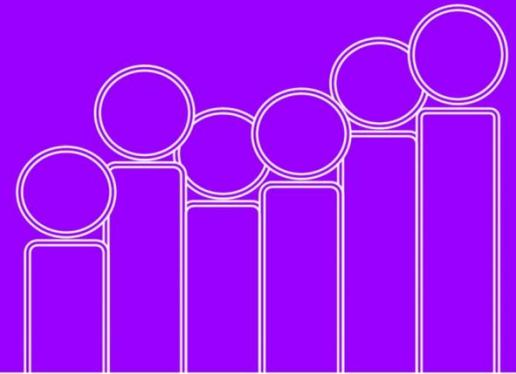




Improving Health and Lives:
Learning Disabilities Observatory

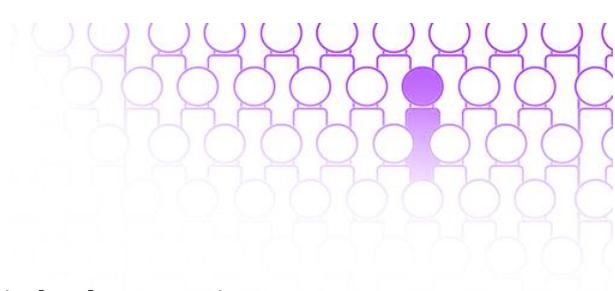
Advocacy by and for adults with learning disabilities in England

Hazel Roberts, Sue Turner, Susannah Baines and Chris Hatton



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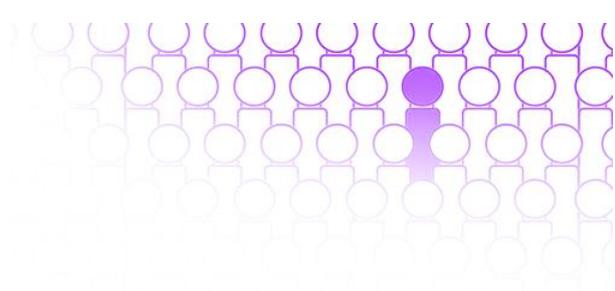




Advocacy by and for adults with learning disabilities in England: Findings from two surveys and three detailed case studies

Hazel Roberts, Sue Turner, Susannah Baines and Chris Hatton

IHAL 2012-03



About the Authors

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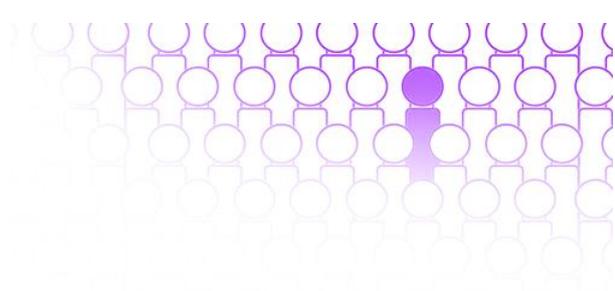
Sue Turner initially trained as a nurse for people with learning disabilities in Bristol. She has worked within training, as a Nurse Advisor in Gloucestershire, and has managed a variety of services for people with learning disabilities in Gloucestershire and Bristol including community learning disability 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 to the region. She later worked closely with the Strategic Health Authority on its implementation. Sue is now leading on the Improving Health and Lives project for the National Development Team for Inclusion

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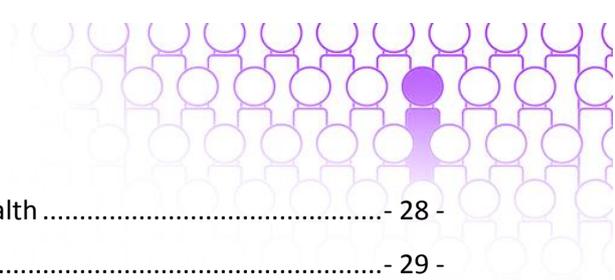
Acknowledgements

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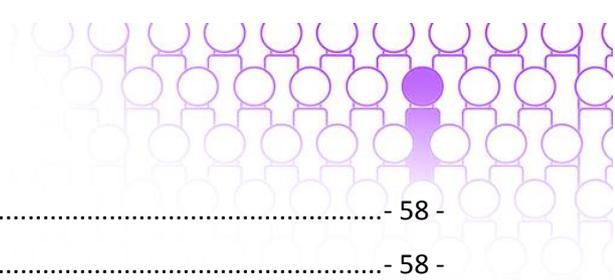


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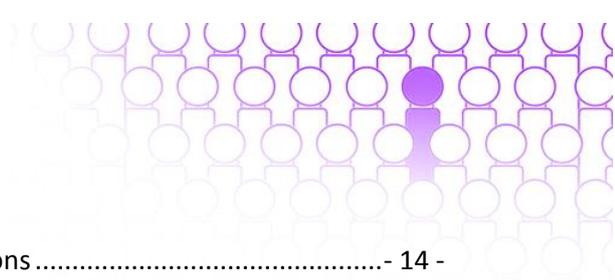
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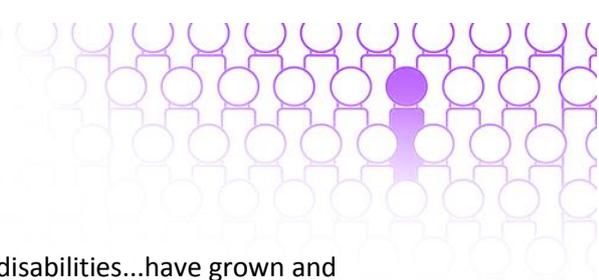
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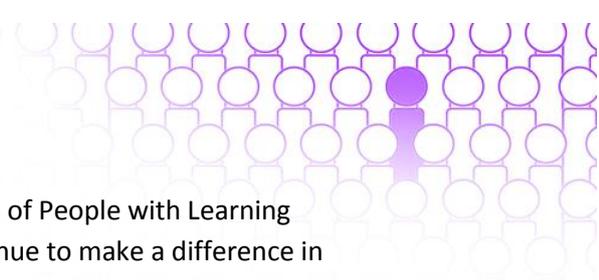
Background

Lawton (2009) describes how ‘advocacy services for people with disabilities...have grown and developed over 20 or 30 years, [but are] often largely built on voluntary origins with weak financial foundations’ (p. iv). This means that advocacy services often face problems of survival when specific funding streams end (EHRC, 2010). Both *Valuing People* (2001) and *Valuing People Now* (2009) helped to strengthen advocacy and highlight its importance in giving people with learning disabilities a voice, and the introduction of statutory advocacy such as Independent Mental Capacity Advocates (IMCAs) should mean help for the most vulnerable people (Lawton, 2009). It is important to note that the use of IMCAs is limited to people who are formally assessed to lack mental capacity to take decisions which are required at that time about their long term accommodation, serious medical treatment or protection from abuse.

In addition, there are concerns that this focus on statutory advocacy may be at the expense of other types of advocacy (Lawton, 2009; Action for Advocacy, 2011). This is in addition to the ‘widespread recognition of inherent difficulties in attempting evaluation’ of advocacy services (Lawton, 2009, p.vi), although attempts have been made within the sector to develop measurable and relevant advocacy outcomes (e.g. Action for Advocacy, 2009). There is also evidence that advocacy services for people with learning disabilities and their family carers may not be reaching some members of the Black and Minority Ethnic (BME) population (Lawton, 2009; Jewell and Mallet, 2010) and people with profound and multiple learning disabilities (PMLD) or complex needs (Lawton, 2009).

It is estimated that 55.4% of UK advocacy organisations provide advocacy services for people with learning disabilities (unpublished interim findings from an Action for Advocacy survey). Two recent reports have raised the issue of the importance, but potentially precarious position, of independent advocacy support for people with learning disabilities. *Advocacy in a Cold Climate* (Action for Advocacy, 2011) found that many people with learning disabilities are not getting access to the advocacy services they need. The report argues that independent advocacy should be seen as an essential service by commissioners, and should include ‘community based, non-statutory advocacy as well as IMCA[’s]’ (p.4). Action for Advocacy maintain that local commissioners should recognise the benefits and cost savings provided by independent advocacy services and ensure that advocacy is a priority, while advocacy providers should ensure that the need for and benefits of their work are fully understood by a broad range of stakeholders. This will include developing systems for the effective monitoring and analysis of relevant data.

Action for Advocacy (2011) argue that the personalisation of health and social care, personal budgets, and changes to NHS and social care and GP commissioning will increase demand for advocacy services. Access to high quality independent advocacy can also assist people with high support needs who are less likely to access personalisation and have opportunities for increased choice and control (EHRC, 2010). In addition they highlight a general concern from the advocacy sector about cuts and reforms to services in relation to safeguarding and abuse, arguing that there will be a move towards crisis intervention rather than early intervention and this will result in increased costs for health and social care services. According to Action for Advocacy, potential impacts of reduced advocacy services include disempowerment (which will undermine health and social care reforms aiming for increased choice and control), debt and homelessness, deterioration in mental health, fewer opportunities for gaining skills and fewer opportunities for employment in advocacy services (Action for Advocacy, 2011,p.13).



Staying Strong: Taking Advocacy Into The Future (National Forum of People with Learning Difficulties, 2011a) considers how self advocacy groups can continue to make a difference in people's lives with less money available from government. The National Forum of People with Learning Difficulties surveyed 80 self advocacy groups in England, asking about the work groups do now and their plans for the future. Some self advocacy groups in *Staying Strong* said that commissioners did not always understand what self advocacy is, and some said that large organisations are getting advocacy contracts because they have more time and experience to write the funding bids.

Staying Strong suggests that groups need to show commissioners how they change people's lives using numbers and stories, and to find other ways of making money. The report also suggests that self advocacy groups should think about working with other organisations using existing networks and contacts and making the most of existing skills such as Easy Read and consultation skills. Groups could also work with other local community and support groups on bidding for money for projects, e.g. GP surgeries, housing associations, libraries, and could also consider becoming social enterprises.

The follow up work to *Staying Strong* was *Staying Strong – but for how long?* (National Forum of Learning Disabilities, 2011b). The report found that most self advocacy groups got the same amount of money for 2011/12 compared to 2010/11 but did not know what would happen to funding after April 2012. Self advocacy groups are often competing with other organisations for less funding, and for contracts that join up advocacy activities with other areas such as Advice and Information. To manage on less money a lot of groups have fewer workers or staff working reduced hours.

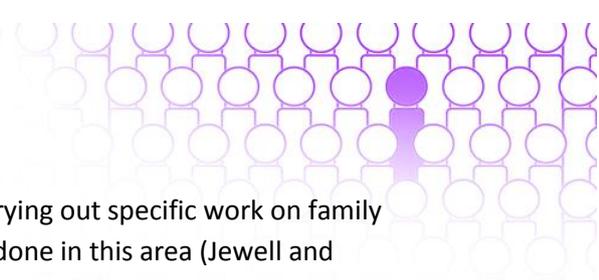
Methods

In response to our service user advisory group raising the issue as a high priority and in light of the issues outlined above concerning advocacy services for people with learning disabilities, the Improving Health and Lives Learning Disabilities Observatory wanted to find out about:

- The nature and extent of advocacy services for people with learning disabilities in England
- How funding changes would affect these services
- The impact of advocacy on health and health services for people with learning disabilities

To start this project we carried out a consultation of advocacy commissioners, advocacy organisations and advocacy networks to find out what they thought about specific questions about the nature of advocacy services and how funding changes might affect these services. We also invited comments and suggestions concerning the advocacy project in general.

Feedback from this consultation indicated the importance of measuring changes to funding over time and being clear about advocacy definitions and differences between different types of advocacy. There were also indications of a move towards generic providers of advocacy that may not specialise in providing services to people with learning disabilities.



As part of this consultation, we asked about the possibility of carrying out specific work on family advocacy services and found that some previous work had been done in this area (Jewell and Mallett, 2010). This report provides a useful focus on issues related to defining family advocacy and also highlights issues of sustainable funding and the importance of maintaining family advocacy as a separate strand of advocacy rather than being subsumed by a generic provider. Given the need for further work on the definition of family advocacy and the fact that relatively few (11) organisations were identified as carrying out independent family advocacy it was decided that our project would not be able to significantly progress Jewell and Mallett’s work. However the organisational case studies (see below) do explore issues related to family carers.

The consultation asked about the definitions of advocacy to be used within the surveys. The main point of feedback from advocacy organisations was that we needed to include a definition of professional or case based advocacy. The box below gives details of the definitions of advocacy we used for the surveys. An alternative set of definitions is provided by Action for Advocacy:

<http://www.actionforadvocacy.org.uk/articleServlet?action=display&article=716&articletype=20>

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)

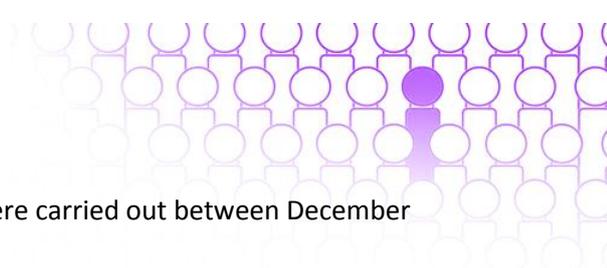
Non-instructed advocacy- is advocacy for a person who has not asked for an advocate or who finds it difficult to say what they want. The advocate will try to understand the client and their needs and wishes and make sure the client has as much input as possible in decisions.

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)

For this project we carried out two separate surveys, one for advocacy organisations and one for commissioners. Both surveys were made available online and in paper format on request. Because the advocacy organisations we sought to contact included self advocacy groups the advocacy



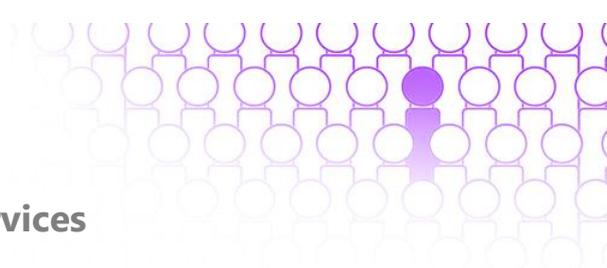
organisation survey was in an Easy Read format. The surveys were carried out between December 2011 and January 2012.

A total of 88 advocacy organisations responded to the questionnaire, mostly by using a link to a SurveyMonkey questionnaire, with 53 completing the entire survey. 78 commissioners of advocacy services responded (all local authorities), predominately using the SurveyMonkey link. 39 commissioners reached the end point of the survey. Advocacy organisations and commissioners completing the survey came from all regions of England.

The two surveys covered similar themes but the specific questions differed. Advocacy organisations were asked a range of questions on the organisation's profile, funding, gaps and barriers in advocacy provision, examples of good practice and work with social care and health organisations. The commissioners were asked for information regarding advocacy in their local area including funding, collaborative working, barriers to advocacy, what advocacy should achieve and good practice in health and social care. The surveys are available on the Improving Health and Lives website at: <http://www.improvinghealthandlives.org.uk/projects/advocacy>

We have presented the results of the surveys for both advocacy organisations and commissioners thematically, usually outlining survey results for advocacy organisations first, followed by the commissioner results. Quotation numbers refer to a specific (anonymised) organisation or commissioner.

In addition to the advocacy organisation and commissioner surveys, the third aspect of the advocacy project involved in-depth work with three advocacy organisations to find out more about what they are doing to promote better health. Three organisations (People First Merseyside (Sefton Group), Your Say and My Life My Choice) were selected from respondents to the advocacy organisation questionnaire who had indicated they were willing to be contacted, and were visited in February 2012. This work is presented in the form of case studies within the report.



Chapter 1: Information about Advocacy Services

In this section we discuss the characteristics of the organisations providing advocacy services for people with learning disabilities, as reported by themselves and commissioners. This includes the type of non-statutory advocacy offered by each organisation. We also discuss the ways in which advocacy organisations and commissioners monitor information about those using their service.

Organisational profile

We asked advocacy organisations whether they provided advocacy services just for people with learning disabilities. 44 organisations (50% of total responders) stated that they provide advocacy services just for people with learning disabilities, with a further 44 (50%) saying that they provided services for a range of people including those with learning disabilities.

Commissioners were asked how many local advocacy organisations they are aware of in their area providing non-statutory advocacy/self-advocacy services to adults with learning disabilities. 74 respondents answered the question, giving a number of known organisations ranging from 1 to 7 (mean 2.8). Of these organisations between 0 and 6 (mean 1.6) were known to cater specifically for people with learning disabilities. There were between 0 and 5 (mean 1.5) general advocacy organisations which included people with learning disabilities within their client group.

Advocacy organisations: activities

When asked about the main activities their advocacy organisation does for people with learning disabilities, 77 organisations responded. 39 organisations said they provided advocacy services for a range of people including those with learning disabilities and 38 organisations provided advocacy services just for people with learning disabilities.

We asked organisations about the type of advocacy services they provided.

- 73% (56 organisations) said they provided professional or case based advocacy, with nine organisations stating that they provide 1-1 advocacy and a further five saying that they carried out issue based advocacy.
 - Of these organisations 35 provided advocacy services for a range of people including those with learning disabilities (90% of this group) and 21 just for people with learning disabilities (55% of this group).
- 62% (48 organisations) said that they provided self advocacy, with 23 organisations mentioning running or supporting self advocacy groups and eight describing how they supported people to speak up for themselves.
 - Of these organisations 22 said that they provided advocacy services for a range of people (56% of this group) and 26 just for people with learning disabilities (68% of this group).

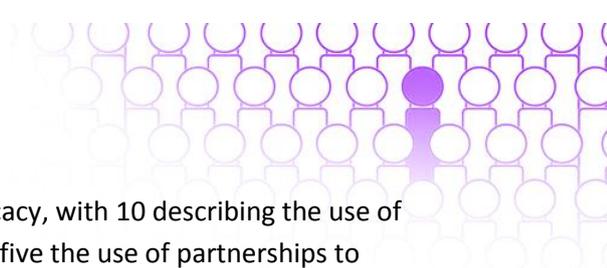
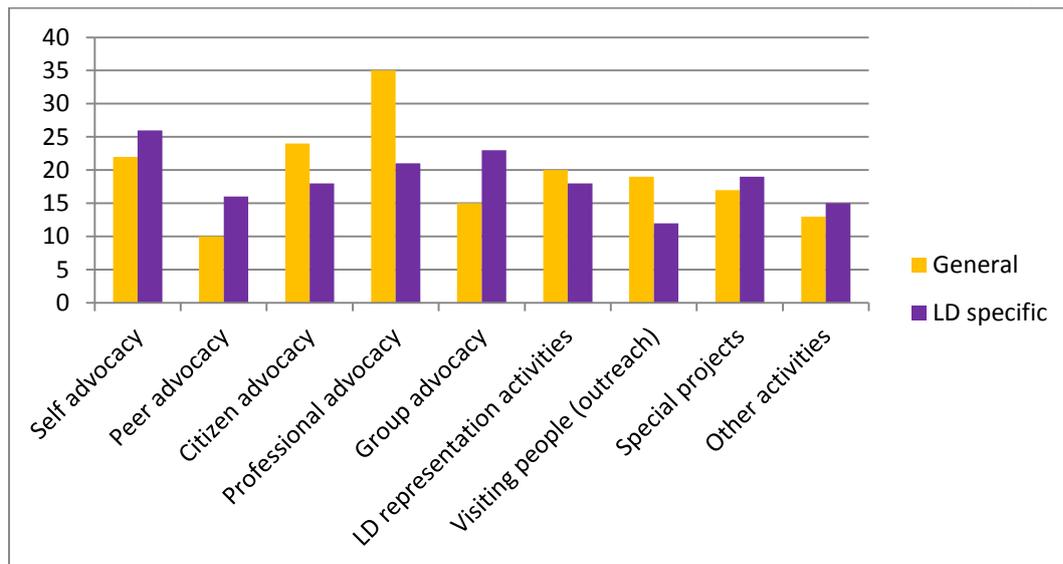
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- 55% (42 organisations) said they provided citizen advocacy, with 10 describing the use of volunteer citizen advocates, six the use of projects and five the use of partnerships to deliver citizen advocacy.
 - Of these organisations 24 said that they provide advocacy services for a range of people (62% of this group) and 18 just for people with learning disabilities (47%).
 - 49% (38 organisations) said that they supported activities involving the representation of people with learning disabilities such as running learning disability parliaments, regional forums or supporting people to be members of learning disability Partnership Boards.
 - Of these organisations 20 provided general advocacy services (51% of this group) and 18 just for people with learning disabilities (47%).
 - 49% (38 organisations) said that they provided group advocacy services.
 - Of these organisations 15 said they provided advocacy services for a range of people (38% of this group) and 23 just for people with learning disabilities (61%).
 - 47% (36 organisations) said they did special projects for groups of people, such as parents who have learning disabilities (15 organisations), people with profound and multiple learning disabilities (PMLD) or complex needs (five organisations) and work with young people during transition (four organisations).
 - Of these organisations 17 provided advocacy services for a general client base (44% of those groups answering the question) and 19 provided services solely for people with learning disabilities (50%).
 - 40% (31 organisations) said that they spent time visiting people (providing outreach), with eight organisations stating that most of their work involves outreach, and a further five that they would generally provide advocacy as part of their case work.
 - Of these organisations 19 provided advocacy services for a general client base (49%) and 12 provided services solely for people with learning disabilities (32%).
 - 32% (26 organisations) said that they provided peer advocacy, with four organisations describing how their members provided peer support for each other and a further four describing peer support activities taking place within groups.
 - Of these organisations 10 organisations provided advocacy services for a general client base (26% of these groups) and 16 provided services solely for people with learning disabilities (42%).
 - When asked about anything else their organisation did for people with learning disabilities, 27 organisations gave details of their work, which included:
 - Work with prisoners with learning disabilities.
 - Supporting quality checkers or auditors.
 - A project ensuring that services such as shops treat people with learning disabilities with respect.

Figure 1: Activities carried out by surveyed advocacy organisations



Commissioners: Funded advocacy services

Commissioners were asked to indicate what types of non-statutory advocacy they fund for people with learning disabilities, both from advocacy organisations that have a general client base that includes adults with learning disabilities within the client group, and from organisations providing services solely to adults with learning disabilities.

Due to a survey error commissioners could not tick both boxes. Three commissioners highlighted this as a problem, as they had both general organisations and organisations providing solely to people with learning disabilities offering the same service. Although we recognise the problem with the form, we expect that commissioners chose whichever advocacy organisations did the majority of the particular type of advocacy with people with learning disabilities.

Figure 2: Types of non-statutory advocacy for people with learning disabilities funded by commissioners

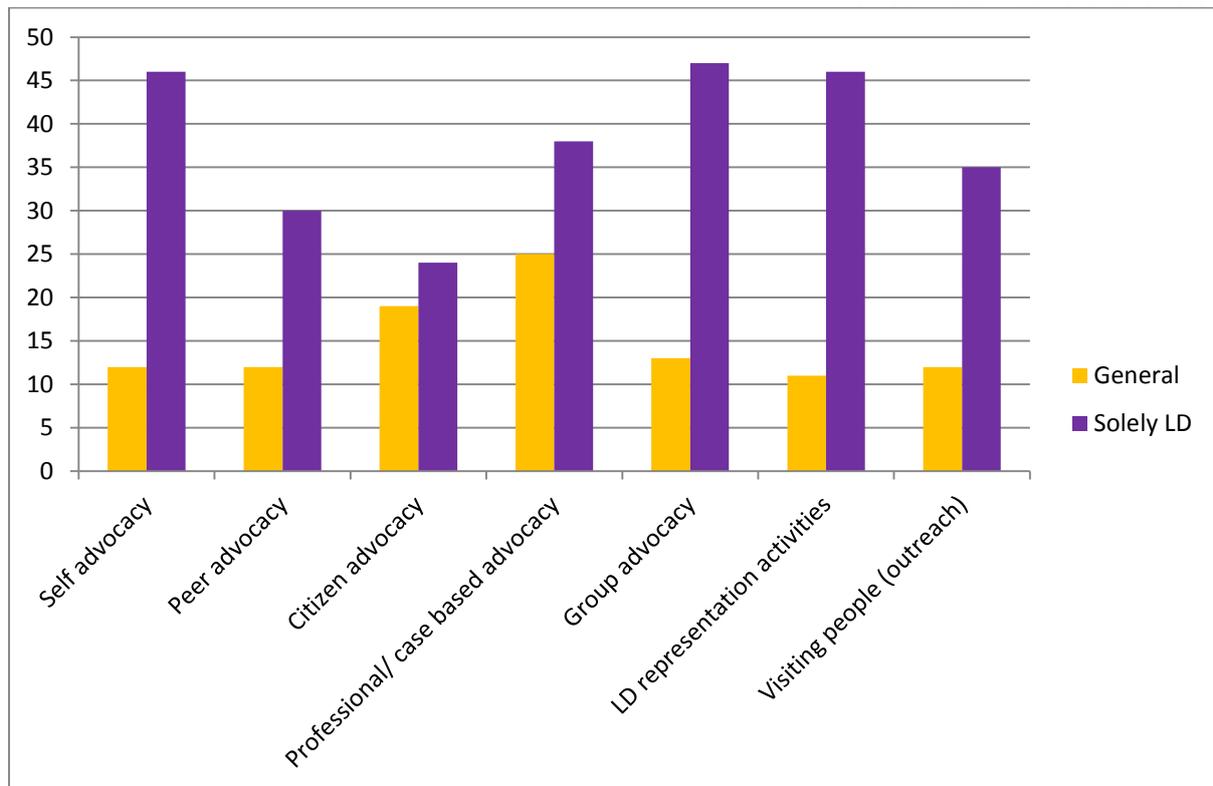
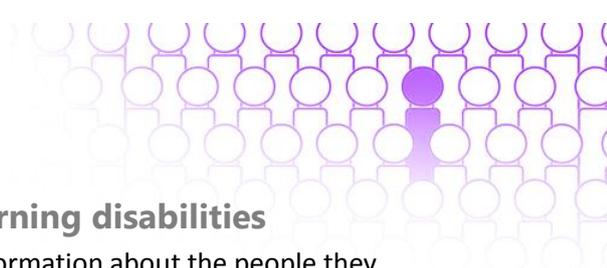


Figure 2 shows that people with learning disabilities were more likely to receive advocacy services from organisations providing services solely to people with learning disabilities, according to the commissioners responding to our survey. More generic advocacy groups were more likely to provide professional or case based advocacy than other forms of advocacy, although people with learning disabilities were still more likely to be receiving all types of advocacy from groups catering solely for people with learning disabilities.

Other types of non-statutory advocacy activities included providing training and addressing specific issues.

- Training was cited by five commissioners as being provided by their local advocacy organisations:
 - ‘Training programmes, staff training courses etc’. [3]
 - ‘Training in relation to advocacy skills/inspection.’ [29]
- Involvement in addressing specific issues was cited by 5 commissioners:
 - ‘We also commission one off pieces of advocacy around specific changes or a set piece of work.’ [51]
 - ‘Odd projects for example Sports Activity Posts.’ [71]

Organisations were also involved with holding one off events, user led inspections, and developing Easy Read documents.



Monitoring information about people with learning disabilities

93% of 54 advocacy organisations stated that they recorded information about the people they provided advocacy services to, such as age, gender, ethnicity and disability. When asked to provide details:

- 15 organisations (28%) stated that they recorded information for all four characteristics: age, gender, ethnicity and disability
- Seven organisations (13%) said that they recorded this information on monitoring forms or as part of their monitoring processes
- Other information mentioned as being recorded by at least one organisation include:
 - Eligibility for council services
 - Communication preferences/ needs
 - Postcode or address
 - Reasons for referral
 - Risks or behaviour issues
 - Successes.

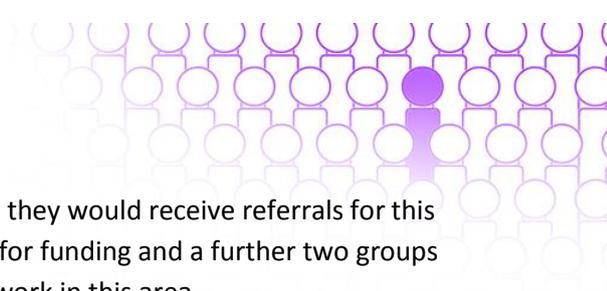
Commissioners were asked if the advocacy organisations they fund supply information on service user characteristics such as age, gender, ethnicity and disability.

- 89% of those commissioners who answered the question stated that these aspects were monitored:
 - ‘We ask for details of all the Single Equalities Act protected characteristic strands - that includes all the demographic details you have listed.’ [42]
 - [named group] send on the data on a quarterly basis on the numbers of people, the age, sex, and the issue raised and outcome achieved.’ [55]
- Four commissioners noted that this data was reported to them during quarterly or annual reports or reviews:
 - ‘Full half-yearly equalities monitoring + individual monitoring per service user for [named] purchased services.’ [54]

Advocacy organisations: Supporting specific groups of people

We asked organisations whether they did anything to make sure that the following groups of people were included in their advocacy services as clients:

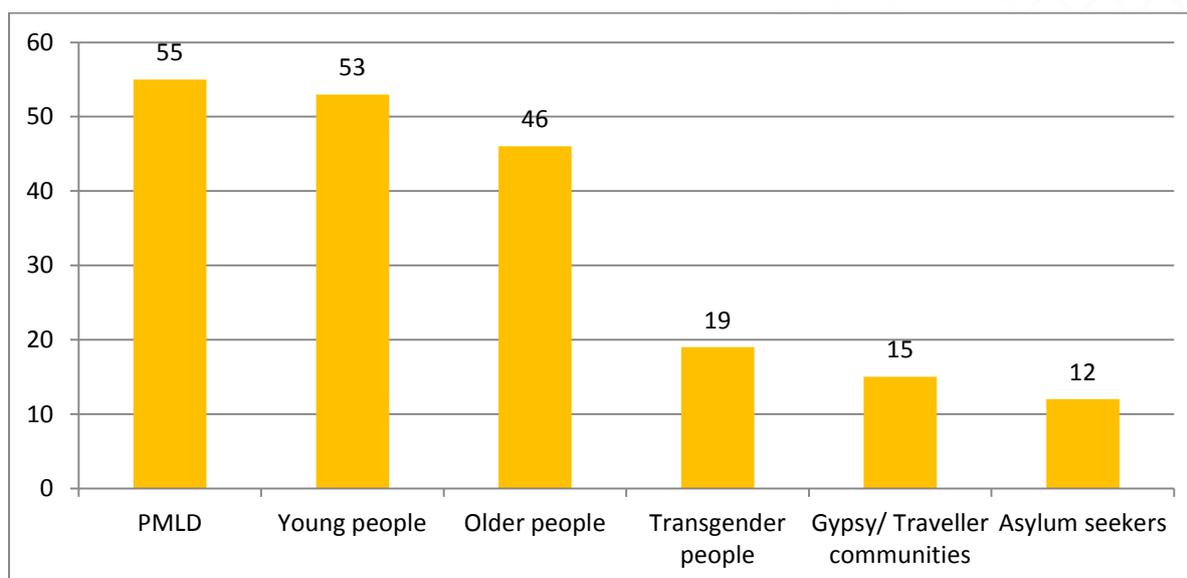
- People with profound or multiple learning disabilities (PMLD):
 - 55 organisations (83% of the 66 organisations answering) said that they ensured that people with PMLD were included in their advocacy services, of which seven organisations described links with service providers, six organisations said they provided non-instructed advocacy in this area, and four organisations said they provided 1-1, professional or case advocacy.
 - Overall there was a mixed response in relation to the degree to which work with people with PMLD took place. In addition to the specific examples of work listed above, six groups said that people with PMLD were included as part of their general



activities, with a further two groups stating that they would receive referrals for this group. Two groups said that they were looking for funding and a further two groups said that they were developing or had ongoing work in this area.

- Young people moving from school or college into adult life:
 - 53 organisations (80%) said that they took steps to ensure young people were included in their services.
 - Examples of this include work within and links to schools and colleges (13 organisations), engaging with local authority transitions or other services (eight organisations) and running specific transitions projects (six organisations).
- Older people:
 - 46 organisations (70%) stated that they took steps to ensure that older people were included in their advocacy services, including making links to other service providers (five organisations) and partnership work with or links to Age UK (three organisations).
- Transgender people:
 - 19 organisations (29%) said that they took steps to ensure that transgender people were included in advocacy services, although there were few examples of specific practice in this area.
- Gypsy and Traveller communities:
 - 15 organisations (23%) said that they tried to ensure that Gypsy and Traveller communities were included in their advocacy services. Relatively few examples of specific practice were provided, including work as part of a BME project (two organisations), links with the traveller community (one organisation) and links with traveller services (one organisation).
- Asylum seekers:
 - 12 organisations (18%) said that they took steps to ensure that asylum seekers were included in the provision of their advocacy services although there were few examples of specific practice provided.

Figure 3: Organisations trying to ensure the following groups are included in advocacy services



Commissioners: Supporting specific groups of people

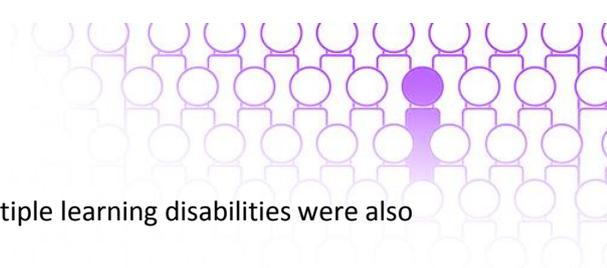
Commissioners were asked whether people with learning disabilities from specific groups were included within advocacy services. The groups listed were: young people at transition, older people, Gypsy and Traveller communities, asylum seekers, transgender people, people with profound and multiple disabilities.

53% of those who answered the question said that this information was recorded. This question was not answered in depth indicating that this type of information is often not well monitored.

- Young people in transition (38% of 21 responses) and people with profound and multiple disabilities (33% of 21 responses) were the groups most commissioners mentioned.
- Five stated that information was requested about all these groups.

Commissioners were asked to give details of any specific projects they fund for adults with learning disabilities e.g. for parents with learning disabilities, Black and Minority Ethnic communities, people with Profound and Multiple Learning Disabilities, people with challenging behaviour, etc.

- The most frequently cited specific projects, noted by six commissioners, were around supporting parents with learning disabilities.
 - ‘Parents with a learning disability facing child protection processes.’ [32]
 - ‘Parents with learning disabilities are supported by representational advocates through any statutory process.’ [19]
- Four projects supporting people from black and minority ethnic communities were noted.
 - ‘A BME Advocacy service is funded. This service primarily works with adults with a learning disability and their carers from the Asian community.’ [15]
 - ‘Funding to [named group] includes money to support a Black Members group.’ [63]

- 
- Four projects supporting people with profound and multiple learning disabilities were also funded.
 - ‘People with profound and multiple learning disabilities and people with challenging behaviour are matched with volunteer citizen advocates who develop long term advocacy partnerships for people with complex needs that may be un-befriended.’ [19]

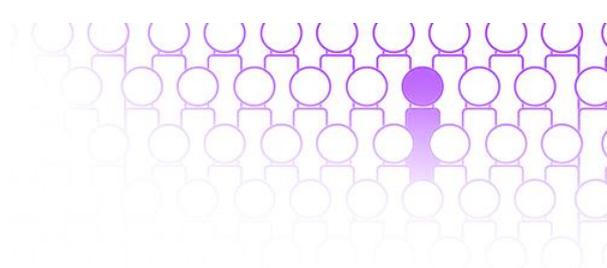
Other funded projects included young people in transition, mental capacity advocacy, and older carers.

Summary

Half of the organisations responding to our survey provided advocacy services just for people with learning disabilities and half provided services for a range of people, including those with learning disabilities. Almost three quarters (73%) of responding organisations stated that they provided professional or case based advocacy services, while six in ten (62%) provided self advocacy. This provides an indication that some organisations provide more than one type of advocacy.

We found a difference in commissioner data on advocacy funding between general providers and advocacy organisations providing advocacy solely to people with learning disabilities. Funded general advocacy groups were more likely to offer professional or case based advocacy for people with learning disabilities. According to this data, advocacy groups working just with people with learning disabilities were more likely to provide self advocacy and group advocacy. Therefore learning disability-only advocacy groups were more likely to provide advocacy that is directed, and administered, by people with learning disabilities themselves. However a survey error may have affected these figures.

We found that advocacy organisations are not always being monitored very closely. Although 93% of advocacy organisations said that they recorded demographic information on those who used their service, and 89% of commissioners stated that these aspects were monitored, only just over half of commissioners said they recorded information about groups at risk of exclusion from advocacy, such as people with profound and multiple learning disabilities. Better sharing of information between advocacy groups and commissioners could ensure both parties are more aware of who uses advocacy services and which groups remain at risk of exclusion.



Chapter 2: People

In this section we outline information provided by advocacy organisations on the number of people involved in advocacy. This included staff, volunteers and people using the advocacy service.

Number of clients

Advocacy organisations were asked how many people with learning disabilities they provide advocacy services to at the moment (i.e. their current caseload). 48 organisations provided data for this question.

Figures given for total caseload ranged from 5 to 600. Some (mostly self advocacy) organisations gave data for membership of their organisation for this question. Excluding the data given for members, the caseload ranged from 5 to 350, with a mean of 70 persons per organisation.

Number of employees with learning disabilities

We also asked organisations how many people with learning disabilities were employees in their organisation. 42 organisations provided data for this question.

Answers provided ranged from 0 to 25 employees (mean 2.7). Of these organisations,

- 18 (45%) did not employ people with learning disabilities
 - Of these 11 were organisations providing advocacy services solely to people with learning disabilities (44% of this group of responders to this question).
 - Seven were organisations providing advocacy to a range of different client groups (41% of responders).
- 11 (28%) employed one person with a learning disability.
- 13 (33%) employed two or more people with learning disabilities.

In addition three organisations said that they worked with volunteers or paid the expenses of people with learning disabilities. Three organisations said that people were paid on a freelance basis or for training they provided and two organisations said that more employees were employed nationally within their organisation.

Number of volunteers with learning disabilities

Organisations were asked how many people with learning disabilities were volunteers. 27 organisations provided data in relation to this question, with answers ranging from 0 to '100 regularly active members'. The mean number of volunteers was 11.8 people.

Number of members with learning disabilities

Finally, we asked how many people with learning disabilities were members of the organisation. 32 organisations provided data for this question. Answers ranged from 0 to 450. Seven organisations (22%) of responders said that this question was not applicable to their organisation although no reason was given.



Family carers

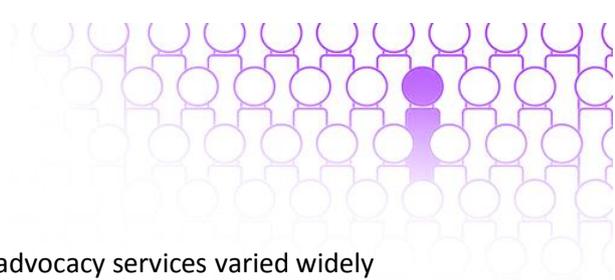
We asked organisations whether family carers were involved in or supported by their organisation. 59 organisations answered this question, of which 32 (54%) answered 'yes'. Of those organisations answering 'yes',

- Six organisations (10%) said that family members may be involved in some way in the provision of advocacy:
 - 'Advocates engage family carers in advocacy where possible.' [66]
 - 'All our advocacy is done in conjunction with family carers.' [59]
 - 'Our direct support is to adults with learning difficulties/disabilities, however as many of the partnerships are of a long term nature, it is inevitable that the advocates have contact with the family carers. [84]'
- Six organisations (10%) said that family carers were involved in the administration of their organisations, for example as trustees or sitting on groups and committees
- Five organisations (8%) said that they provided support for family carers
- Three organisations (5%) said that they provided advocacy for family carers directly
- Other examples of the involvement of family carers include:
 - Support is provided if family carers have a learning disability themselves (two organisations)
 - Provide signposting to other sources of family carer support (two organisations)
 - 'Family carers are consulted about our work and input into everything we do.' [66]
 - '4 years ago we sought funding to set up and co facilitate a local family carer group to help a carer become a LIG member, this group next year will continue independently, using our hall and with information and help we can provide.' [38]
 - 'We encourage carers to visit our office and see what we do and how we work so they know people who come here are safe, listened to, welcomed. We invite carers to social events.' [53]
 - 'We supported people with learning disabilities to lead on a consultation with parent /carers around a short break service in [local area]. A report was presented to the PCT and made a series of recommendations from the parent/carers.' [15]

Number of advocates/number of people served by organisation

Commissioners were asked for the number of advocates funded within the organisations they commissioned. Figures were provided for the number of advocates across 27 organisations. The average number of advocates per organisation was 2 (range 1-6).

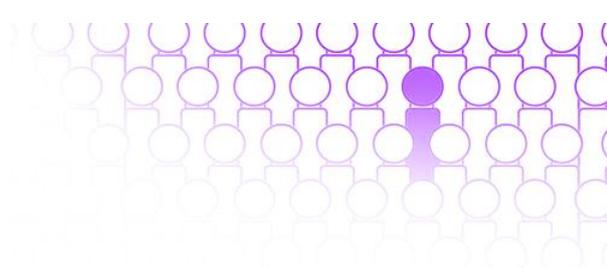
Some commissioners differentiated between and gave figures for paid and volunteer advocates. The mean number of volunteer advocates per organisation was 36.3 (range 10-100). Figures were provided across 28 organisations for the number of people served by the advocacy activities. There was a mean of 107 people helped yearly by service (range 15-420).



Summary

Figures on the number of people served by and working within advocacy services varied widely depending on the size of organisations and type of advocacy provided. Overall the mean average of clients supported per service was higher according to commissioners (mean 107, range 15-420) than the data provided by the advocacy organisations responding to this survey (mean 70, range 5-350).

61% of responding organisations stated that they employed at least one person with a learning disability. Just over half of responding organisations stated that family carers were involved in or supported by their organisation, including providing family advocacy and involving family carers in administration.



Chapter 3: Collaborative Working

Collaborative working is a key area that may help advocacy organisations to continue and develop their work with people with learning disabilities (EHRC, 2010). We wanted to know more about the range and scope of collaborative working undertaken. We asked about links with other organisations or commissioners, and about work with regional or national forums and with Partnership Boards.

Work with other groups and organisations

Advocacy organisations completing the survey were asked if they worked with other groups such as local councils or other advocacy organisations to provide advocacy services for people with learning disabilities. 60 organisations answered this question, of which 43 (72%) answered 'yes' and 17 (28%) answered 'no'.

Organisations answering 'yes' were asked to give details of their work with other groups or agencies.

- 20 organisations (33%) described work with local authorities, for example:
 - 'We actively take part in consultations with our local council.' [32]
 - 'Regularly work with the council and other service in order to achieve client objectives.' [46]
 - 'We work closely with the local authority on the learning disability partnership board and with the various task groups.' [86]

- 12 organisations (20%) said that they worked with other local advocacy groups, such as:
 - 'We work with other charitable organisations in the area which provide peer advocacy, as well as citizen advocacy.' [84]
 - 'We also work with other advocacy organisations referring clients to each other.' [86]
 - 'Work alongside another advocacy group to support people with LD to attend and participate on the LD partnership board.' [47]

- Six advocacy organisations (10%) said they worked with charities such as Mencap.

- Other groups or agencies mentioned by advocacy organisations include:
 - Advice, information and support agencies.
 - Councillors and MPs.
 - Community services such as day services and community nurses or learning disability nurses.
 - IMHAs and IMCAs.
 - Local advocacy networks, coalitions or consortia.
 - Local Learning Disability Partnership Boards.
 - NHS organisations or staff.
 - Police and probation.

- Psychology services.
- Schools and colleges.
- Solicitors.
- Universities.

Work with regional or national forums

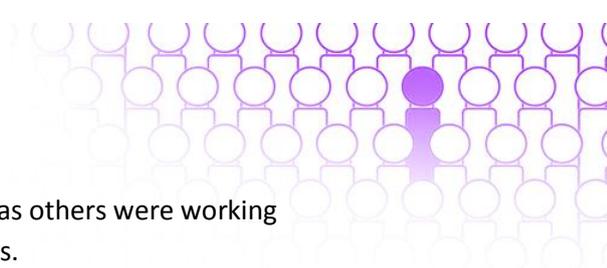
Staying Strong (2011) said that one of the things that self advocacy groups do is attend regional and national forums. For our survey we asked advocacy organisations whether they worked with regional or national forums. 71% of the 59 organisations answering this question said ‘yes’. Of those organisations stating ‘yes’:

- 13 (31%) attended regional forums or supported members to attend. One organisation said that they worked with regional forums but did not attend because they were held too far away.
- There was no significant difference between the number of organisations providing advocacy services just for people with learning disabilities (21 answered ‘yes’) and the number of organisations with a more general client base (20 answered ‘yes’).
- Nine (21%) attended both regional forums and the national forum of people with learning disabilities or supported their members to attend.
- Six (14%) described work with national advocacy networks such as Action for Advocacy (A4A) and Advocacy Resource Exchange (ARX).
- Other examples provided of work with national and/or regional forums include:
 - BILD.
 - BME health forum.
 - Mencap.
 - National Family Carers Network.
 - Regional Training and Development team.

Working collaboratively with other commissioners

Commissioners were asked whether they work collaboratively with other commissioners of advocacy to provide advocacy for adults with learning disabilities. This initiated a broad range of answers. 67% of the 42 who answered the question were to some extent engaged in collaborative working. This ranged from working with NHS commissioners to being involved in a wider borough-wide scheme. Some were currently in the process of changing to a more collaborative way of working.

- 14 commissioners indicated that they worked collaboratively with NHS commissioners.
 - ‘Health and social care commissioners work in partnership to provide advocacy services.’ [15]
 - ‘NHS commissioners.’ [12]
- 11 commissioners discussed working with other commissioners and commissioning bodies. The scale of the joint working varied. Some worked within their own local authority with



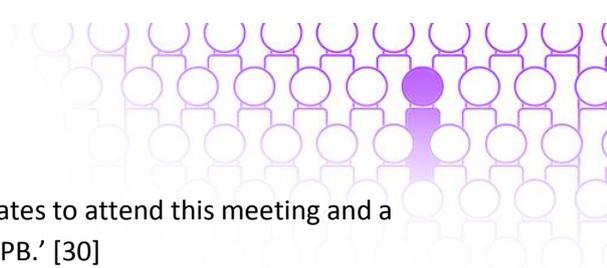
other service commissioners, e.g. mental health, whereas others were working collaboratively with commissioners from other boroughs.

- ‘Other Commissioners within the Adults and Communities Joint Commissioning Unit.’ [6]
 - ‘Currently working with [local boroughs] to jointly commission a new professional advocacy service in 2012 as a framework [named localities] will investigate a tri-borough approach to group, board and self advocacy for the future.’ [40]
 - ‘Advocacy for people with learning disabilities is commissioned through the Learning Disabilities Management Group which includes health and social care commissioners who manage the learning disabilities pooled budget.’ [72]
- One authority brought both these ideas together in a recent initiative designed to streamline advocacy and save money.
 - ‘We jointly commission and monitor generic advocacy services with NHS [named] and [named] Council. Following a joint service review of all our voluntary sector contracts in 2010/11, we realised that between us we had many contracts with a number of different organisations for three areas; information & advice, carers support and advocacy. In terms of advocacy we had 14 different contracts with 5 different providers, which was causing duplication, confusion, waste and gaps between which people were falling, with some client groups not having advocacy services available to them at all. Therefore we pooled our resources and tendered for one contract for generic advocacy and service user engagement.’ [10]

Advocacy representation on Partnership Boards

Commissioners were asked whether there was any representation of advocacy services on their local Learning Disability Partnership Board. Answers did not always make a clear distinction between attendance by people with learning disabilities as self advocates or as peer advocate supporters. Neither was the distinction always clear between advocacy services attending in their role as advising and supporting members of the Partnership Board with learning disabilities, versus as members of advocacy groups in their own right.

- 39 provided a written response. 34 of these indicated the presence of either self advocates and/or advocacy groups as members of the board. For example:
 - ‘Representation from [named group] as third sector representatives. 3 service user representatives who are also trustees of [named] self advocacy group.’ [6]
 - ‘two people with learning disabilities on the Board.’ [10]
 - ‘Both Advocacy services attend our Partnership Board.’ [21]
- 13 responses indicated that advocacy groups attended the board in their capacity of supporting people with learning disabilities at the meeting. Sometimes this was in addition to the advocacy group attending as third sector representatives.
 - ‘The advocacy provider supports local people with LD at partnership boards.’ [40]
 - [named group] support service users on the Learning Disability Partnership Board.’ [67]

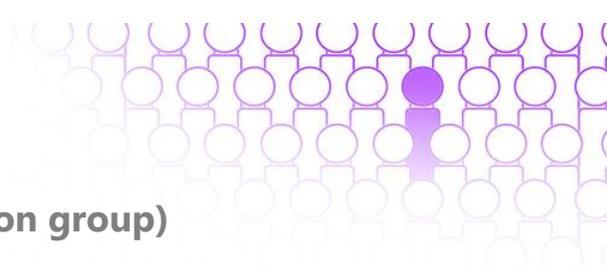
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- '[named group] support a number of self advocates to attend this meeting and a number of other meetings that feed into the LDPB.' [30]
 - Seven commissioners stated that people with learning disabilities acted as chair or co-chair of the Partnership Board with support from advocacy.
 - 'co-chair is a person with learning disabilities'. [9]
 - 'the board is also co-chaired by a self advocate.' [19]
 - 'They support the co chair who is also someone who has a learning disability.' [51]
 - At two Board meetings advocacy groups have a standing item on the agenda which is designed for bringing up any new issues or concerns.

Summary

The most common collaborations for advocacy organisations were with local authorities, but they also often mentioned working with other advocacy groups. The majority of advocacy organisations worked with regional or national forums but specific examples of this were fewer. This indicates the survey sample may be less connected to the regional forum structure.

For commissioners, collaboration was mainly with NHS commissioners but also occurred with other commissioners or commissioning bodies. Almost all commissioners responding to a question about Learning Disability Partnership Board representation stated that advocates or self advocates were members of the Board, although the distinction between advocates present in their own right or attending to support others was not always made clear.

Case Study 1 provides an example of a self advocacy group, People First Merseyside (Sefton group) with strong links to the regional network structure.



Case Study 1: People First Merseyside (Sefton group)

The group

The Sefton Group of People First Merseyside is a relatively small organisation with approximately 20 active members, and another 35 on the mailing list. They also work with another 20-30 people with a learning disability through outreach work and meetings (and connect with many others through visits to day centres, resource centres and other organisations) Ten of the twelve directors on the Board have a learning disability, and people are elected to formal roles by their peers. They would like to get more people involved. The group do some joint work with the Liverpool Group of People First Merseyside

The group provides mainly self-advocacy, peer advocacy, group advocacy, and occasional 1-1 support, for example when a member has difficulty with a housing provider. Little things can make a big difference, and providers need to treat people with learning disabilities in the same way as other customers.

The group are exploring how to include people with autism more in their work. They are getting guidance about this, they feel they need a better understanding themselves. They know that the Partnership Board meetings, with 80 people in a big hall, is not the best way of doing it.

The group would like to include more people with complex needs, but it is difficult with current resources. They are talking to the Council about this. They try to connect with other people, but are not clear how many people there are locally: 'We know there are many hundreds with a learning disability in Sefton and want to work with the council and others to make sure those with more complex needs do not get left out of "speaking up"'.

For more information see the website: <http://peoplefirstmerseyside.com/seftongroup.htm>

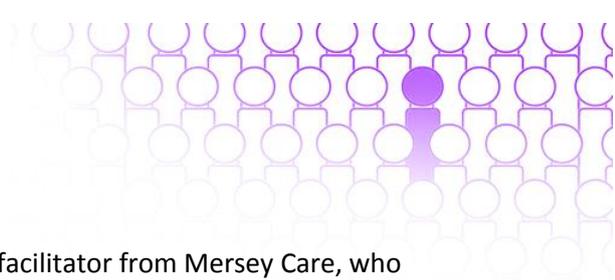
Links with the North West Training and Development Team

There are strong links with the regional group, and Sefton regularly send a representative to regional meetings. 'The regional group allows us to share good practice and ideas, and find solutions to problems. One area had a problem as the co-chair wasn't getting Partnership Board papers. Another area which had experienced this problem previously was able to help. It helps us get a view across the region, and identify what needs to be fed up to the national forum. Being part of the regional network ensures our voice is heard in the North West'. One of the members had just come back from a regional event, where she was helping run a workshop on health issues.

'Through People First Merseyside, we have reps who attend or feed into the national forum set up by Valuing People Now. We do NOT want to lose this link'.

Family carers

People First Merseyside (Sefton group) encourage family carers to come to the office, and are exploring how to link up via social events. They network with the carers centre in Sefton, and take a partnership approach to working with carers.



Health

Health is a big topic. The group work with a primary healthcare facilitator from Mersey Care, who does a lot of work with hospitals on improving health. In February 2012, they did a 'Love yourself, love your health' project including a quiz which asked questions like:

- Who would you see about getting a health action plan?
- How can you get a health passport?
- Have you had an annual health check?

They want to look at this in six months to see if there has been a change.

The Learning Disability Partnership Board has a Get Involved Group (GIG) which the group run. The GIG is open to anyone (people with learning disabilities, family carers, support workers and professionals). Up to 50 people attend, and about half have learning disabilities. One or two meetings a year are focused on health. The GIG feeds back to the Partnership Board, and the group co-ordinate agendas.

The group are involved in the Big Health Check day, and have two getting ready meetings.

'We helped a group of hospitals in Merseyside with an accessible complaints form, and this made us think about whether people knew what to expect when they went to hospital, so they would know when to complain. So we did some work on people's rights and what to expect'.

'We often find letters from health services are not in Easy Read. One letter was about rearranging an appointment and it didn't even have a telephone number on it. There are also letters with a tiny box at the end saying that the letter can be reproduced in different formats, but no one will read this'.

The women's group is doing work on cervical screening. They are doing a DVD to help women understand what it is all about.

The group have done an emergency information card, the 'E' card with Merseyside police. The card includes details of who to contact in an emergency, medical information and a 'how I communicate' section.

'We train student nurses about how to treat people with learning disabilities. We do a drama with bad and good scenarios. The students are asked to identify what went wrong and some of them think we are being a bit far-fetched with the bad stuff. But the examples in the scenarios are based on real experiences. We had one example of a person with learning disabilities and family carer visiting the doctor, and the doctor said to the family carer "how is it today?"'

Supporting people with learning disabilities about their health

The group support people to understand health issues. The weight management/healthy eating group has helped participants to eat more healthily (they talked about using less sugar and salt, eating vegetables and understanding calories). They also ask guest speakers in to talk about specific issues. A future topic is going to be about stress. The group decide what they want to address at the January meeting, when they review what has happened in the last year, and plan for the new year.



‘We are doing a walking group – we want to do more work like this. As a group we are getting healthier, and this is important as health has an impact on the whole of your life’.

Other work

The group get lots of requests for training and consultation, and have to balance what they do for free and what they need to charge for. In order to prepare for events they get information from other people depending on the event (nurse from Mersey Care, representative from the police, Information officer from the Council, the North West regional group). They also have to learn about training and presentations. ‘We did a conference with the police about hate crime. We had a ‘big brother’ diary room before the event, so people could share their experiences. There were some very powerful stories. One member presented at the hate crime conference to 250 people. A lot of people would be scared to do that. It helps give members more confidence when they can do things like that. We wanted actions from the day, from all participants. We want to work better together to tackle hate crime. Working in partnership is important’.

Friends and relationships are the 4th big topic for the region, along with health, housing, employment and personalisation. It is a big issue. The group are thinking of having a directory of places it is good to go to, and they run social events. Employment is also a big issue. It is really difficult to get jobs, and there are lots of negative attitudes and ignorance’.

What would self-advocacy groups find helpful?

‘We have very limited resources. Just a little bit more, enough for another worker, would make all the difference. We haven’t had an inflationary uplift since 2009, so it means we are getting a bit less each year in real terms. We have to plan on the basis of funding for another year, but this isn’t certain. There has been talk of tendering, although we hope they will reconsider this. It would help a lot if we could have guaranteed funding for 2-3 years so we could plan ahead’.

There is a gap in advocacy for young people in transition, also helping people into paid employment, and social activities/relationships.

How can self-advocacy groups prove their worth?

‘We can help organisations get better information. For example, the first Big Health Check day the region ran in 2010 was okay, but when we ran it last year, people said they got much better information and feedback about services. The Partnership Board has also changed the way it works based on its experience of the GIG.

We are doing a social return on investment exercise. We calculate the hours that people attend each month at the minimum wage. If a member has a specific role in the organisation (chair, treasurer etc), we calculate an hour’s work at £12.50. When you add it up, it demonstrates that pound for pound, we give very good value.

We are carrying out a quality assurance exercise on our organisation using the Practical Quality Assurance System for Small Organisations (PQASSO). This covers how we run the organisation and is designed for small charitable organisations like ours.



We send out lots of information about what we are doing and attend various meetings. We have a facebook site and tweet. We speak up when we need to but our approach is to work together when possible, and be professional'.

Chapter 4: Funding

Organisations and commissioners were both asked about funding levels. Organisations were asked for information about the amount of funding they received for previous years and how much they were going to receive for the next financial year (2012/13). Organisations were also asked about the effect of funding changes on their provision.

Commissioners were asked about their overall advocacy budget, and the amount allocated to individual organisations. We asked about the amount of funding they provided in previous years and how much they were planning to provide in the next financial year (2012/13). Commissioners were also asked about how they measure advocacy outcomes in their area.

We asked both advocacy organisations and commissioners why they felt funding advocacy was important and to outline the three most important reasons for funding advocacy services for people with learning disabilities.

Figures provided by advocacy organisations

A total of 48 advocacy organisations answered questions about how much funding they received for the years 2009/10, 2010/11, 2011/12 and 2012/13, although fewer organisations provided funding information for 2009/10 and planned funding for 2012/13. Median values have been calculated due to large outlying values from one organisation. Figure 4 shows that the median level of funding declined from £85,000 in 2010/11 to £55,500 in 2012/13. However the median value for 2012/13 may have been affected by a lower number of organisations being able to provide this information.

Figure 4: Table of learning disability advocacy funding

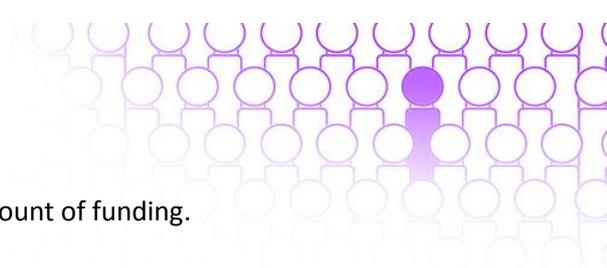
Date	Number answering question	Range	Median
2009/10	25	Nil-£1.1 million	£75,000
2010/11	31	Nil-£1.4 million	£85,000
2011/12	35	£2,000-1.3 million	£64,375
2012/13	23	£9,000-1.3 million	£55,500

Next year (April 2012-March 2013)

Where figures were given (23 organisations) the median level of funding was £55,500 (range £9,000-£1.3 million). The median value was £55,000 for the 9 organisations providing advocacy services specifically for people with learning disabilities and £99,142 for the 14 organisations providing advocacy services for a more general client base (see Figure 5).

It was not always possible to ascertain a trend, but of those organisations providing data about their funding:

- Six (26%) indicated that they would be getting less money this year.

- 
- Five (22%) said that they would be getting the same amount of funding.
 - Three (13%) said that their funding would increase.

A further 18 organisations indicated that their funding for next year was not known, three of which said that they were currently going through the tendering process.

We also asked advocacy organisations about funding next year:

- 51 (82%) organisations thought it would be more difficult to get money next year.
- 9 (15%) organisations thought it would be about the same effort to get money next year.
- 2 (3%) organisations said that they thought it would be easier to get money next year.

This year (April 2011-March 2012)

The median level of funding for this year was £64,375 (range £2,000 to £1.3 million; data provided by 35 organisations).

Of those organisations providing data:

- The median value for the 19 organisations providing advocacy services solely to people with learning disabilities was £34,000.
- The median for the 16 organisations with a more general client base was £100,000.
- 12 organisations (39%) said that their funding was less since last year (2010/11) (6 organisations providing services solely to people with learning disabilities and 6 for a more general client base).
- 15 organisations (48%) indicated that their funding had stayed the same since last year (10 organisations providing advocacy services solely to people with learning disabilities and 5 to a more general client base).
- Four organisations (13%) said that their funding had increased since last year (3 organisations providing advocacy services solely to people with learning disabilities and 1 to a more general client base).

Last year (April 2010-March 2011)

The median value of funding for last year was £85,000 (range £nil to £1.4 million; data provided by 31 organisations).

In relation to 2010/11, where it was possible to ascertain a trend:

- The median value of funding for the 17 organisations providing services solely to people with learning disabilities was £55,000.
- The median value of funding for the 14 organisations providing advocacy services for a range of people including those with learning disabilities was £100,000.
- Five organisations (16%) said that their funding had decreased compared to 2009/10 (3 solely providing advocacy services for people with learning disabilities and 2 for a more general client base)

- 16 (52%) organisations said their funding had stayed the same (12 organisations providing advocacy services solely for people with learning disabilities and 4 for a more general client base)
- Nine (29%) organisations said that their funding had increased (3 solely providing services for people with learning disabilities and 6 for a general client base)

The year before last (April 2009-March 2010)

25 organisations gave details of their funding for 2009/10, and the median value was £75,000 (range £nil to £1.1 million). The median funding value was £52,000 for 15 organisations providing advocacy services solely to people with learning disabilities and £134,142 for 10 advocacy organisations with a generic client base (see Figure 5).

Figure 5: Median levels of funding by year

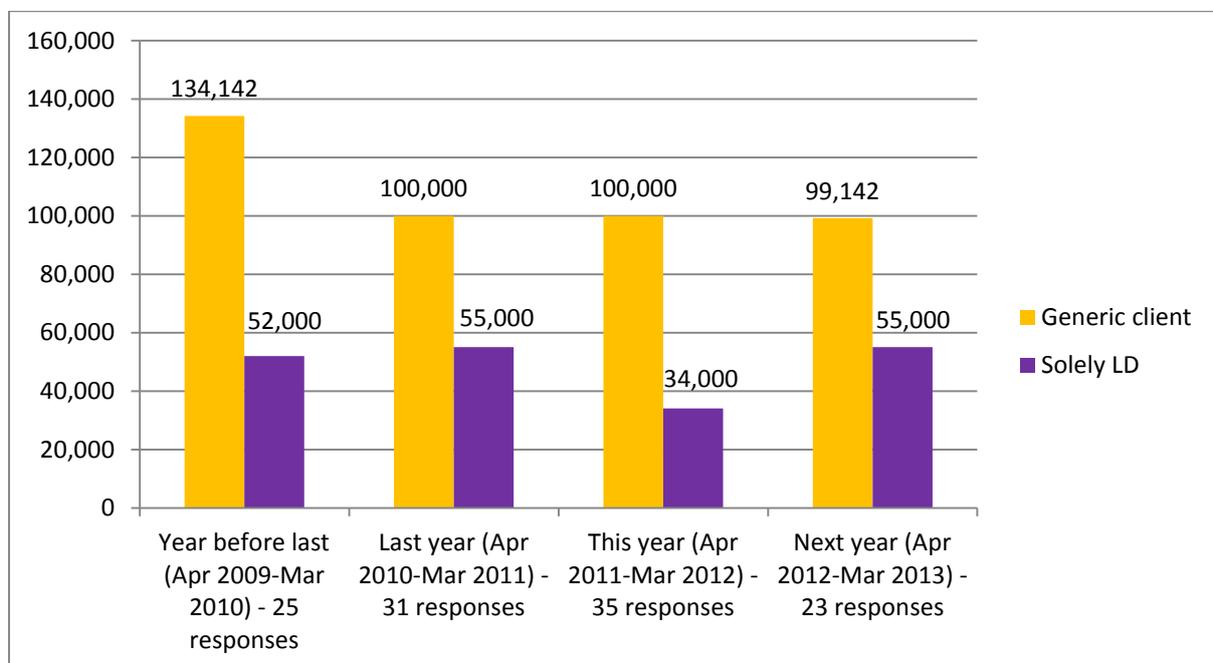
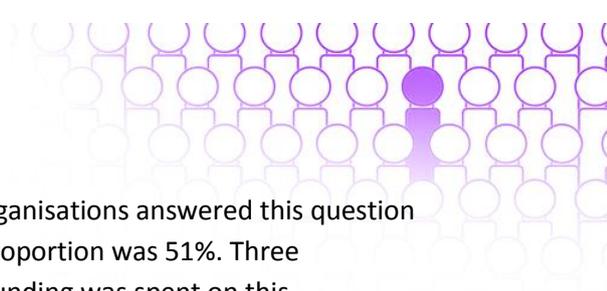


Figure 4 indicates a reduction in funding since 2010/11 for the advocacy organisations surveyed. However this picture is less clear cut when groups are divided into those providing advocacy services for a generic client base and those solely for people with learning disabilities, as shown in Figure 5.

Figure 5 shows a drop in median values from £134,142 in 2009/10 to approximately £100,000 for the years 2010/11, 2011/12 and 2012/13 for organisations providing advocacy services to a generic client base. For organisations providing advocacy services solely to people with learning disabilities the median value rises slightly from £52,000 in 2009/10 to £55,000 in 2010/11 before falling sharply to £34,000 in 2011/12. The median value for 2012/13 returns to £55,000 but this figure may have been affected by a smaller number of organisations being able to provide data (as noted above).

Proportion of funding spent on people with learning disabilities

Organisations that supported lots of different people were asked what proportion of their money



was spent on supporting people with learning disabilities. 17 organisations answered this question and proportions ranged from 10% to 94%. The mean average proportion was 51%. Three organisations said they did not know what proportion of their funding was spent on this.

Source of funding

Advocacy organisations were asked about where their money came from and 59 organisations answered this question.

- 18 organisations said that their funding came solely from local authorities.
- One organisation said that their funding came solely from an NHS Foundation Trust.
- A further four organisations stated that their funding came from a mixture of local authority and NHS sources, with another six organisations giving the NHS as one of several sources of funding.
- Ten organisations said that they received funding from foundations, such as the Lloyds TSB Foundation, and trusts. A further ten organisations said that their funding came from charities, amongst other sources, including two learning disability charities
- Lottery funding was another prominent source of funding, with two organisations saying that their funding was shared between local authorities and the Big Lottery fund and a further five that their funding included lottery funding.
- Eight organisations said that donations formed part of their funding while five mentioned fundraising activities.
- Other funding sources mentioned by at least one advocacy organisation include:
 - Charging for training.
 - Statutory organisations.
 - Personal/ individual budgets.
 - Consultancy.
 - Membership.

Figures provided by commissioners

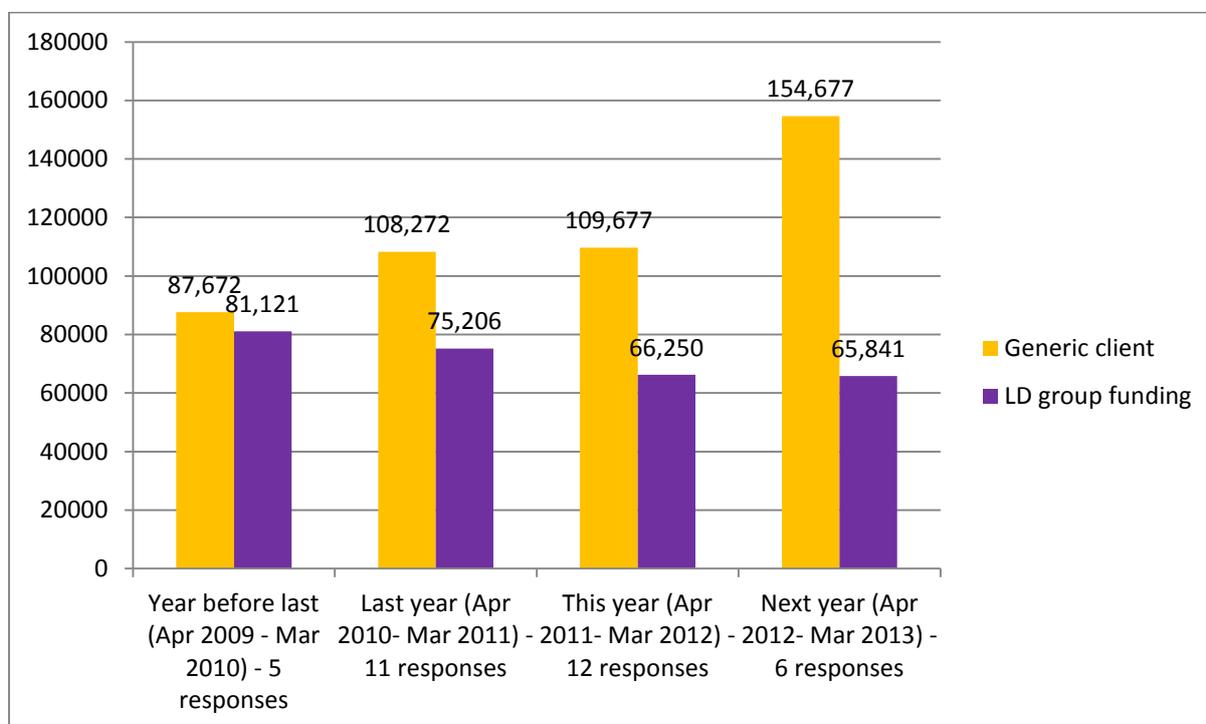
We asked for information on each organisation funded by commissioners that provides non-statutory advocacy and the total amount spent on advocacy. With regard to specific organisations we asked for funding figures for years 2009/10 to 2012/13 inclusive.

Within the summary of activities funded commissioners have sometimes recorded statutory advocacy activities e.g. IMCAs, rather than just the non-statutory activities which we asked about. They may therefore have recorded within their funding totals for monies for non-statutory advocacy, monies set aside for statutory advocacy. Commissioners did not all provide a full set of yearly figures and some indicated that the amount stated was approximate.

Figure 6 below illustrates the average yearly funding for the organisations, which shows a year on year increase in median levels of advocacy funding for organisations providing services for a generic client base, from £87,672 in 2009/10 to £154,677 in 2011/12 (a rise of 76%). However, it also shows a decrease in median funding values for specific learning disability advocacy, from £81,121 in

2009/10 to £65,841 in 2012/13 (a decrease of 23%). These trends may have been affected by a low number of responses for 2012/13.

Figure 6: Figures from Commissioners on specific organisations: Median levels of funding by year



Commissioners: Total advocacy funding

Commissioners were asked about their total funding for learning disability advocacy/self advocacy and their total advocacy spend.

Figure 7: Table of learning disability advocacy/ self advocacy funding

Date	Number answering question	Range	Mean	Median
2009/10	10	£46,000 to £149,000	£87,022	£81,121
2010/11	11	£35,000 to £149,000	£80,631	£75,206
2011/12	12	£35,000 to £150,000	£75,106	£66,250
2012/13	6	£35,000 to £140,000	£73,884	£65,841

Figure 7 shows that, not taking inflation into account, the drop in mean average funding from 2009/10 to 2012/13 is 15.1%. The drop from 2009/10 to 2011/12 is 13.7%, so although the 2012/13 figures are based on only 6 responses, they do correspond with the previously indicated trend in Figure 6 towards a drop in funding for specific learning disability advocacy.

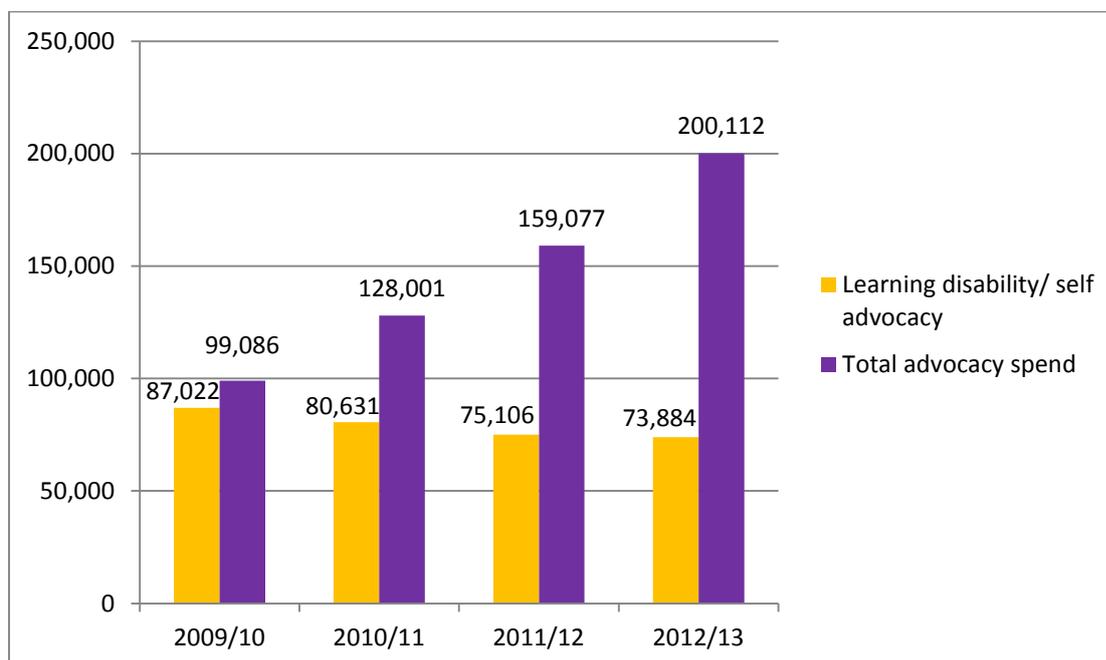
We also asked for the total amount spent on advocacy services. Figure 8 gives details of commissioners' answers.

Figure 8: Total advocacy funding by commissioners

Date	Number answered question	Range	Mean	Median
2009/10	5	£52,500 to £222,574	£99,086	£87,673
2010/11	11	£45,000 to £283,961	£128,001	£108,272
2011/12	12	£45,000 to £276,000 (excluding one off sum for campus closure project)	£159,077	£109,678
2012/13	6	£45,000 to £508,086	£200,112	£154,678

The data in Figure 8 indicate that total advocacy funding has increased year on year since 2009/10, although the figures for 2009/10 and 2012/13 are based on just five and six organisations respectively.

Figure 9: Learning disability/ self advocacy funding compared to total advocacy funding



The figures provided by commissioners in Figure 9 suggest a move away from funding specific learning disability advocacy or self advocacy within commissioners' total advocacy spend. Data for 2009/10 was based on a small sample of 5 commissioners but shows that spend on learning disability/ self advocacy was estimated at 88% of total advocacy spend. This fell to 63% in 2010/11, and fell again to 47% in 2011/12. Data for 2012/13 is based on a sample of 6 commissioners but



indicates that spend on learning disability/ self advocacy reduced further to 37% of total advocacy spend. This trend correlates with the decrease in spending on organisations providing funding solely to people with learning disabilities and the rise in spending on organisations with a generic client base, as shown in Figure 6. This may be linked to the increased use of large advocacy providers as highlighted in the *Staying Strong* report (2011a). However the scope of the survey did not address the number of people being served by generic advocacy providers, which may be increasing.

Organisations: The effect of changes to funding

Organisations were asked, if there had been a change in how much funding they got, how this had affected the work that they do. This question was answered by 52 organisations. None of the organisations described examples of an increase in funding, so examples related to either a reduction in funding or funding staying the same.

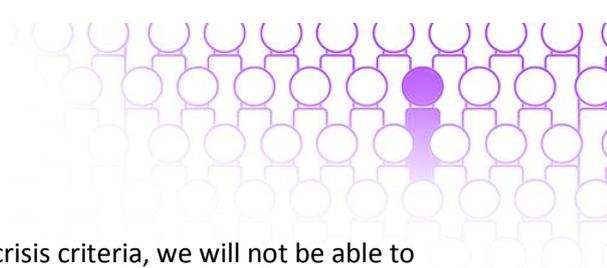
13 organisations indicated that a reduction in funding would impact on the quality of the advocacy services they provided:

- ‘Over the past 3 years the money has been less and less, therefore less and less quality of advocacy. i.e. each person only gets a little bit of advocacy, rather than a "proper" advocacy relationship.’ [3]
- ‘We feel like the people who have moved to a small house but still have lots of belongings. We are trying to keep all that we offer going, we have been growing and developing for 10 years and we and our members have expectations. We have had to be creative and focused in our case based work as we are unable to offer a full service to everyone, groups are continuing largely due to the commitment of everyone.’ [38]
- ‘Working in different ways to ensure the best value for money - moving focus from professional advocacy to peer and self advocacy. Less money does make it more challenging to give people with more complex needs the time they need and deserve to build up relationships etc.’ [65]

13 organisations said that a reduction in funding would mean that reduced numbers or fewer groups of people receive advocacy services, including the use of waiting lists:

- ‘It has meant we've no longer been able to provide advocacy for parents with learning disabilities and community advocacy for young people.’ [40]
- ‘Money from the Learning Disability Development Fund has been significantly reduced. This means that the number of advocates in the team has been reduced. The case load has increased, therefore making waiting lists longer and it harder to sustain an efficient service.’ [45]
- ‘We lost our funding from the Council, which ended July 2010. ...We reduced the breadth of families we support to just those who are affected by severe LD and complex needs, rather than any family who were affected by any degree of LD. We are struggling for funding now - and only have enough to keep us going in our present for until April 2012.’ [59]

12 advocacy organisations said that a reduction in funding had meant fewer members of staff or reduced staff hours:

- 
- ‘We have had to make redundancies and prioritise our crisis criteria, we will not be able to do the 14-19 years transition work, and made redundancy for adult LD advocate.’ [7]
 - ‘A project fund runs out this April 2012 and no replacement funds have been raised so we will at the very least have our funding reduced by a minimum of a half and so will lose one of our two advocacy coordinators.’ [28]
 - ‘We employ more people on a part time basis than previously.’ [71]

10 advocacy organisations said that they had not yet had any change in funding:

- ‘There has been no change as yet. If the funding is cut there would be no access to advocacy services for people who have learning disabilities in [town].’ [16]
- ‘No cost of living increase but costs are going up so we are eating more into our reserves.’ [35]. A lack of cost of living increase in funding was an issue mentioned by four organisations in relation to this question.

Seven organisations indicated that they would be spending time on fundraising or tendering to raise funds in future. But this had the potential to adversely impact on advocacy services, as two of these organisations pointed out:

- ‘The provision of advocacy is compromised by the additional needs to fundraise.’ [83]
- ‘Competitive tendering has led to the award of some contracts and the loss of others. Our revenue has decreased over the next two years as a result of this. This process does little to promote effective partnership working and inter-agency collaboration and seriously impacts on smaller grass roots community based advocacy projects.’ [87]

Telling funders about advocacy work

We asked commissioners how they monitor advocacy organisations and asked advocacy organisations how they inform funders about the work they do.

Organisations

Organisations were asked about how they told their funders about the work they do. 60 organisations answered this question.

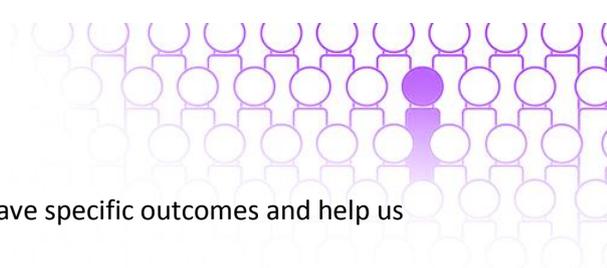
- 55% of organisations (33) answering this question said that they told funders about their work through the use of reports, including the use of quarterly and annual reports and annual reviews.
- 42% of organisations (25) mentioned meetings as a way of telling funders about their work, including Annual General Meetings and quarterly monitoring meetings.
- 25% (15 organisations) said that they made use of newsletters, publicity, advertising, leaflets or social media to tell funders about their work.
- 25% (14 organisations) described the use of monitoring or monitoring information to tell funders about their work. Relatively few organisations gave specific details of monitoring processes, but these included details of expenditure, how service level agreements are being met and outcomes.

- 20% (12 organisations) said that they used a website.
- 10% (six organisations) said that they informed funders about their work through the Partnership Board, including through reports and meetings.
- 10% (six organisations) said that they attended or led events such as workshops, sessions in BME organisations or colleges, and local authority or community events.

Commissioners

Commissioners were asked how the impact of advocacy is measured in their area. This brought a range of responses with some areas having done little to monitor advocacy outcomes previously while others monitored advocacy by looking at reports from advocacy groups, outcomes for people with learning disabilities, and feedback from professionals and people with learning disabilities. Some areas looked at all of these areas in order to monitor advocacy whereas others covered only one area (or none).

- 44% of commissioners who provided a written response reported that the groups were monitored through numbers or reports from the advocacy organisations. This varied from statistics covering user groups and frequency of use, to biannual reports incorporating case studies. For some this was part of a broader range of measures which also looked at outcomes, feedback etc.
 - ‘Contract monitoring process - they tell us what they have done and provide some numbers etc.’ [50]
 - ‘Volume/ gender/ client analysis (i.e. whom is advocacy reaching?).’ [53]
 - ‘We don't have a uniform method of measuring outcome impacts though we collect data on activity.’ [66]
 - ‘Annual AGM Annual Report.’ [69]
- Other monitoring methods included looking at outcomes. Some commissioners were not specific about what outcomes they measured. Specific outcomes listed included health monitoring, increasing numbers coming forward to be advocates, and success and participation in schemes.
 - ‘People in [town] with a Learning Disability have 100% attendance for Health Screening.’ [21]
 - ‘Growth of the [advocacy] Group as it moves to becoming a user led organisation, Improvement in services driven by people with LD through the Checking Out project. Increased numbers of advocates and self confidence to be involved in various planning groups.’ [61]
- Feedback from either professionals or people with learning disabilities was another way in which advocacy was monitored, e.g.
 - ‘Soft feedback information from Social Workers, Health Professionals and service providers as well as from individuals themselves.’ [3]
 - ‘Feedback from service users and their carers.’ [9]
- Some areas did not currently monitor advocacy whereas others were seeking to do so with the renewal of contracts.
 - ‘Previously there has been very little monitoring in place and the new contract deals with this issue.’ [2]

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- ‘We are developing a new contract which will have specific outcomes and help us measure the impact of advocacy.’ [25]

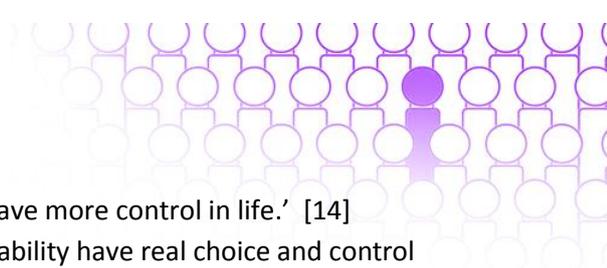
Other ways in which advocacy was monitored included looking at case studies and the level of engagement of people with learning disabilities with Partnership Boards.

Why fund advocacy?

Organisations

58 organisations answered this question, with answers by organisations providing advocacy services solely for people with learning disabilities and those by organisations with a more general client base being broadly similar.

- The giving of a voice, speaking up or having a say was the most common theme identified by organisations in relation to this question, with 35 organisations (60%) giving an answer in line with this theme. Some examples included:
 - ‘It is important that the voices of people with learning disabilities are heard by others.’ [86]
 - ‘To give people with learning disabilities real voices in their lives.’ [48]
 - ‘So people can speak up about the things that are important to them and are affecting their lives.’ [31]
 - ‘Advocacy is a frontline service that ensures people get a say in their lives.’ [38]
- 21 organisations (36%) said that advocacy allowed people with learning disabilities to achieve equality and gain their rights:
 - ‘We should be given the same chance in life as anyone else.’ [14]
 - ‘People are treated as equal citizens.’ [16]
 - ‘So people can have equal access to their rights as people.’ [31]
 - ‘It is important that people with learning disabilities have their rights upheld’. [86]
 - ‘To ensure people understand their rights.’ [86]
 - In addition one organisation stated that ‘It’s their right to have an advocate, no matter the issues.’ [79]
- 16 advocacy organisations (28%) said that advocacy facilitated the empowerment of people with learning disabilities, or was needed because they are marginalised or vulnerable as a population:
 - ‘To help people with learning difficulties to be empowered.’ [32]
 - ‘Advocacy helps change and supports empowerment.’ [79]
 - ‘Traditionally a group who are marginalised.’ [80]
 - ‘People with learning disabilities are vulnerable and need the support we can provide.’ [55]
- Choice and control was another theme that emerged from the data, with 13 organisations (22%) mentioning this:

- 
- 'More people with learning difficulties should have more control in life.' [14]
 - 'To ensure that more people with a learning disability have real choice and control over their lives.' [73]
 - 10 organisations (17%) talked about the importance of advocacy for accessing and challenging services:
 - 'There is compelling evidence that despite 11 years of 'Valuing People' people with learning disabilities continue to be discriminated against by mainstream services.' [2]
 - 'Ensure fair access to services.' [49]
 - 'Empowering people to challenge services.' [52]
 - 'Local authorities need the help of specialist organisations in order to consult people with learning disabilities.' [71]
 - Other reasons for advocacy included:
 - To ensure people with learning disabilities can make informed choices about their lives and have the knowledge and skills they need (8 organisations).
 - To enable people to make the most out of life, make positive changes or achieve positive outcomes (7 organisations).
 - To promote independence and/ or independent living (7 organisations).
 - Advocacy provides people with an independent source of support (7 organisations).
 - Six organisations said that the current economic climate or service cuts made people with learning disabilities more vulnerable or more in need of support.
 - To prevent or protect people from abuse and hate crime (4 organisations).
 - To tackle discrimination and prejudice (2 organisations).
 - To address social exclusion or encourage participation in society (2 organisations).
 - To support or enable communication for those with non-verbal communication or PMLD (2 organisations).

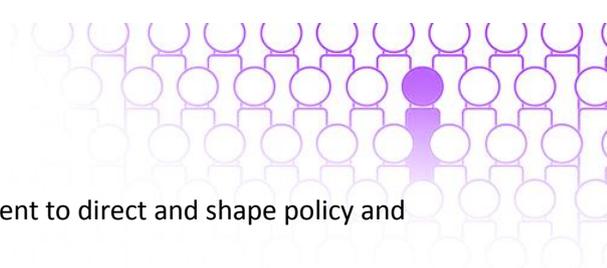
Commissioners

The top three responses were: to give people with learning disabilities a voice (69%), involvement in decision making (55%) and the opportunity to live equal and enriching lives (36%).

1. To give people with learning disabilities a voice, was the response most often stated. Encompassed in this was the recognition of the imbalance of power between people with learning disabilities and services, e.g.
 - 'To enable people to speak up in disagreement with statutory services/ help rectify imbalance of power and knowledge.' [46]

Similarly the link between the ability to speak up as individuals and as a group of people with learning disabilities was acknowledged, e.g.

- 'To provide people with a learning disability with an individual voice and a collaborative voice.' [16]
- 'Having a big voice.' [51]

- 
2. Involvement in decision making and using this involvement to direct and shape policy and practice was highlighted by many commissioners.
 - ‘Influences local decision making.’ [9]
 - ‘To facilitate strategic involvement.’ [16]
 - ‘For consultation and service development.’ [42]

The qualities that make advocacy groups useful partners were also noted.

- ‘Self advocates make fantastic partners and allies in helping to transform and improve services. Enthusiasm and commitment is second to none and very powerful.’ [61]
3. Equality and equal rights were stated as being important reasons for advocacy.
 - ‘So they can achieve their rights, the same as anyone else.’ [10].

Commissioners noted that information and help in making decisions were at the forefront of helping people with learning disabilities achieve equality.

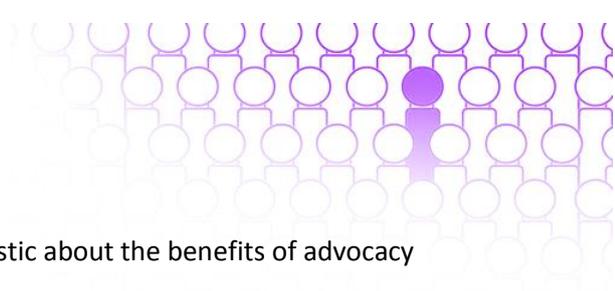
- ‘Support to people to develop confidence and skills in taking their place in society.’ [66]
- ‘So they can live a normal life, the same as anyone else’ [12]

Other suggestions for reasons for funding advocacy included:

- People with learning disabilities often need help to understand and make complex decisions.
- Safeguarding.
- To identify issues and examples of good and bad practice.
- The importance of having independent support.
- To ensure quality of access to services and overall service quality.
- Raises the profile of people with learning disabilities.
- Personalisation.
- Access and relationships with other people with learning disabilities.
- Saves services money - the ability of advocacy to save money by supporting people to be independent and avoiding expensive packages of care.
- Legal and statutory requirement.

Summary

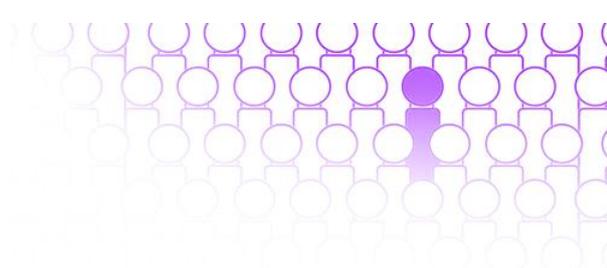
Data from advocacy organisations indicate an overall decrease in funding levels since 2009/10, although when this data is broken down into organisation type this trend is less discernible. The data from commissioners suggests that advocacy organisations providing services solely to people with learning disabilities (which are more likely to be led by and run for people with learning disabilities) are getting reduced funding, whereas general advocacy organisations are getting level/more funding. Similarly, spending on learning disability/ self advocacy as a percentage of total advocacy spend has declined from 63% in 2010/11 to 37% in 2012/13 according to commissioner figures.



Advocacy organisations and commissioners were both enthusiastic about the benefits of advocacy for people with learning disabilities.

- Organisations: The most frequent answers were giving people a voice, having a say, equality and rights, empowerment, choice and control, accessing and challenging services.
- Commissioners: The most frequent answers were to give people with learning disabilities a voice, involvement in decision making, and the opportunity to live equal and enriching lives

Organisations and commissioners agreed that giving people with learning disabilities a voice was the most important reason for funding advocacy. They also agree that reduced funding will make it more difficult to deliver good advocacy support



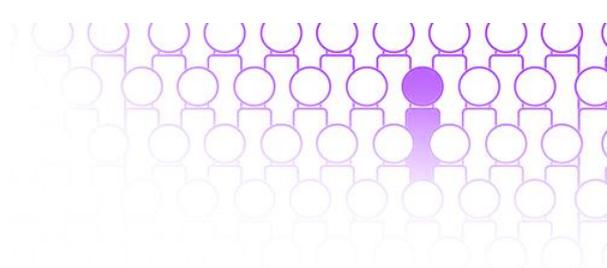
Chapter 5: Gaps and barriers

In this section we discuss the gaps in advocacy provision as highlighted by advocacy organisations themselves. We also asked both advocacy organisations and commissioners about the barriers that exist to prevent individuals or groups from accessing advocacy.

Gaps in advocacy provision

This question was asked solely of advocacy organisations. The survey asked advocacy organisations if they thought there are any gaps in the provision of advocacy services for people with learning disabilities in their area. Of the 56 organisations answering this question, 82% (46) thought that there were gaps in advocacy provision in their area.

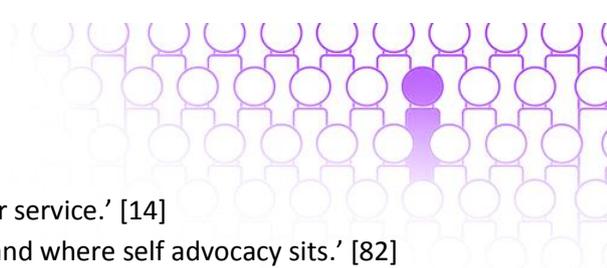
- 10 organisations (18%) said that there were gaps in advocacy provision for parents with learning disabilities:
 - ‘We support parents that have a learning disability who are on the Child in Need or Protection registers. There is a big gap in this area as there is no provision to assist these.’ [88]
 - ‘I feel that parents who have a learning disability need separate advocacy provision (family advocacy) to work well with CYPS social services around child protection/child in need issues.’ [49]
 - ‘Different geographical areas place a different priority on Advocacy and on different groups of people - especially parents with a learning disability.’ [48]
 - One further organisation said that there was a gap in relation to people with caring responsibilities. [87]
- Six organisations (11%) said that there were gaps in relation to transition between children’s and adult services.
- Six organisations (11%) stated that a lack of funds had reduced the amount of advocacy they could provide:
 - ‘There is never enough money to be honest, our service is always over prescribed and we do operate a waiting list.’ [46]
 - ‘Not enough funding for the services we have.’ [80]
- Four organisations (7%) said that people with mild or moderate learning disabilities were less likely to receive advocacy support:
 - ‘People who have a mild learning disability but receive no service, these groups of people receive little or no support.’ [33]
 - ‘Currently to access advocacy people need to be accessing a health or social service. There are a number of people with mild to moderate learning disabilities who do not qualify.’ [64]
- Other examples of gaps identified by at least two advocacy organisations include:

- 
- 1-1 citizen advocacy (two organisations).
 - BME population (two organisations).
 - Children’s advocacy (three organisations).
 - Crisis advocacy (two organisations).
 - Lack of advocacy in certain geographical areas (two organisations).
 - Housing (three organisations).
 - Not enough support for volunteers to befriend people with learning disabilities (two organisations) or not enough volunteer advocates (one organisation).
 - Offenders or ex-offenders (four organisations).
 - Support to enter paid employment (two organisations).
 - People who are isolated and may live alone without knowledge of advocacy services (three organisations).
 - People with PMLD or complex needs (four organisations).
 - People not eligible or qualifying for local authority services (four organisations).
 - Self advocacy (two organisations).
 - Support on direct payments and personal budgets (two organisations).
 - Young people (three organisations).

Barriers

The survey asked if there were things stopping organisations from supporting people with learning disabilities. 76% (41 organisations) answered ‘yes’ to this question. Of these organisations:

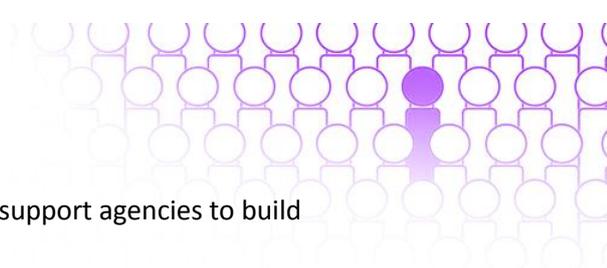
- Thirty four organisations identified funding as a factor stopping them from supporting people with learning disabilities:
 - ‘We don't have the money to pay support staff to help run the groups we would like. We always have so much work to do, but not enough time or people to do it. We would particularly like to do more campaigning, training and running forums for people to have their say.’ [17]
 - ‘Yes the potential loss of our funding from [City] Council which has been like core funding.’ [35]
 - ‘Lack of consistent and sufficient funding to develop new projects and services, and improve what we already do. Really hard to plan when funding is short-lived.’ [53]
 - ‘We need to obtain replacement funding to continue our project supporting people with learning disabilities.’ [57]
- Five organisations mentioned attitudes as a barrier, either towards advocacy or people with learning disabilities:
 - ‘General attitude towards advocacy.’ [3]
 - ‘Negative attitudes or ignorance about people with learning disabilities. E.g. some employers cannot see that they would make great employees.’ [53]
- Four organisations described a lack of understanding or knowledge about advocacy as a barrier:
 - ‘We need more social workers and support brokers to know about our services so

- 
- that people can use personal budgets to use our service.’ [14]
 - ‘Confusion over formal and informal advocacy and where self advocacy sits.’ [82]
 - Four advocacy groups identified a lack of staff as a factor, and this was linked to a lack of resources (also mentioned by four groups) by one organisation:
 - ‘Not enough resources – advocacy should be every vulnerable adult’s statutory right – with enough staff!’ [61]
 - Four organisations mentioned eligibility criteria for services or contract restrictions, an issue which may be linked to a lack of advocacy services for people with mild to moderate learning disabilities:
 - ‘Only able to provide those who are in receipt or eligible for services. Need to support all people with LD who ask for support/info/advice.’ [25]
 - Other examples of things identified as preventing organisations supporting people with learning disabilities include:
 - Need for more volunteers (two organisations).
 - Time (three organisations).

Commissioners were also asked about the main barriers to providing advocacy services for adults with learning disabilities in their area.

There were 34 written responses to the question and 17 of those (50%) cited funding as being the major barrier to providing advocacy services. The other major barriers cited were a lack of awareness of advocacy and geography.

- Funding issues was by far the most common response (50%). Within this the uncertainty of continued funding year on year was noted. One respondent cited a cut in staffing due to budget cuts.
 - ‘The main barriers to providing advocacy primarily relate to the availability of funding.’ [15]
 - ‘Lack of funding as the post of a full time co-ordinator in [named] was lost.’ [31]
 - ‘Uncertain nature of funding.’ [61]
 - ‘We have reasonably good advocacy services for adults with learning disabilities. The barrier to making them better will always be funding.’ [72]
- Making people with learning disabilities and their carers aware of the help and support offered by advocacy services was cited as a major barrier, particularly those who live independently and who do not have links with services. This included whether people felt able to approach services (17.8%).
 - ‘To reach adults with learning disabilities where a referral has not been made on their behalf and they are unlikely to self refer, the self-advocacy and peer advocate services use an outreach approach by visiting community groups/events to promote



their services. They also work closely with local support agencies to build relationships and encourage referrals.’ [48]

- ‘Making sure that all people with learning difficulties (particularly people who live independently in the community) are aware of the advocacy services and how to access them.’ [63]
- People knowing that a service exists. People feeling they can approach the service.’ [74]
- The size and location of the service area was also cited as a difficulty.
 - ‘Geographical due to large area covered by council.’ [12]
 - ‘Rurality.’ [38]

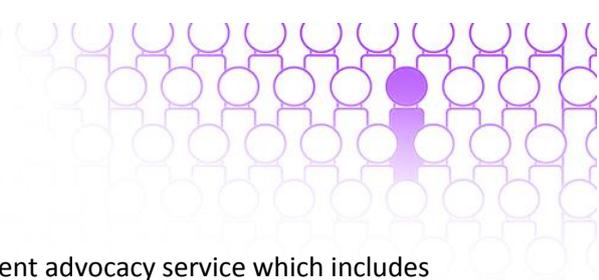
Other barriers cited by commissioners were a lack of self advocacy in their area, and lack of appropriate advocacy for people with complex needs.

Summary

Advocacy organisations have highlighted gaps in the provision of advocacy services, particularly parents with learning disabilities, transition and lack of funds meaning a reduction in advocacy.

Organisations and commissioners agreed that the number one barrier to improving advocacy services is funding. Lack of understanding or knowledge about advocacy and what advocacy is was also noted as preventing access to advocacy. Some organisations reported eligibility criteria as being a barrier preventing some people with learning disabilities accessing advocacy. Allowing only those in receipt of services access to advocacy discriminates against those with mild to moderate learning disabilities or those not currently accessing services e.g. those living with older parents.

Case Study 2 gives an example of a self advocacy organisation, Your Say, which is working with some of the groups who struggle to access advocacy services.



Case Study 2: Your Say

Your Say is owned and managed by one person. It is an independent advocacy service which includes self-advocacy. It provides 1-1 advocacy and supports a number of self-advocacy groups including three networks in Bath and North East Somerset (B&NES). The members run the networks, choose what should happen and how it should be done. For more information see www.yoursay-advocacy.co.uk or www.banes-networks.co.uk.

The groups

Your Say runs self-advocacy groups attached to provider organisations. The groups tend to look at specific topics such as employment, social lives or issues related to the organisation such as home closures or organisational issues.

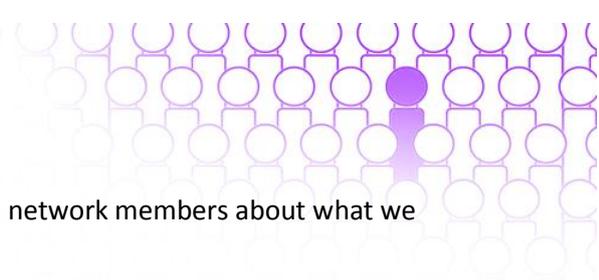
Your Say also runs the Bath and North East Somerset (B&NES) self-advocacy networks. There are three of these based in Bath, Midsomer Norton and Keynsham. The networks are open to anyone who believes they have a learning disability their supporters, carers, family members, providers and professionals in B&NES (so about 600 people). So far, the networks have engaged with at least 300 people. The networks were set up about six years ago, and the aim was to give people with learning disabilities a voice in B&NES. 'When we set the networks up, we found that people were used to sitting back and waiting for others to do something. Now we have a friendly but quite militant group of people who know there are things they would like improved in their lives and want to be active in making the changes happen'. The networks know things need to change and want to work in partnership with others to make things happen. This is important, as otherwise it can become people with learning disabilities 'against the world'. That is not how they work.

The networks are still interested in the Valuing People priorities of employment, housing, health and personalisation, but it is important for the networks to know about what this looks like locally. It is important to the networks that the work they do will make a difference to the members. They are not so interested in banging the drum nationally – though do make sure they keep themselves up to date with national issues and get involved when the group feel it is right to do so.

Your Say have spent quite a lot of time supporting people to understand representation, so they know it is not just about themselves but the group. 'As an organisation, we (the Advocates) don't do things for the networks, but do it 'with' them'.

Having a supportive commissioner in B&NES has been very important. It has enabled Your Say to have time to grow the group between the meetings. It can take 20-30 hours preparation between meetings. It also gives Your Say someone to feed back to. The commissioner takes issues raised to the Health and Wellbeing Board. There are also regular formal meetings with the lead councillor, the commissioner and the network reps. The Partnership Board has been put on hold, but will be set up again. It may be handed to the networks to organise, but this has yet to be decided.

One of the network groups are very passionate about where they live (as lots of changes are planned). As one of the consulted groups in the community the members are very proud to be included in the decision making. They go to the town hall and ask to see any new plans. 'As supporters, we don't always know any more than the network members. For example, we didn't



know about town planning and so our start was thinking with the network members about what we need to consider’.

The networks include a significant number of people who would be defined as having challenging behaviour and complex needs, although it is difficult to meet everyone’s needs in a group setting.

A group of people in the Keynsham network, who would be described as having challenging behaviour (the group included someone who had been detained under the Mental Health Act), designed a training course called ‘I am challenging, are you?’ The course is designed to provoke thought and challenge attitudes. The trainers tell their stories and participants are asked questions like ‘have you ever been so angry you have wanted to throw something?’. ‘The training is currently targeted at staff, but we are planning to roll it out into the community.’ A core group deliver the training but the whole network is involved. It can be difficult for people to talk about their experiences, but as one person said ‘if I talk about my history, I hope it means it won’t become someone else’s history’.

‘The on-going challenge for the network is to think about how we really become part of the local community. We are out there, but are we part of it? We are looking at how we can use our skills and knowledge to increase work opportunities for people with learning disabilities in their own community’.

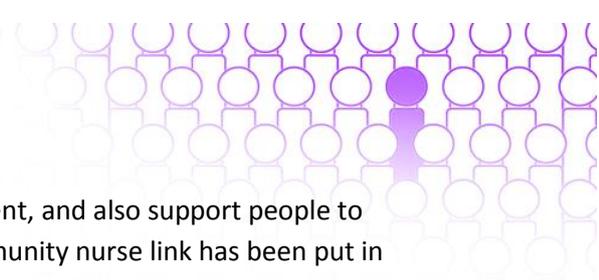
Health

Health has been a priority for the B&NES network from day one. There has been constant communication with the commissioner regarding health work. Your Say developed a questionnaire for people attending their annual health check, in order to understand what should be in a health check, and did this through discussion with a friendly GP, and in collaboration with the commissioners and community nurses. The responses to the questionnaire go to the network for discussion and collation. This means the network members are able to talk with confidence about the findings. Your Say are just finishing a DVD on what people can expect from a health check.

The health check work was a collaborative process. The group knew that health was important, but weren’t always clear if they had had a health check or what this meant. Your Say fed this back to the commissioner, and community nurses who have recently been linked to GP practices, and know when people are being asked for a health check so they can support them if necessary.

Your Say have done work with the network members on what it means to be healthy. There is a lot of confusion about this. People were asked to do a daily exercise diary. One person recorded knitting as an exercise. Your Say have done work with the Bath Inclusive Sports and Activities group, and also do work on a healthy diet (5 a day and eat a rainbow). Some network members have weight related health concerns including obesity. There is a huge issue with informed choice about food. People who live in supported living can have shocking diets. Diet and health is often overlooked. Your Say have set up some social networks which are very popular. ‘They are based on the ‘Come dine with me’ TV series. We cook a three course meal from scratch – these are always really well supported’.

Your Say have done work on what it means to have specific ailments. What does it mean if you have a cold for example. They supported the PCT with accessible information about Swine Flu when that was a big concern a few years ago.



They have done 1-1 work with people who need medical treatment, and also support people to access their GP. This has improved in B&NES a lot since the community nurse link has been put in place.

People with learning disabilities are more likely to ask questions about health matters now in B&NES, and are more aware of their own health. 'But there are still real issues about the inequality of some health services for some of the individuals with whom we work.'

Family carers

Some family carers come to the networks. A cohort come regularly and support the groups in a variety of ways. The networks meet when people with learning disabilities want to meet (in the evening), which can be difficult for family carers. A group also come to conferences, and get meeting notes. They are very supportive. Your Say did interviews with them about what it means to be a family carer. They have quite a good link with the family carer network in Midsomer Norton.

1-1 advocacy

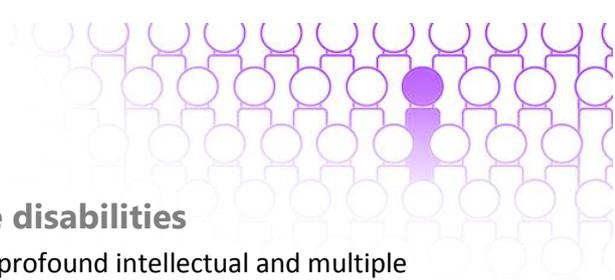
Your Say's 1-1 advocacy often informs their group advocacy. It is about empowering individuals. 'We give individuals the help they need to do it for themselves. We are commissioned on Block contract basis in a number of areas and will also do spot purchased advocacy. As the networks have grown, self-referrals for 1-1 advocacy have reduced in B&NES - because people feel more confident to check things out with us when they see us at Network activities. The 1-1 advocacy can be on difficult issues such as home closure, parenting issues, detention etc. We do get some revolving door clients, those individuals who come back to us to help with recurring issues or new issues as they arise'.

Parents with learning disabilities – the Parents 1st group

Through the 1-1 work Your Say found that parents with learning disabilities felt very isolated. They thought no one else was experiencing the same things they were. Bringing people together was helpful as they realised they were not on their own. It is a self-directed group. Your Say's role is to network people together. They don't sit down formally as a group, but Your Say can use them to consult on issues. They had some funding from Esmée Fairbairn which has enabled them to do some activities with the parents, and it has also enabled them to purchase bits and pieces to help the parents. For example, Your Say bought a school uniform once, when a child had to change schools.

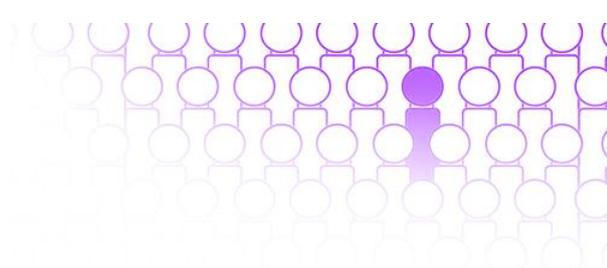
Your Say get parents who come back on a regular basis. 'We haven't found enough changes to services in the last 10 years and parents with learning disabilities still very often are judged more harshly than others, but legal services (not courts) have improved. We have spent a lot of time nurturing solicitors. Some are very good. Just having a good solicitor can make all the difference.'

'I imagine Children's services love or hate us. They can be very good if we get involved early enough and can understand how we can support communication and help to build better working relationships. Once proceedings have started or a protection plan is in place it often becomes a 'them and us' situation which can make the situation more difficult for all parties. Unfortunately, as a lot of the people we work with have borderline learning disabilities, there can be a delay while an eligibility assessment is done before we can start to engage'.



People with profound intellectual and multiple disabilities

A significant amount of Your Say's 1-1 work is with people with profound intellectual and multiple disabilities. It is often about changes that are going to be imposed on the individual, so they are working on a best interests model. Although they collect a lot of information from people who know the individual, they can't always rely just on that and spend an extended period of time, sometimes days, observing the individual in their environment, so that they can see what is really happening in their lives. 'People get used to us and forget we are there. We bring a fresh pair of eyes to the situation. All situations are different. It is important not to think you know the answer'.



Chapter 6: Advocacy achievements

Organisations and commissioners were both asked questions related to the achievements of advocacy. Organisations were asked about things that are done really well in their organisations, and commissioners were asked about the difference advocacy had made in their local area. We also asked an additional related question to commissioners: What do you think advocacy should achieve for people with learning disabilities?

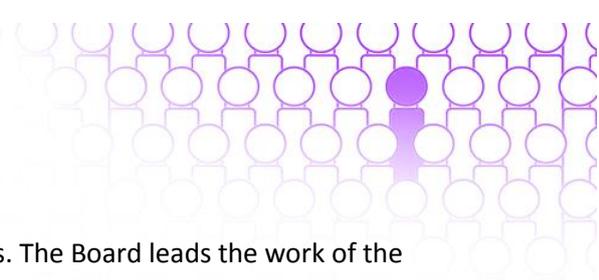
Things that are done really well in advocacy organisations

This question was asked only to advocacy organisations. 54 organisations gave examples for this question, and the most common answers related to the following:

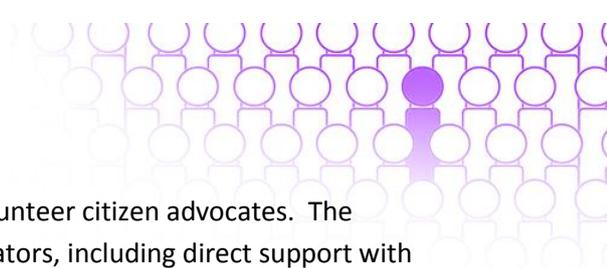
- Supporting parents with learning disabilities, including child protection issues (8 organisations).
- Good practice examples associated with self advocacy, including self advocates having a role on management boards (8 organisations).
- Training, including training volunteer advocates and people with learning disabilities leading training activities (8 organisations).
- 1-1 case advocacy, including crisis advocacy (7 organisations).
- Links with other organisations, including councils, police and schools (6 organisations).
- Involving service users in the organisation, including as a user led organisation and involvement in the AGM or Board meetings (6 organisations).

Specific examples provided by organisations providing advocacy solely to people with learning disabilities included:

- ‘Case advocacy is very successful. We have no criteria and offer advocacy services to all who have a learning disability. Increasingly supporting parents who have LD through court system. The self advocacy group are well established and are well known and willing to take part in consultations, be a member of the Partnership Board and represent the Group.’ [16]
- ‘Training professionals on things like Hate Crime awareness, learning disability awareness. We are also good at lobbying and campaigning to local MP's and councillors. We are good at giving feedback from service user consultation - we have often been the only group for people with learning disabilities that has given feedback.’ [17]
- ‘The training work we do is very good. Our work around hate crime and the work we do in schools. The magazine we produce is very good. We work very well as a team. We have achieved good things e.g. receiving an honorary fellowship from our local university, winning this year's Community Pride award for the best community project. Our ex Trustee with learning difficulties becoming a town councillor. We do a lot with very little. We have learnt to take responsibility for ourselves. As well as our advocacy work we have our own theatre company and history group.’ [32]



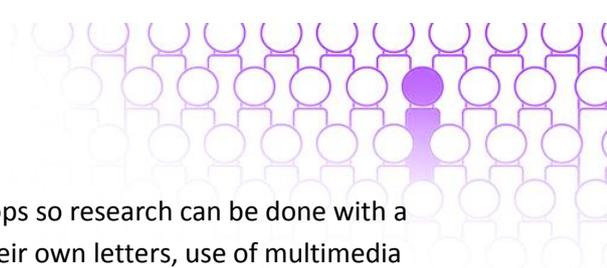
- ‘We have a Management Board that is half self advocates. The Board leads the work of the project. We undertake project work that the board supports and have paid roles for self advocates as it was a Board decision that project work would only be undertaken if it could provide opportunities for co production. Advocacy, people tell us that it’s good to be heard, even when they don’t get the decisions they were looking for. We have supported some big achievements for people and some small that were just as important.’ [38]
- ‘Advocacy is long-term. Advocates know their service users really well, e.g. how they express themselves, their likes and dislikes - they are often the only person in the person with learning disabilities’ life who is NOT paid to be there. The loyalty of our advocates has been truly outstanding. Our service is a new one, but many have been with the service user for 3 years already.’ [39]
- ‘We listen REALLY well. Members said they needed a bigger and more accessible office - we worked with them to find them one. We succeeded (and got a better deal on rent and service charges into the bargain). We are EXPERTS in creating EASY READ documents. Everything we send out is in Easy Read (which is not the case with all organisations and certainly not many councils or public bodies). We genuinely offer a "user led organisation" for people with learning disabilities. 10 of the 12 directors on our Board of Directors have a learning disability; people are elected to committee roles like Chair, Secretary and Treasurer by their peers; we ask members what they want the organisation to be doing; members are supported to plan, run and review their own meetings and to arrange meetings for the wider community (e.g. Get Involved Group); we encourage SELF advocacy - supporting people to do things for themselves, not have someone else do it for them - wherever possible. This is the only way to give people the chance to be more independent and genuinely have equal rights and be treated with proper respect.’ [53]
- ‘Many of our advocates support their advocacy partners to get out and about in the community. This ranges from having a coffee in the local cafe to taking a partner to the local integrated drama group. We have recently started a social club for people with a learning disability which gives advocates another opportunity to spend quality time with their partners.’ [55]
- ‘We include people with a learning disability in our organisation really well. We have service users on our Board and also an Advisory Group to the Board so that they can have a real say in the direction of the organisation. We pride ourselves on providing meaningful support as we feel anything less would be a disservice to our service users. This sometimes means things take a lot longer to get done but we have included our service user's views. We will not just tick boxes!’ [73]
- ‘Supporting people to participate in many events and encourage them to be recognised as champions. We have developed unique training packages co delivered by people with learning disabilities as trainers and also doing lots more filming and offering our media skills and resources.’ [82]

- 
- ‘The recruitment and preparation, and retention, of volunteer citizen advocates. The management of advocacy partnerships by the Co-ordinators, including direct support with difficult issues in their partnerships. Encouraging and supporting independence for our partners. Increasing confidence levels of our partners. Social inclusion - encouraging partners to take part in social activities and introducing them to other organisations and social groups.’ [84]

Advocacy being user led is a major theme emerging from these examples of good practice. These examples outline ways in which some organisations fully include people with learning disabilities within their organisations, sometimes as paid self-advocates, sometimes as part of management committees or boards, therefore giving people with learning disabilities a say in the direction of the organisation. They illustrate that people with learning disabilities can take on various roles including committee members, trainers, campaigners etc. People with learning disabilities therefore also have a say in the types of work undertaken by self advocacy organisations such as the focus illustrated in two examples on hate crime.

Specific examples provided by organisations providing advocacy services for a range of people as well as people with learning disabilities include:

- ‘We have a lot of experience of working with people using non-instructive advocacy. We have also developed a communication toolkit to help advocates to communicate better with people.’ [37]
- ‘Enabling clients to self-advocate, particularly clients with challenging and complex needs; Enabling clients to achieve their goal (80% success rate); Developing resources for people, for example an accessible booklet presenting the child protection system for parents; Enabling a high number of people to benefit from advocacy whilst maintaining quality.’ [40]
- ‘We are a user led organisation and try to involve people with learning disabilities in everything we do. We have particular success in self advocacy and peer advocacy where people are encouraged to help each other to speak up when things are not right for them.’ [44]
- ‘Supporting people who have had their care packages/ Individual Budgets cut. Supporting people to get what they need on CHC packages. Supporting people to make formal complaints, Supporting people through safeguarding issues, fighting cuts to services, especially where they may contravene legal statute , supporting people through life’s transitions, utilising Circles of Support, person-centre approach, personalisation, keeping on at statutory bodies until we get answers for people, taking a family-centred approach and supporting where there are other complexities within families (e.g. parents or other family members with LD, physical health or MH problems), working positively in partnership with statutory agencies to get a positive outcome - I could go on and on.....’ [59]

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- ‘Involving the client in the process - advocates use laptops so research can be done with a client and the clients can be supported to type/write their own letters, use of multimedia technology - people can record their views prior to a meeting which can then be played at the meeting. Supporting people to put together their own reports for meetings.’ [63]
 - ‘We are expert on inclusive communication. We therefore regularly use communication aids and books that we make ourselves. We use objects, choice mats, changeback, photosymbols and drawings we do ourselves. Also we do Advocacy Plans to ensure we focus on the advocacy role also useful to monitor our work with partners. We also to break the ice at first visit use "About Me". The advocate will show their About Me booklet with easy words and photos and then later start to complete an About Me (profile) of the new partner. We co-train well with adults with LD on our training courses we produce.’ [72]

General advocacy groups emphasised the need to be user led in self, group and or case based advocacy. They outlined how professional or case based advocacy clients can be included in collating their own reports and information for meetings. They also highlighted their work to develop resources with people with learning disabilities.

Commissioners: Local impact of advocacy

Commissioners were asked what difference advocacy had made in their local area. All of those who answered the question said that advocacy had made a positive difference in their area. A number of themes emerged from this including steps to address safety and hate crime, improvements in speaking up, and examples of improvements to local services through advocacy.

- Safety was raised as an issue by people with learning disabilities and several local initiatives have taken place to attempt to address this. E.g.
 - ‘Keeping safe was a real concern for [advocacy group] - without them we would not have developed an Easy Read Hate Crime reporting pack or funded the development of a Safe Place Scheme in [town].’ [50]
 - ‘[named group] involvement with [named] police around hate/mate crime. [named group] have developed the safer in [town] scheme that enables all vulnerable groups.’ [45]
- Advocacy was cited as having improved the ability and confidence of people with learning disabilities to speak up and make decisions about their lives. E.g.
 - ‘The impact of Peer advocacy has been noticeable in that people’s confidence in speaking up in groups, boards, meetings etc has increased dramatically.’ [78]
 - ‘As well as enabling people to have a voice it has also given people an identity and sense of presence.’ [63]
- Improvements to local services through increased representation by people with learning disabilities at meetings have been instrumental in shaping changes within services. E.g.
 - ‘Establishment of a People’s Cabinet with Expert Ministers who canvass views of the wider learning disability population. This in turn is starting to influence local strategy and development of services.’ [48]

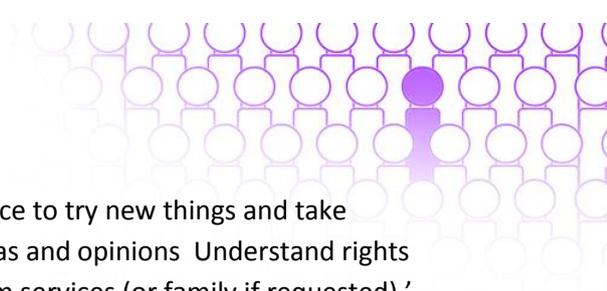
- People experiences of healthcare have been raised and have made a difference to provision of services at the local acute hospital.’ [48]
- Specific service developments identified included: ‘Pregnancy and parenting: support to 3 young women during pregnancy and continue to support one of them.’ [69]

Other influences of advocacy in commissioners localities included: improving socialising opportunities, increasing self employment, use of mainstream services e.g. leisure centre, and influencing public perception of people with learning disabilities in conjunction with local media.

Commissioners: What should advocacy achieve for people with learning disabilities?

Commissioners were also asked about what advocacy should achieve for people with learning disabilities. The most frequent response was that advocacy should assist people with learning disabilities to have a voice and be able to put across their views about the life they want to live. Included within this was the right to good independent support to help them understand what is involved in making those decisions. The question was answered both with regard to all people with learning disabilities and individuals.

- On a collaborative level, e.g.
 - ‘Should provide a collective voice for people with a learning disability.’ [25].
 - ‘I think that in [town] it has really defined people who have a learning disability as having a really loud voice. No-one would ever think that this is a group of people who will sit quietly when something is done to them that they don't like. I think that is a fantastic achievement.’ [51]
- Also on an individual level, e.g.
 - ‘To enable individuals to be aware of and achieve their rights, to ensure people who lack capacity have their choices and rights respected and listened to, and that services consistently uphold these.’ [46]
 - ‘Being able to express what is important to you, having your voice heard, having your views respected, taken seriously and acted upon, greater choice and self-determination about issues that are important to you, change on the issue that is at stake, greater respect & dignity at an individual level.’ [53]
- Participation for people with learning disabilities in the development and monitoring of services. Particularly engaging within the policy making and strategic direction.
 - ‘To create positive change in services through individual cases and influencing work via the local engagement structure and their contract monitoring feedback.’ [46]
 - ‘That individuals can take an active part in shaping policies and practices that will impact on them and future generations.’ [38]
- Promotion of independence and individual decision making was highlighted. The opportunity for people with learning disabilities to explore, make decisions and take calculated risks.

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- 'To have the right to disagree To have the chance to try new things and take calculated risks Have the right to their own ideas and opinions Understand rights and responsibilities Advocacy independent from services (or family if requested).'
[32]
 - 'Protecting and promoting their rights and independence.' [72]

Other suggestions about what advocacy should achieve were: best interest for individuals, and to help raise concerns about services.

Summary

Good examples were given both from advocacy organisations about the things they do well and from commissioners regarding the local impact of advocacy. Organisations highlighted aspects of their work which they felt were successful. This included how they help people on an individual basis, e.g. not having a strict criteria regarding who they can help, and also ways in which their organisations work which makes them work particularly well, e.g. being led by people with learning disabilities.

Commissioners felt that advocacy was able to help people with learning disabilities achieve a greater autonomy and say in the direction of their own lives. They noted the importance of advocacy for people with learning disabilities as a whole, as well as on an individual basis. This highlights the importance of funding group and self advocacy, as well as professional or case based advocacy. Advocacy can only be a collective force for people with learning disabilities if they are able access a service which helps them speak up for themselves.



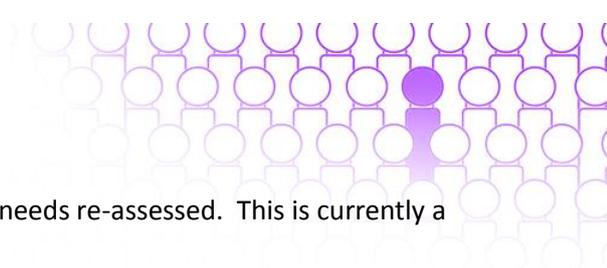
Chapter 7: Good practice in social care and health services

Both advocacy organisations and commissioners were asked for examples of advocacy best practice in relation to social care services and health services.

Social care services

The survey asked advocacy organisations whether they had done any advocacy work or other work to improve social care services for people with learning disabilities. Of the 53 organisations that answered this question, 45 (85%) said that they had done some work of this kind. 59% of responders thought that their work to improve social care services had been or would be affected by funding changes.

- 10 organisations said that they had done work around challenging, campaigning for or complaining about services:
 - ‘Fighting for services right up to and including appeal stage and involving legal help as required.’ [11]
 - ‘Campaigning and complaining to senior social care managers.’ [69]
 - ‘All our advocacy work is about challenging, complaining to make things better in social care. We regularly challenge and complain to poor care providers especially in domiciliary care settings. We recently had to whistle blow on a poor provider to the council. We will complain if a support worker is not competent. We also feed back to commissioners what they need to address.’ [72]
- Nine advocacy organisations mentioned the use of consultations:
 - ‘We have been involved in consultations and workshops locally about improving services.’ [38]
 - ‘We have a long running and strong Forum, which does consultations for the council.’ [20]
 - ‘We have been involved in projects which consult users of services to let their voice be heard.’ [14]
- Seven organisations (13%) made reference to the role of Learning Disability Partnership Boards in improving social care services. This relatively low figure may indicate that links to LDPBs were not strong for the advocacy organisations in the survey sample and this issue may relate to links to regional or national forums:
 - ‘Met with speak up groups and helped them to participate in the LD partnership board.’ [47]
 - ‘We get the experiences and views of people with a learning disability through the Get Involved group. This is fed to the Partnership Board.’ [53]
- Four groups said that they supported service users to help improve social care services:
 - ‘In [area] we run lots of groups in day centres, and so we support our members to give regular feedback about the services they are using.’ [71]

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- ‘Regularly support people who are having their needs re-assessed. This is currently a large proportion of our work.’ [23]
 - A further four organisations said that they worked individually to improve social care services through the provision of 1-1 advocacy.
 - Other examples of work to improve social care services include:
 - ‘We began providing advocacy for a campus re-provisioning project - all had been in an NHS campus for most of their lives. The change to social care has been a major one. Getting the services they have received continued along with their relationships and social contacts have been outcomes we have focused on.’ [39]
 - ‘We have created Steps to Respect a manifesto for carers to use to ensure that people with learning disabilities are treated with respect.’ [86]

Commissioners were asked whether the provision of advocacy has made a positive difference to social care services provided for people with learning disabilities. 97% of respondents who answered the question indicated that advocacy had helped people with learning disabilities be better represented in policy and service developments.

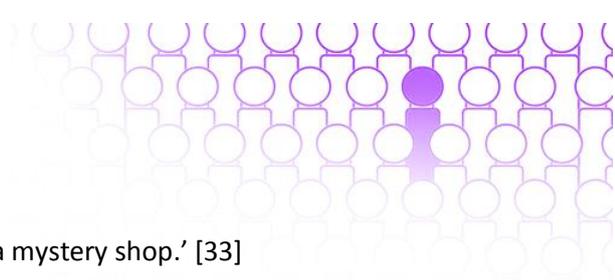
- Examples were given of advocacy groups being involved in the modernisation of day services. E.g.
 - ‘[advocacy group] were central to the modernisation of Day Services in the county ensuring that the views and opinions of service users were central to the planning and development of modernised services. They continue to support regular self advocacy groups within current day services. They worked alongside social care and family carers to develop the Open Door quality checking project which acted as a critical friend to day services to help support services to make sure that what they are delivering is good quality and meets the needs of service users.’[13]
 - ‘closure of day services/leaving school led to loss of contact with friends - self advocates have highlighted this and opportunities are now found to maintain these links.’ [48]
- Examples were given of groups taking steps to tackle safety concerns and hate crime. E.g.
 - ‘group advocacy has raised fears around staying safe in town and the Strategic Partnership is organising a pilot safe haven scheme.’ [48]

Improving health services and work on better health: Organisations

We asked organisations whether they had done any advocacy work or other work to improve health services for people with learning disabilities. 87% of the 54 responding organisations said that they had done work of this kind.

Of the 47 organisations that answered ‘yes’ to this question,

- 10 organisations gave examples of how they had facilitated the involvement of people with learning disabilities as part of improving health services. Examples included:
 - ‘Been involved in health consultations with people with LD.’ [1]
 - ‘We worked with people with LD to complete surveys on NHS services detailing their



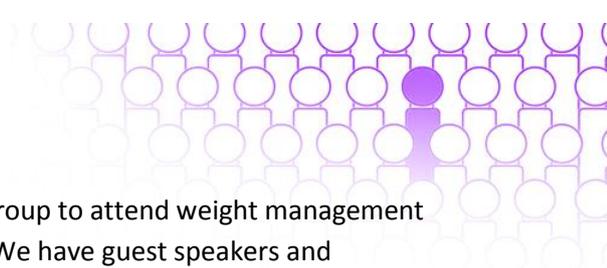
- experiences.’ [3]
- ‘We take individuals to the local hospital to do a mystery shop.’ [33]
- Nine organisations described events that they had supported or held. Responses included:
 - ‘Enabled people to part of the Big Health days and take part in smaller health groups looking at health.’ [64]
 - ‘Recently held a joint conference with health to promote a range of health services for people with learning disabilities.’ [80]
- Seven organisations described delivering training as part of the improvement of health services. Examples included:
 - ‘Self advocates were a part of the team training GPs in Annual Health Checks last year.’ [38]
 - ‘We deliver training on disability awareness to student nurses and care staff (our members deliver the training with our support).’ [53]
- Six organisations described the use of groups to help to improve health services, including:
 - ‘attend a Disability Action group at the local hospital where measures have been taken to improve the communication with people with learning disabilities.’ [44]
 - ‘Support for one advocacy client to participate in the regional health sub-group as a self-advocacy rep.’ [49]

60% of organisations answering (a total of 30) thought that this work to improve health services for people with learning disabilities would or had been affected by changes to their funding.

Organisations were also asked about whether they had done any work with people with learning disabilities about better health. 76% of the 53 responding organisations said that they had done this kind of work.

Of the 40 organisations answering ‘yes’ to this question,

- 18 advocacy organisations described carrying out or supporting events such as conferences, workshops and Big Health days:
 - ‘Holding health events. We also speak at local and national events about people's experiences of healthcare - e.g. optician's services.’ [17]
 - ‘We support people to get involved in the Big Health Check Up day every year.’ [71]
 - ‘We have run a series of workshops about women's health issues.’ [86]
- Six organisations described some kind of activity related to health promotion and healthy living, for example:
 - ‘We have run healthy eating/weight management programmes funded by the NHS. This has included bike riding and other exercise programmes.’ [16]
 - ‘We have a dedicated 'Healthy Living Group' that is funded by [NHS Trust]. The aim of the group is to promote health issues for people with learning disabilities in [town] - e.g. through training, campaigning, providing service user representation at meetings and holding health events.’ [17]

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- ‘We supported a men’s group and a women’s group to attend weight management courses (which will be followed up next year). We have guest speakers and workshops around health issues. Our men’s group has done a series of health walks. We want to do more.’ [53]
 - Other examples of work on better health include:
 - Consultations (four organisations).
 - Accessible information and booklets about health issues (three organisations).
 - ‘[Organisation name] supports groups to monitor the Annual Health Checks being offered in their areas and feedback to SHA and GP’s.’ [48]
 - ‘On an individual basis, supporting individuals to health appointments, supporting individuals to understand health information and make their choices.’ [28]

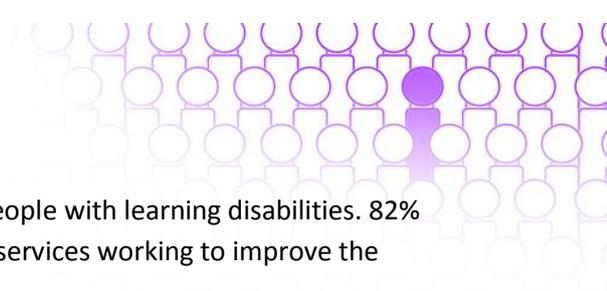
66% of advocacy organisations (27) said that their work on better health for people with learning disabilities had been or would be affected by changes to funding.

Work on health services and better health: Commissioners

83% of commissioners who answered the question said that advocacy services were working to improve health services used by people with learning disabilities.

Examples included:

- Work being undertaken by people with learning disabilities in gathering information about existing health services. In some cases this information has helped to shape health policy and developments such as health passports. Other examples included a review of acute healthcare and visits to GPs.
 - ‘Advocacy and self advocacy group was involved in doing a local review of people’s experiences in acute healthcare settings.....ie did the recommendations from 6 lives make a difference locally.....the answer was yes but there is still more to be done.’ [59]
 - ‘Checking visits to GP surgeries by local self advocacy organisation, fed back to GP consortia.’ [47]
- Improvements in access to routine health screening for people with learning disabilities. E.g.
 - ‘the breast screening department now provides several orientation visits for individuals before screening is undertaken to suit the needs of the individual.’ [17]
- Big Health days which aim to increase awareness of health issues amongst people with learning disabilities and make health professionals aware of issues relating to access for people with learning disabilities.
 - ‘One of the best days of the year. Fun packed event in which health services are brought together with people with a learning disability to address health issues.’[50]
 - ‘The LDPB fund Big Health Check Up days where people with learning difficulties are consulted on the health services they receive.’[63]



We also asked about the impact of advocacy on the health of people with learning disabilities. 82% of commissioners said that they knew of examples of advocacy services working to improve the health of people with learning disabilities.

Examples included:

- Forums where health and health awareness is raised as an issue such as Partnership Boards, Task Groups or local groups. E.g.
 - ‘The LDPB also provided funding to [named group] to facilitate a service users focus group meeting on health. The purpose of this meeting was to find out from people their views and experiences of their annual health checks and what could be done to improve these.’ [63]
- Involvement in the training of health professionals.
 - ‘linking with University of [city] to deliver a session on learning disability awareness to medical students.’[13]
- Addressing the importance of leading a healthy lifestyle. E.g.
 - ‘[named group] are supporting people with learning disabilities to learn healthy eating and cookery skills.’ [41]
- Running a Big Health Day. E.g.
 - ‘Fun packed event in which health service are brought together with people with a learning disability to address health issue.’ [50]
- Commissioners included several examples of the impact of advocacy on the health of specific individuals. E.g.
 - ‘Through advocacy support the individual was able to clearly vocalise her wishes and intentions about future treatment which medical professionals had to accept and acknowledge.’ [69]
- Other examples of good practice included:
 - ‘The Health Trainers project for people with learning difficulties is a joint [area] initiative with [city] Primary Care Trust. 4 people with learning difficulties successfully completed a 1 year training course at the [named] University They work 3 days a week to support other people with learning difficulties to access better healthcare.’[64]

Summary

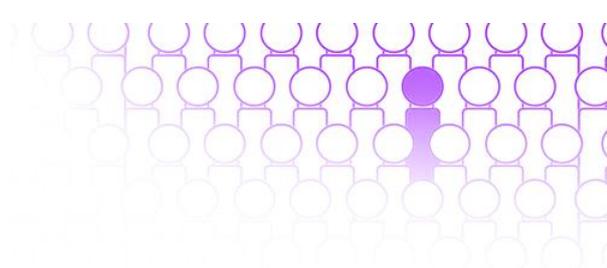
Organisations, commissioners and the case studies have highlighted areas of good practice around improving the health of people with learning disabilities and the health services offered to people with learning disabilities. Encouragingly the vast majority of organisations said they had done work on health and most commissioners stated that they had funded organisations which had completed projects regarding health.

Good examples of improvement in health services include where people with learning disabilities have been directly involved in health training, such as training student health professionals or ‘mystery shopping’ health services and screening. Advocacy organisations have also undertaken work in health promotion including educating people with learning disabilities about healthy living and diet.



However, two thirds of organisations answering our survey state that their work to improve health services for people with learning disabilities would or had been affected by changes to their funding.

Case Study 3 gives an example of an advocacy organisation, My Life My Choice, carrying out work on better health and health services for people with learning disabilities.



Case Study 3: My Life My Choice

My Life My Choice is an Oxford based user-led charity, with 450 members, which works to improve the quality of life for people with learning disabilities in Oxfordshire. The 12 trustees of the charity, who make the key decisions for the organisation, all have learning disabilities. There are also twenty five Champions with learning disabilities, who act as consultants, and lobby/campaign on a wide variety of issues. In addition, there are seven group meetings a month around Oxfordshire for another 100 people with learning disabilities. For further information see:

www.mylifemychoice.org.uk/groups/oxford.html

Health related projects

Health checks

The Partnership Board initially funded the Champions to train GPs on health checks following the implementation of the DES. This was a big forward step, and enabled the Champions to focus on something very practical; they were able to be a part of the solution to improving health services following the reports such as Death by Indifference. My Life My Choice already had a good relationship with the local provider Trust, and this was strengthened when the Champions delivered joint training with the local community nurse. They wanted to work in partnership with services to improve uptake and quality of health checks and worked extensively with Oxfordshire PCT, Oxfordshire GPs, and the Strategic Health Authority providing free user-led consultancy and training. In 2009/10 the Champions, with Jan Walmsley of the Open University, carried out their own research into health checks in Oxfordshire. This research highlighted some good practice, but also raised major concerns about the implementation of health checks locally. The Champions health work helped to secure My Life My Choice the Guardian Newspaper's National Charity of the Year Award 2010.

Although health checks increased, Oxfordshire PCT remained in the bottom third of the national health check league tables in July 2011; some three years after the start of the initiative only 41% of people with learning disabilities in Oxfordshire had had a health check. It became clear that more action was needed. The Champions reluctantly wrote to their MP asking her to contact both Oxfordshire PCT and the Thames Valley Strategic Health Authority to ask three clear questions.

1. What is the Action Plan of NHS Oxfordshire to improve the quality and take up of health checks?
2. Who is responsible for leading NHS Oxfordshire in this?
3. What are GPs doing to increase the take up of health checks in Oxfordshire practices?

The Champions also presented their case to Oxfordshire's Joint Health Overview and Scrutiny Committee, who promised to ask questions of Oxfordshire PCT and local GP representatives.

The Strategic Health Authority is now asking all of its PCT areas to construct a clear action plan on how they will increase the number of health checks. This Action Plan will have a local leader responsible for its implementation and will be monitored by the Strategic Health Authority.



The Champions have also gained the commitment of Oxfordshire County Council's Learning Disability Commissioning team to amend local service provider contracts. Service providers need to show that they are promoting 'good health' with the people that they support; part of the measurement of whether a service provider achieves its 'good health' objective will be based on the percentage of people with learning disabilities, in their care, who go for a health check.

Training staff about health and people with learning disabilities

The training My Life My Choice have done on health checks has had a knock on effect, and they now train trainee doctors and nurses at the John Radcliffe Trust, and have done training with medical staff in prison.

They have done a DVD with the South Central Ambulance Service, about better communication with people with learning disabilities. The work was the result of a thank you letter a member of My Life My Choice sent following a positive experience with the service.

They did some work with local dental practices, to check on the quality of services offered, using a tool they developed. See:

<http://www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=190>

They are doing a project funded by the Department of Health, providing digital stories on health by people with learning disabilities (see www.healthtalkonline.org). These stories will be available in Autumn 2012.

My Life My Choice has also worked with the SHA on the validation of the health self-assessment framework.

Supporting people with learning disabilities about their health

The PCT has funded My Life My Choice to do a number of road shows on healthy living for large groups of people with learning disabilities. Subjects included a "tooth day", healthy eating and encouraging people to go for health checks.

Other work

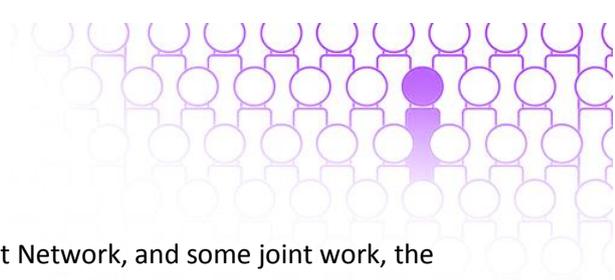
My Life My Choice have a social networking site 'Up2Us' which is like an accessible and safe Facebook (designed by People and Places). Very few councils have done anything to enable people to grasp personalisation. This is a way of doing it. People can pool their personal budgets to do things together.

They work through schools and colleges to reach young people and do a regular session at the local college. It is important to attract young people. They won't always be interested in things like consultations.

My Life My Choice have Sting Radio. People can learn to be DJs and gain interviewing skills. They also run a nightclub.

Working with people with complex needs

My Life My Choice try to involve people with complex needs in events and local groups, but don't have the resources to provide 1-1 support themselves.



Working with family carers

There is a good relationship with the Oxfordshire Family Support Network, and some joint work, the most recent example being Winterbourne View. The two organisations often end up at the same conferences. They don't always agree but 'family carers have a great deal of experience and knowledge that needs to be recognised; we agree on far more things than we disagree about'.

What would self-advocacy groups find helpful?

It would be helpful to have an extra staff member to support consultations and do some extra training. The more exposure health staff and others have to people with learning disabilities the better. There are still lots of unspoken and possibly unrecognised assumptions about a person's quality of life, which can lead to people being treated differently, or not receiving the treatment they need. If staff can see people contributing to society and enjoying their lives, it challenges those assumptions and makes people think differently.

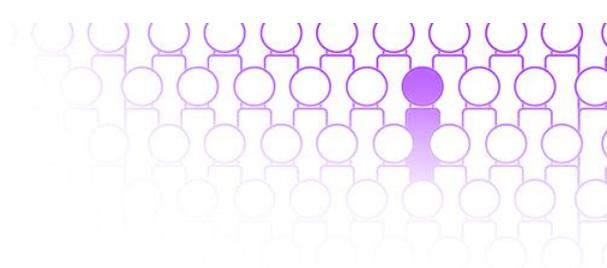
'It is important to have a bit of money that isn't attached to pieces of work as we need to do things like upgrade the website, produce brochures for marketing and build relationships.'

Links to other groups (regional and national)

My Life My Choice used to have a member on the national forum and two on the regional one. Unfortunately the regional meetings were a long way away and there was no budget for transport, so it didn't feel like an effective use of time to continue. They do sit on the Partnership Board although there is less reason to attend now that the LDDF money has gone.

How can self-advocacy groups prove their worth?

Lobbying and campaigning are important, but you also need something to offer. It is no good just being a bunch of moaners. Self-advocacy groups need to be proactive, and provide good services so that they are seen as credible. This is crucial. They need to be able to offer solutions as well as point out the problems, and need to present themselves in a professional manner. It is important to turn up to meetings prepared and able to contribute. A lot of work goes on behind the scenes. This means that support workers need to understand the issues the organisation is expected to contribute on, so they can support the Champions appropriately. It can be difficult to keep up to date with what is happening. Succinct information on easy to access websites etc. is helpful. Health checks information on the IHaL website for example. It may be helpful to provide some one page summaries of health issues for self-advocacy organisations to download.



Chapter 8: Summary and conclusions

Our survey findings clearly demonstrate the importance of advocacy services for people with learning disabilities. The most important reasons for funding advocacy identified by advocacy organisations included giving people with learning disabilities a voice, achieving equality and gaining rights, empowerment, choice and control, and accessing and challenging services. Commissioners also believe that advocacy has a key role to play in their area, stating that it provides a voice for people with learning disabilities to speak up on matters that concern their specific situation, e.g. housing or employment, yet also gives a 'big voice' to people with learning disabilities to work together about issues that concern them such as hate crime.

There were many examples of good and innovative practice provided by advocacy organisations. Organisations were able to give a range of examples of how their work was valuable to a wide range of people with learning disabilities and local services, including in relation to social care services, better health and health care services. Big Health Check days were a common example. Good practice examples cited by commissioners included gaining a 100% attendance to annual health checks locally, developments of pilot schemes to tackle hate crime, involvement in day service reform, and involvement in training healthcare professionals. Overall it seems clear that advocacy provides individual benefits for people with learning disabilities but also provides mechanisms for groups to act collectively to make important changes to local health and social care systems.

Organisations and commissioners described reductions in funding from local authorities and the short lived nature of advocacy funding as particularly significant barriers to the operation of advocacy services. Other barriers include negative attitudes, a lack of knowledge or understanding of advocacy, lack of staff and restrictive eligibility criteria or contracts. The issue of restricted eligibility criteria may be linked to an identified lack of services for people with mild to moderate learning disabilities. However it is clear that funding is the major barrier to advocacy organisations continuing to provide effective advocacy services to people with learning disabilities.

The main effects of a reduction in funding identified by advocacy groups were a reduction in the quality and quantity of advocacy services. Two thirds of organisations, when asked, believed that their work to improve health services would be affected by changes to funding. This means that it will be very important that emerging Healthwatch organisations ensure that the voice of people with learning disabilities continues to be heard in discussions regarding services and are adequately supported by advocacy organisations where necessary.

Data provided by advocacy organisations indicates that funding has been declining since 2010/11, although the picture is less clear cut when divided between organisations providing advocacy services solely for people with learning disabilities and those for a more general client base. 82% of organisations thought that it would be more difficult to get funding for next year.

Commissioner data suggests that funding for organisations providing services specifically for people with learning disabilities has decreased by 15.1% between 2009/10 and 2012/13. In addition, although total spending on advocacy has increased year on year, funding for self-advocacy/learning disability advocacy has been declining since 2009/10. This indicates a move in funding away from user led organisations towards larger professional organisations. However in some cases



commissioners gave approximate figures and it also seems likely that some commissioners included statutory advocacy funding within their figures despite the survey's focus on non-statutory advocacy.

Reductions in funding for self advocacy are problematic because user led organisations provide an important means for people with learning disabilities to have a 'big voice', develop choice and control or empowerment, or to access, shape and challenge services, all aspects of advocacy highlighted as important by advocacy organisations and commissioners. Commissioners should try to ensure that an appropriate mix of advocacy services are made available for people with learning disabilities, including self advocacy and group advocacy as well as both statutory and non statutory professional or case advocacy.

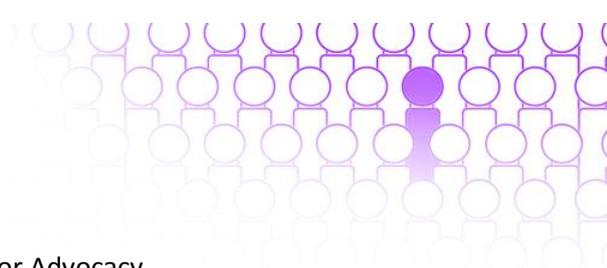
Areas for further research

Staying Strong (2011) highlights the importance of groups taking responsibility for their own funding and developing innovative solutions. This includes activities such as networking and working with other groups. In our survey of advocacy organisations 71% stated that they attended regional or national forums. There is a need for further research in this area to consider how these links might help advocacy organisations to continue to deliver high quality advocacy services to people with learning disabilities.

There was some evidence from our research that commissioners may conflate statutory and non statutory advocacy so further research on how commissioners understand the different types of advocacy, including self advocacy, would be useful.

Further work on how advocacy outcomes can be monitored effectively by commissioners could help to establish common areas of good practice in relation to the collection and consistency of data and perhaps reduce the workload related to outcomes monitoring for individual advocacy groups.

Further research on family advocacy is needed, including how to develop an agreed definition, the role of agencies in advocating for families, the role of families in acting informally as advocates and links to self advocacy and statutory advocacy.



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