in England: Findings from two surveys and three detailed case studies* report. [2] The report summarises the results of two surveys covering similar themes that were sent to advocacy organisations and commissioners, and contains three case studies. Eighty eight advocacy organisations responded to the survey, half of which provided advocacy services just for people with learning disabilities, while the other half provided advocacy services for a range of people including people with learning disabilities. Seventy eight local authority commissioners responded to the survey. Both reports can be downloaded from: www.ihal.org.uk/publications

The survey report used the following definitions of advocacy:

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**Advocacy definitions**

**Self-advocacy**-when a person speaks up about their own interests. A person with learning disabilities may need the support of a self-advocacy group to do this.

**Citizen advocacy**- a citizen advocate is a person who speaks up for a person who needs support to make their wishes known.

**Peer advocacy**-Is like citizen advocacy, but both people have learning disabilities. Peer advocacy is often supported by self advocacy groups.

**Group advocacy**- happens when a group of people speak up about an issue that affects them. This type of advocacy can also be called 'self advocacy'. Examples of groups for people with learning disabilities include People First and Speaking Up groups.

Meanings from: BILD factsheet- advocacy (2009) [3]

**Non-instructed advocacy**- is advocacy for a person who has not asked for an advocate or who finds it difficult to say what they want. The advocate will try to understand the client and their needs and wishes and make sure the client has as much input as possible in decisions.

Source: POhWER website www.pohwer.net  (2012)

**Professional/case based advocacy** – advocacy provided by a person who is being paid to work as an advocate. This can include support to an individual to self-advocate.

Source: Advocacy – an introduction (Mencap 2011) [4]

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Improving Health and Lives:
Learning Disabilities Observatory

The findings from the report indicate that there are a number of key issues for commissioners and advocacy organisations as follows:

- Collect information about the number and demographic characteristics of those accessing advocacy organisations, including information on groups who struggle to access advocacy.
- Include the information collected in the Joint Strategic Needs Assessment.
- Understand the different types of advocacy available and commission a balance of provision, including smaller groups, which meet the differing needs of the local population, not just those eligible for services.
- Consider the issues that smaller advocacy groups face when tendering for services, and adjust the process accordingly.
- Agree a way of monitoring activity and outcomes with advocacy groups.
- Commissioners and advocacy groups should work collaboratively to plan better services.
- Good information on advocacy provision should be available to commissioners and others who can signpost people with learning disabilities to services.
- Understand the potential of local, regional and national groups to strengthen and support advocacy, and support local advocacy groups to be part of the wider network
- Gather information on the role advocacy groups play in improving health and social care services, and consider these roles when reviewing advocacy funding.
- Be clear about the type of activity advocacy organisations are providing, and ensure that non-advocacy provision is contracted for separately.

The following chapters explore these issues in more detail.
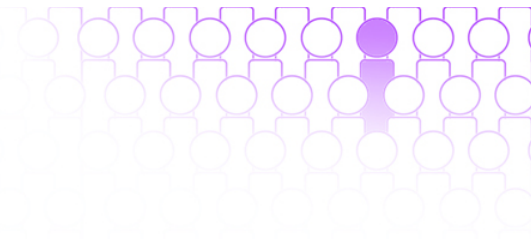
# 1. Information about who uses advocacy

Only 53% of commissioners said they received information on the demographic characteristics of those who used advocacy groups or services, although most advocacy organisations said they recorded this information. There was also a difference between the number of advocacy groups which said they worked to include groups known to be at risk of exclusion from advocacy, such as people with profound and multiple disabilities, and the number of commissioners who said they received this information.
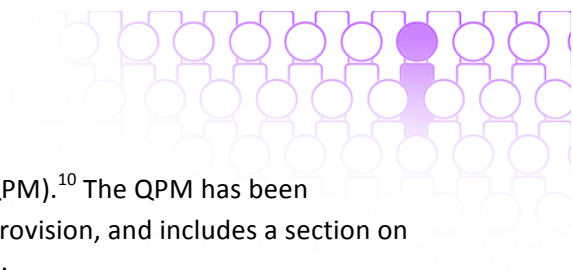
## Suggested actions for commissioners and advocacy groups

Unless commissioners are receiving information about the numbers of people with learning disabilities accessing advocacy and their demographic characteristics, they will not know if they are meeting the needs of their local population, or understand the impact of their services on those groups with protected characteristics under the Equality Act 2010 such as age, gender and ethnicity.[5] One aim of the Equality Duty is to advance equality of opportunity. Public bodies should consider 'the need to:

- remove or minimise disadvantages suffered by people due to their protected characteristics;
- take steps to meet the needs of people with protected characteristics where these are different from the needs of other people;
- encourage people with certain protected characteristics to participate in public life or in other activities where their participation is disproportionately low' .[6]

Although advocacy organisations are not public bodies, they are often commissioned by public bodies, who should build equality considerations into their relationships with organisations they commission.  In addition to people with protected characteristics, there are a number of groups of people with learning disabilities who may not be picked up by routine demographic monitoring and are also at risk of not having their needs met. For example survey responses indicated that parents with learning disabilities and young people in transition may struggle to access advocacy. Advocacy organisations should alert commissioners to gaps in provision, [7] and better sharing of information between advocacy groups and commissioners will ensure both parties are in a better position to judge whether the needs of some of those most at risk of exclusion are being met.

Self-advocacy organisations have found many innovative ways to reach out to communities of people with learning disabilities, such as working with schools and colleges, visiting day centres and holding big events. Outreach has been identified as an important way of reaching people in protected groups who may otherwise be excluded. [8] Sometimes just attending self-advocacy meetings can be enough to give people the confidence to do more themselves, as noted in the Your Say case study in the survey report.[2] As well as examples in our survey report, there are a number in *Staying Strong*, [9] the report by the National Forum. The report has a number of helpful tips for self-advocacy groups, including the importance of recording the numbers of people supported. Commissioners could use this report in discussions with their local self-advocacy groups about plans for the future and monitoring requirements. Information about those accessing advocacy, as well as any gaps in provision should be included in the Joint Strategic Needs Assessment (JSNA).

Improving Health and Lives:
Learning Disabilities Observatory

Action for Advocacy has produced a Quality Performance Mark (QPM).[10] The QPM has been recognised nationally as a robust test for the quality of advocacy provision, and includes a section on equality, accessibility and diversity. The document can be found at: http://actionforadvocacy.org.uk/articleServlet?action=list&articletype=60

Information on how public bodies can work with local support and development organisations to develop good commissioning practice, including analysis of need can be found in *Bridge between two worlds.* [11]

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**In Summary**
- Collect information about the number and demographic characteristics of those accessing advocacy organisations, including information on groups who struggle to access advocacy.
- Include the information collected in the Joint Strategic Needs Assessment.

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Improving Health and Lives:
Learning Disabilities Observatory
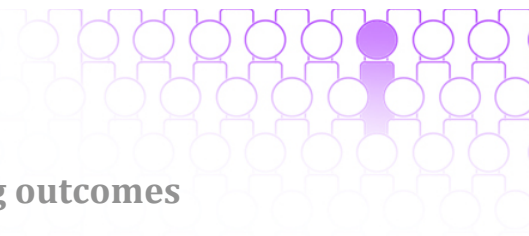
## 2. Funding of advocacy provision and monitoring outcomes

Both advocacy organisations and commissioners agree that advocacy is important, particularly with regard to giving people with learning disabilities a voice. They also agreed that reduced funding will have a negative impact on good advocacy support. Data from advocacy organisations indicates that there has been an overall decrease in funding levels since 2009/10 although the picture is less clear cut when the groups are divided into those providing advocacy for a generic client base and those providing only for people with learning disabilities. Data from commissioners suggests that the latter group are getting reduced funding whereas generic advocacy services are getting the same or more funding (however, the scope of the survey did not address the number of people being served by generic advocacy, which may be increasing). Funding changes will impact on the type of advocacy offered. Advocacy groups that catered only for people with learning disabilities were more likely to be directed and administered by or with the involvement of people with learning disabilities, whereas general advocacy groups were more likely to offer case based advocacy to people with learning disabilities. The short term, inconsistent nature of some funding, was also a problem, particularly for smaller (often self-advocacy) organisations who struggle to find the time and resources to bid for contracts. Some advocacy organisations were only being funded to work with those eligible for services, which meant that a large group of people were denied access. Monitoring of advocacy provision was patchy, particularly with regard to outcomes.

### Suggested actions for commissioners and advocacy groups

Commissioners should be clear about the types of advocacy they are funding and why. Case based advocacy is important. A number of examples are given in the survey report including supporting parents with learning disabilities through the courts. But learning disability specific groups are more likely to provide self, peer and group advocacy, are more likely to be involved in activities such as running learning disability parliaments, and are more likely to be directed and administered by people with learning disabilities. Giving people with learning disabilities a voice was the most important reason given for funding advocacy. The ability of self, peer and group advocacy to enable people to have a strong, collective voice was recognised by respondents, as was the positive impact it had on people's confidence and ability to make decisions. Supporting people to train and present to others can also have a positive impact on wider services. [12] Information like this is particularly important when services are being cut and commissioners are being asked to increase the span of services they commission. Commissioners who are new to learning disability services may not understand the importance of advocacy for people with learning disabilities, or the different types of advocacy provision. Therefore good information for commissioners about what is being provided to whom, and the relative benefits are increasingly important.

Smaller organisations can find it particularly difficult to find the resources to bid for money, and are vulnerable when it comes to short term funding. However, many provide valuable support to people who may struggle to access services otherwise, and may be better connected to local networks of people. Commissioners need to be aware of the strain that smaller advocacy services are under and should take this into account when considering funding criteria and tendering processes.

If advocacy services are restricted to working only with those who are eligible for social care services, an increasing number of people with learning disabilities will be denied advocacy as Fair Access to Care criteria tighten. Not only has advocacy got the potential to reduce the need for services and prevent crises, but restricting access runs counter to the QPM [10] which state that: 'You can only achieve real equality and diversity by offering your services to all'.

Improving Health and Lives:
Learning Disabilities Observatory
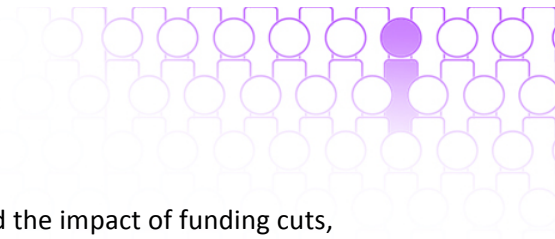
In order to gain a better understanding of the value of advocacy and the impact of funding cuts, Commissioners and advocacy groups should agree a way of monitoring activity and outcomes related to the reasons both advocacy organisations and commissioners gave for funding advocacy. [2] Examples of quantitative and qualitative methods were mentioned by respondents, and although evaluating the impact of advocacy services is difficult, better information may help advocacy groups and commissioners argue the case for continued funding. *Lost in Translation* [13] is a toolkit for understanding, defining, measuring and communicating advocacy outcomes. It sets out the specific issues relating to outcomes monitoring and includes practical ways of developing an outcome focused approach to monitoring quality. The toolkit can be found at: http://www.aqvx59.dsl.pipex.com/Lost_in_translation.pdf

Any outcomes or activity monitoring agreed should not compromise the independence or integrity of the advocacy organisation.  As well as giving people a voice, the survey yielded clear examples of service improvement following advocacy intervention. Current policy stresses the importance of local people holding services to account in order to improve quality.[14] Without advocacy to support individuals with learning disabilities to challenge services, it is hard to see how they could do so effectively.

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**In summary**
- Understand the different types of advocacy available and commission a balance of provision, including smaller groups, which meet the differing needs of the local population, not just those eligible for services.
- Consider the issues that smaller advocacy groups face when tendering for services, and adjust the process accordingly.
- Agree a way of monitoring activity and outcomes with advocacy groups.

# 3. Collaborative working

The majority of advocacy organisations collaborated with other groups or organisations, the most commonly mentioned being local authorities, although some also described work with other advocacy groups. Regional or national forums were regularly mentioned, although specific examples were fewer, perhaps indicating that the survey sample was less well connected with the regional/national structure. However nearly all commissioners noted that representatives from advocacy organisations were members of Partnership Boards.

## Suggested actions for commissioners and advocacy groups

In order to ensure that advocacy organisations meet the needs of people with learning disabilities, it is important for commissioners to work with advocacy groups who are well placed to tell commissioners what is needed. The potential benefits of collaboration include reduced duplication, better use of resources and a better understanding of the benefits of advocacy, although it is also important that advocacy organisations maintain their independence. In the survey report, one of the advocacy groups interviewed (Your Say), particularly noted the importance of a supportive commissioner both for the group's development, and as a conduit to the local Health and Wellbeing Board. Collaborative working also has the potential to increase the coverage of advocacy for those people in protected groups.

Social workers, care managers, support brokers and providers are well placed to signpost people with learning disabilities to advocacy services, but need to understand what is on offer and the value of advocacy. Spending time with advocacy organisations is one way of doing this. Some advocacy organisations also offer placements for trainee social workers and other students. *Staying Strong* [9] suggests that advocacy organisations use a variety of media to tell people about themselves such as websites, newsletters and e-mails. Using people's stories to show the benefits of advocacy is also very powerful.

Supporting advocacy groups to maintain their contacts and networks including attendance at regional and national forums has the potential to help advocacy groups stay strong.[9] People First Merseyside (Sefton group) (details in survey report) were particularly clear about the value of a regional group that enabled them to 'share good practice and ideas, and find solutions to problems'.[2] Partnership Boards can also provide advocacy groups with a forum to express their views and concerns, and can be a valuable source of information and expertise for emerging Healthwatch organisations and Health and Wellbeing Boards. However in some areas Partnership Boards are being changed, and it is not clear what role they will play.[10] Commissioners need to understand the potential for local, regional and national groups to strengthen the voice of advocates, and ensure that positive practice is safeguarded.

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**In Summary**
- Commissioners and advocacy groups should work collaboratively to plan better services.
- Good information on advocacy provision should be available to commissioners and others who can signpost people with learning disabilities to services.
- Understand the potential of local, regional and national groups to strengthen and support advocacy, and support local advocacy groups to be part of the wider network.

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Improving Health and Lives:
Learning Disabilities Observatory

## 4. Good practice in social care and health services

Most advocacy organisations said they had done work to improve both social care and health services. Many had also done work with people with learning disabilities about their health.

### Suggested actions for commissioners and advocacy groups

If advocacy groups do not have the resources to both challenge and work with health and social care services, an important lever for service improvement will be lost. There are a number of examples of advocacy groups challenging services in the survey report including complaining about services and whistle blowing. Intervention by advocacy groups can be particularly powerful, as illustrated by My Life My Choice (details in survey report), who approached their local MP, the Joint Overview and Scrutiny Committee and the local commissioning team, because they were unhappy about numbers of health checks in their area. Advocacy groups also support service development through activities such as consultation, training staff, developing resources and big health check days. Getting Ready meetings and big health check days involving people with learning disabilities and family carers are a crucial part of the Health Self-Assessment Framework (SAF), and many advocacy groups are an important part of this process. For example People First Merseyside (Sefton group) noted that when they ran the big health day 'people said they got much better information and feedback about services'.[2] The SAF is a powerful tool to review progress in addressing health inequalities, and has been updated in advance of the report of the Department of Health review following the events at Winterbourne View. [15] For further information see:
http://www.improvinghealthandlives.org.uk/projects/self_assessment/materials2012
Commissioners and advocacy groups should gather information on this activity, which should be taken into consideration by commissioners when reviewing advocacy funding.

As well as doing work to improve services and access to services, a number of advocacy organisations have done work with their members on better health. People with learning disabilities have poorer health than the general population, differences in health status that are to an extent avoidable, and are in part to do with personal health risks and behaviours.[16] For example, people with learning disabilities are much more likely to be obese than their peers.[16] Raising awareness and understanding of what constitutes a healthy lifestyle is therefore important and while this isn't advocacy, it is clear, both from our survey and from the *Staying Strong* report,[9] that a number of advocacy organisations are also providing these services. As resources for advocacy are stretched, it is important that money for advocacy is spent on advocacy, [10] and in order not to blur the boundaries between advocacy and service provision, this type of activity, which can be valuable, should be recorded and recognised in a separate contract with commissioners.

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**In summary**
- Gather information on the role advocacy groups play in improving health and social care services, and consider these roles when reviewing advocacy funding.
- Be clear about the type of activity advocacy organisations are providing, and ensure that non-advocacy provision is contracted for separately.

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Improving Health and Lives:
Learning Disabilities Observatory

## Conclusions

The survey report[2] on which this paper is based suggests that advocacy services catering only for people with learning disabilities, and who therefore tend to be more involved in self and group advocacy, are receiving reduced funding, whereas generic advocacy services are getting the same or more funding. This indicates a move towards professionalised advocacy at the expense of self-advocacy, threatening activities which enable people with learning disabilities to have a 'big voice',[2] even though commissioners and advocacy organisations all agree on the importance of advocacy in giving people a voice.

In order to provide robust evidence on the effectiveness and reach of advocacy services, this paper suggests that advocacy groups should collect better information on the characteristics and number of people they work with to share with commissioners. Further, they should work with commissioners to agree a way of monitoring activity and outcomes although reporting mechanisms need to take account of the restricted resources advocacy services have. As well as providing better evidence to inform commissioning, sharing information may also help address concerns that some commissioners and other key personnel are not clear about the different kinds of advocacy and their benefits. It is important commissioners understand that advocacy isn't just a professional or case based service, and purchase a balance of advocacy services, including self-advocacy. They also need to consider ways of making advocacy services accessible to as many people as possible. Smaller groups can offer valuable services but struggle with complicated funding criteria, so tendering processes need to take this into account.

One way of helping advocacy organisations to stay strong is to support them to be part of a wider network, whether this is via regional or more local networks. There is useful information in the *Staying Strong*[9] report and the *QPM*[10] which can help advocacy groups maximise their potential. The survey report[2] highlighted the important role that advocacy organisations play both in supporting people with learning disabilities, and in helping to improve services. If the 'nothing about me without me'[14] ambition for health and other services is to be realised for people with learning disabilities, it is crucial that self-advocacy as well as advocacy organisations remain strong into the future.
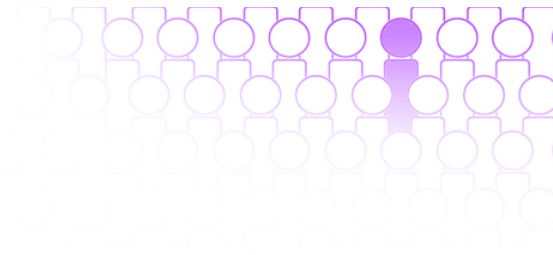
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