FUNDING THE GAP

AN INVESTIGATION INTO THE FUNDING OF SELF-ADVOCACY GROUPS

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A report from the Open University and Learning Disability England.

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EXECUTIVE SUMMARY

This report is about how self-advocacy groups for people with learning disabilities are funded.

This is important because lots of groups have closed because they do not have money, and others are struggling to survive.

WHAT WE WANTED TO KNOW:

- How and why local authorities and Clinical Commissioning Groups fund self-advocacy in some areas, but not others.
- How groups are funded when they receive little or no funding from local authorities.
- The pros and cons of different types of funding from the perspectives of self-advocacy groups.

TO FIND ANSWERS WE TALKED TO:

- Members, staff and volunteers from 8 different self-advocacy groups of varying size and with a range of funding models.
- Six people whose jobs include commissioning (paying for) self-advocacy.
- Our advisory group whose members include leaders of successful self-advocacy groups, a commissioner and representatives from Learning Disability England.

WHAT WE FOUND OUT:

SELF-ADVOCACY GROUPS

- The 8 groups had very different ways of funding.
- Some rely on local authority funding.
- Some do not want local authority funding because they think it stops them from speaking out when services are not good.
- Some sell services like Easy Read, inspections, training, consultancy and producing information for members e.g., about utilities services and Coronavirus.
- Some funders make life difficult by asking complex questions which prevents members being involved, and by asking for a lot of wordy monitoring reports.
- Other funders do their best to make applications easy to understand and allow groups to submit reports by video or in Easy Read.
- Funding is often short term. This makes it difficult to plan, and to employ people with learning disabilities.
- The most successful groups have a range of funding sources and have access to people who know how to write good funding bids.
- Members have lots of ideas of what they could do to make life better for people with learning disabilities if they can get the funding.

THE COMMISSIONERS

- Commissioners value self-advocacy because it helps them get services right first time, and because it makes consultation meaningful and co-production possible.
- One struggled to find a local group which was member led.
- Commissioners have to fund advocacy, but funding self-advocacy is optional.
- Commissioners recognise that working with self-advocates helps them keep in touch with people with learning disabilities and take swift action especially during emergencies such as the Coronavirus lockdowns.

OUR RECOMMENDATIONS

- We need to work hard to make sure the world understands what self-advocacy is and why it is important.
- Self-advocacy groups need to be confident about their value: commissioners need them.
- Commissioners need to understand that self-advocacy saves money and improves people's lives in myriad ways.
- Funders need to find ways to make applications and monitoring inclusive, realistic, and not too onerous.

GLOSSARY OF TERMS

LEARNING DISABILITY

For the purposes of this report we are using the term 'learning disabilities' to refer to some form of difficulty with experiencing and acquiring new information, which typically starts in childhood and impacts on ability understand new or complex information, to learn new skills and to cope independently (Department of Health, 2001).

SELF-ADVOCACY ORGANISATION

Self-advocacy means knowing your rights and responsibilities, speaking-up for your rights, and being able to make choices and decisions that affect your life. In the context of this report, we will use the term 'self-advocacy organisation' to refer to any group or organisation that supports people with learning disabilities to develop the capacity and confidence to self-advocate.

SUPPORT WORKER / STAFF MEMBER

In the context of this report we have used the terms 'support worker' and 'staff member' to refer to someone who is not a self-advocate but is employed by a self-advocacy organisation to support the organisation's activities. This includes: supporting members to self-advocate and supporting project management and the day to day running of the organisation.

COMMISSIONERS

Commissioners are people who plan, pay for and monitor learning disability services.

FUNDING THE GAP: AN INVESTIGATION INTO THE FUNDING OF SELF-ADVOCACY GROUPS

1 INTRODUCTION

This report is about the funding of self-advocacy groups in England. It describes research undertaken in 2021 to explore how self-advocacy groups for people with learning disabilities in England are funded. It was produced by a partnership between Learning Disability England (LDE) and the Open University (OU).[1]

We sought to find out:

- how and why local authorities and Clinical Commissioning Groups fund self- advocacy in some areas, but not others
- how groups are funded when local authorities do not fund them
- the pros and cons of different types of funding from the perspectives of self-advocacy groups
- what self-advocacy might achieve if it was more generously funded.

To do this we interviewed 31 people from 8 self-advocacy groups, and 6 commissioners representing 5 local authority areas.

The project builds on our previous report Filling in the Gaps (Rouse et al., 2020) about the role of self-advocacy groups during the pandemic .

Research has raised concerns over a decline in local authority funding of self-advocacy (Roberts, Turner, Baines, & Hatton, 2012, National Forum 2011, 2012; The Ideas Collective, 2018). Funding related challenges include:

- questions about whether money invested in self-advocacy is wisely spent
- confusion over the concept of self-advocacy which may lead commissioners who are providing information and advice services to believe they are also paying for self-advocacy
- whether public sector funding of advocacy (as a commissioned service) means it is expected to serve the needs of local authorities rather than members
- whether self-advocacy needs to be free to bite the hand that feeds it, i.e. to challenge its funders.

Research by the Improving Health and Lives Learning Disabilities Observatory (IHaL) (Roberts et al. 2012) indicated a drop in funding for specific learning disability advocacy and found that 18 organisations were uncertain of their budget for the following year. IHaL argued that guaranteed funding would allow groups to plan ahead. A report by The National Forum for People with Learning Disabilities found that in some areas, local authority funding for self-advocacy was in steep decline, and that groups were closing as a consequence (Roberts et al., 2012; National Forum of People with Learning Disabilities, 2011, 2012). Learning Disability England wanted to learn more about how and why some commissioners fund self-advocacy on a more sustainable footing.

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[1] The research was funded through an Open University Knowledge Transfer Voucher.

[2] Find the Report here https://www.open.ac.uk/health-and-social-care/research/shld/node/371 This report demonstrated that self-advocacy groups played a crucial role filling in the gaps in support for people with learning disabilities left by other services during the pandemic. It highlighted inconsistencies and challenges in securing sustainable funding to underpin this work meaning that already overstretched groups faced restrictions to the support that they could provide during this difficult time.

What feeds into these decisions, which policy agendas does this align to, and how can such practices be shared with those local areas that have not prioritised funding of self-advocacy?

2   THE ADVISORY GROUP

Learning Disability England recruited an expert advisory group. This group consisted of senior leaders of five large self-advocacy organisations (including people with and without learning disabilities), a commissioner working in a local authority, and the CEO of All Wales People First. The role of this advisory group was to:

- steer the project
- advise on the sample and interview questions
- support access to interviewees
- comment on findings
- review and provide feedback on the project report
- help disseminate the report.

Advisory group meetings covered the following:

- decision-making for recruitment – how to choose which groups to approach
- discussion of the results of a mapping exercise on publicly available information about how self-advocacy groups are funded
- the impact of COVID
- interview questions
- views on confidentiality/anonymity
- naming the project
- recruitment of self-advocacy groups and commissioners to interview.

During our first meeting the advisory group identified a need to define 'self-advocacy' for recruitment.

We agreed that the sample needed to cover:

- a range of funding models
- small and large groups

- those which receive local authority grants, and groups with little or no local authority funding
- those which are reliant on direct payments from members.

It was emphasised that confidentiality is particularly important to commissioners.

Members of the group helped recruitment through their contacts and networks.

During the second advisory group meeting we shared headlines from the interviews conducted so far. Issues included:

- the lack of statutory duty to fund self-advocacy in England, and its impact
- some funders believing they have funded self-advocacy through advocacy funding
- self-advocacy as a term not being widely understood outside the inner circles
- the importance of distinguishing between open ended grant funding, and specific Service Level Agreements
- self-advocacy groups would benefit from rigorous cost benefit analysis when reporting to commissioners.
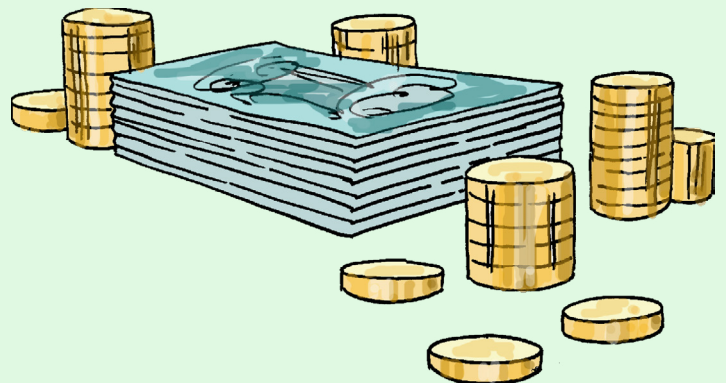
3   METHOD

3.1.   RECRUITMENT AND SAMPLE

3.1.1.   SELF-ADVOCACY GROUPS

The aim was to recruit 8 groups.

Initially we conducted a mapping exercise, identifying publicly available information on the funding of 25 self-advocacy groups from the online records of the Charity Commission and Companies House annual reports. Using this information and taking account of the advice of the advisory group, we selected advocacy groups who represent a range of funding models to approach. Advocacy groups who were involved in the advisory group could not also take part in the study as participants. We continued to invite groups to participate until we had conducted interviews with 8 groups.

For the purposes of recruitment, inclusion was agreed against the following criteria:

- the group defined itself as a self-advocacy organisation or identified itself as providing/ doing self-advocacy activities
- the research team and advisory group agreed that the group's activities came into the category of self-advocacy.

The recruitment invitation asked for participants with some experience/ knowledge of the group's funding. Of 16 groups approached, 8 agreed to take part. Self-advocates included committee members such as treasurers and trustees. Job titles of staff members included Team Leader, Manager, Director and CEO.

Following ethical approval, during June and July 2021 the research team conducted 13 interviews with staff, volunteers, and self-advocates from the 8 self-advocacy groups. 31 people (9 staff, 1 volunteer, 21 self-advocates) took part. See Table 1.

Separate information and consent forms were developed and sent with email invites to self-advocacy groups and commissioners. The information and consent forms for self-advocacy groups were designed to be accessible, and approved by Shaun Picken, self-advocate member of the research team.
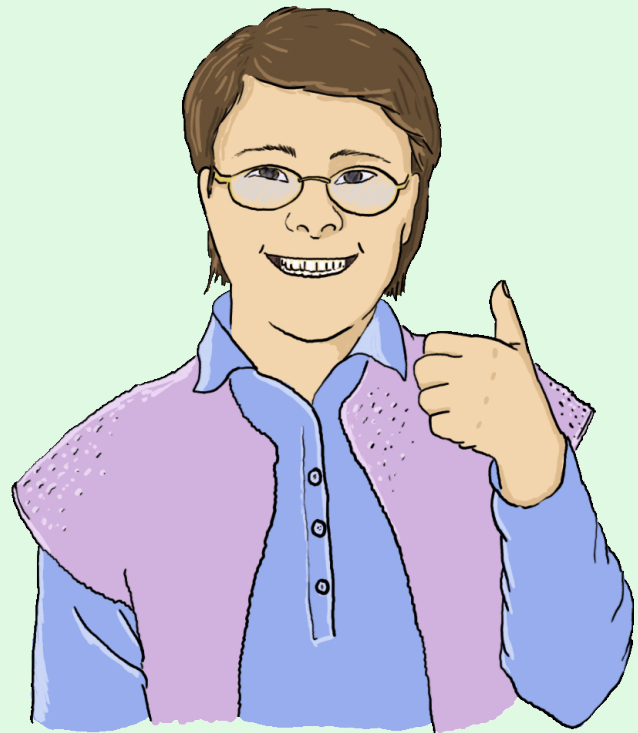
TABLE 1. SELF-ADVOCACY GROUPS

Group	Funding Model	Participants	Interviews
Group 1	No local authority funding. Small group funded through members' personal payments.	2 self-advocates 1 staff member 1 volunteer	4 separate interviews, staff member was present for some parts of self-advocate interviews.
Group 2	Hosted by pan disability group. Currently funded through non-local authority grants/awards*. Has previously received local authority funding.	2 staff members 6 self-advocates	2 separate interviews. 1 group interview with 6 self-advocates and 2 staff members. 1 staff member (who had taken part in the earlier group interview).
Group 3	Combination of funding from local authority and other sources.	1 self-advocate 1 staff member	1 interview with 1 self-advocate and 1 staff member (Director).
Group 4	Nested in advocacy provider. Some local authority funding but most funding from other sources.	1 self-advocate 1 staff member	1 interview with 1 self-advocate and 1 staff member.
Group 5	Local authority only.	2 self-advocates 1 staff member	1 interview with 2 self-advocates and 1 staff member.
Group 6	Formerly well-funded by local authority. Combination of local authority funding and other sources.	1 staff member 7 self-advocates	1 group interview with 1 staff member and 7 self-advocates.
Group 7	Funded through non-local authority grants/awards.	1 staff member (CEO) 2 self-advocates	2 separate interviews 1 interview with 1 staff member. 1 interview with 1 staff member and 2 self-advocates.
Group 8	Combination of local authority and non-local authority grants/awards.	1 staff member (CEO)	1 interview

*Non-local authority funding includes funding secured through successful bids to charitable or other organisations (see section 4.2).

3.1.2   COMMISSIONERS

We interviewed 6 people from 5 different local authorities with experience of commissioning self-advocacy. Commissioners were recruited through the advisory group who distributed project details to their contacts, including an email to members of the ADASS Learning Disability network (71 people) marked for the attention of learning disability commissioners. Additionally, the researcher emailed 20 commissioners to invite them to take part through contacts of the advisory group.

TABLE 2. COMMISSIONERS

Pseudonym	Role	Years in role
Commissioner 1	Director of Commissioning who has recently moved to a new local authority	18 months
Commissioner 2a*	Integrated Commissioner for people with learning disabilities	18 months
Commissioner 2b*	Statutory Director of Adult Social Care	2 years
Commissioner 3	Senior Integrated Commissioner	9 years
Commissioner 4	Head of Integrated Commissioning for Learning and Physical Disabilities	5 years
Commissioner 5	Commissioner for Adult Learning Disability Services	3 years

*Commissioners 2a and 2b belong to the same local authority and were interviewed together.

3.2   INTERVIEWS

Semi-structured interviews were carried out by an Open University researcher, guided by an interview schedule. The research team worked with the advisory group to develop three interview schedules for:

- self-advocacy groups who receive local authority funding
- self-advocacy groups who receive little or no local authority funding
- commissioners.

Questions for self-advocacy groups focused on: the nature of their relationship with the local authority (if any); what kind of relationship they have with individual commissioners; what local authority funding allows them to do; what they would do if they had local authority funding; whether they feel constrained by the funding relationship in what they can speak out about; how they report back.

All interviews took place in June-July 2021 and were conducted remotely due to Covid-19 restrictions, using participants' preferred online platform. All participants had the option of seeing the interview schedule beforehand to help them prepare. During two interviews self-advocates made use of messaging/chat facilities in the online platforms to help them to communicate during the interview.

All self-advocates chose to be interviewed with a staff member present or as a group (with other members and staff). On two occasions, members of staff took part in an additional separate interview (see table 1). Four commissioners were interviewed one-to-one. In one local authority two people involved in commissioning self-advocacy were interviewed together.

Interviews were audio recorded and transcribed by the research team. Data were analysed for themes on how self-advocacy is funded and the impact of funding.

3.3.   ETHICS

Ethical approval to conduct the research was granted by the Open University's Human Research Ethics Committee (HREC/3981/Tilley). Accessible information and consent forms were developed for self-advocacy groups. Participants were given choice to use the method of remote interview they were most comfortable with and whether to be interviewed individually or with the support of others/with other members and/or staff. All participants gave informed consent before taking part in interviews.

4 FINDINGS FROM SELF-ADVOCACY GROUPS

4.1 WHAT DO PEOPLE MEAN WHEN THEY USE TERM SELF-ADVOCACY?

A widely agreed definition of 'self-advocacy' is difficult to find. We explored what self-advocacy groups mean when they use the term 'self-advocacy' during interviews about funding. We found a number of differences in the ways in which self-advocacy groups and commissioners defined 'self-advocacy', discussed further in section 5.1.

What self-advocacy means for self-advocates, staff and volunteers:
• Self-advocacy means making decisions together.
• Self-advocacy is about people with learning disability having a voice and empowerment.
• Self-advocacy should be challenging e.g. to local authorities and independent (of local authorities).
• Self-advocacy is about staying connected which is good for people and so may negate the need for statutory advocacy.
• Self-advocacy is not purely about social events.
• Self-advocacy is about lobbying for change e.g. to the law and local authority/ health services.
• Self-advocacy is distinct from Care Act/statutory advocacy. It is harder to get funding for self-advocacy.
• Self-advocacy groups are there to enable people with learning disabilities 'to get their full rights'.
• Self-advocacy should have an impact and make a difference to people's lives.
• Self-advocacy groups should be able to challenge local authorities and be a 'critical friend'.
• Self-advocacy groups represent people with learning disabilities during partnership board meetings.
• Self-advocacy groups aren't there to be used by councils e.g. to support their cuts to services.

4.2 FUNDING OF SELF-ADVOCACY

The 8 groups reported on 6 major ways of funding self-advocacy.

Major ways of funding self-advocacy:
1. As a service provider (day service). Group 1 is entirely funded this way, using members' direct payments.
2. Selling services. 6 groups did some of this. The services range from producing 'easy read' documents to training, to undertaking inspections and/or Care and Treatment Reviews for Care Quality Commission, local authorities, NHS. One group has been paid to produce material by a utilities company. This same group mentioned working with Universities to do research projects.
3. Local authority or, less frequently, NHS project funding, often under the guise of 'engagement' or taking part in running the Partnership Board.
4. Two groups have local authority grants for their work; one reported that it had diminished every 3 years.
5. Applications to grant giving bodies including the National Lottery, Comic Relief, charitable foundations. One group pays a professional fundraiser.
6. As an offshoot of one to one advocacy, not directly funded. Group 6 were previously funded this way, though now have funding for self-advocacy.

Most groups also do some local fundraising, such as sponsored activities or shaking tins outside supermarkets which is appreciated by members but does not make a significant difference to budgets.

4.3 CHANGE OVER TIME

A number of people commented that funding had changed over time due to:

- the ending of Valuing People Now in 2012
- austerity affecting local authority budgets
- the 2014 Care Act making it a statutory duty for local authorities to fund advocacy, but not self-advocacy.

Several respondents said that the focus for local authority funding has moved away from self-advocacy to Care Act advocacy, making it far more challenging to find consistent/ continuous funding for self-advocacy.

> *So the funding all became tied up with statutory advocacy and not self-advocacy so hence the criteria, hence the attachments*

to things like the Care Act and things like that so there was a shift towards statutory advocacy

(Staff member, Group 4)

> *"the funding changed back in 2012, then we had to really fight for self-advocacy to be seen as important…"*
>
> **SELF-ADVOCATE, GROUP 4**

Four groups reported that they had previously been supported by the local authority, but no longer.

4.4 LOCAL AUTHORITY GRANTS

Two groups still received local authority grants to support their continued existence. Both valued it, but noted that this type of funding was precarious and insufficient.

> *It's always been enough to keep us alive, not enough to allow us to thrive.*

(Staff member, Group 5)

"local authority funding you don't want to rely on it but while it's still there we'd be silly not to go for it."

STAFF MEMBER, GROUP 8

Group 8 reported that they use this core funding to pay a professional fundraiser.

COVID had prompted local authorities to offer money to two groups.

We were given a grant from x county council to get us through, help with wages and what not which was very very useful. We didn't have to apply for that we were just given it. … Which meant we could go and get shopping for people, we could visit them, have a chat on the doorstep, take people for walks, sorting out activities, treat them at Christmas, that kind of thing really…

(Staff member, Group 1)

Group 5 reported that COVID prompted the local authority to pool adult and children's budgets to pay them to support two groups, one for young people and one for adults. This had enabled them to increase membership. Twenty people had attended a Partnership Board meeting online in 2021.

4.5 ADAPTATION TO REDUCED LOCAL AUTHORITY FUNDING

Groups described making efforts to work round the decline in local authority grants and the preference for Care Act Advocacy to become less dependent on local authority funding.

Group 1 is indirectly funded by the local authority. The group adopted this model in 2009 as an alternative to closing when the local authority withdrew previously generous funding. It is recognised as a

service provider and people pay to attend. Relationships with the local authority are weak and there are few referrals meaning the group is limited as to what it can do.

Two groups have shifted to providing statutory advocacy, with self-advocacy as a relatively small part of what they do – and hard to fund.

You know we have two things going on, we have self-advocacy which is the team that you met today and we've got an advocacy project … which is managed by paid staff that work with people individually and that is funded through health and we get purchased Care Act advocacy funding comes from the advocacy hub for that but x self-advocacy project we are constantly having to search for bits of funding and it is just so hard work.

(Staff member, Group 2)

Self-advocates also made the distinction between advocacy (funded by local authorities) and self-advocacy (less likely to be funded and seen by local authorities as less crucial).

We were funded by the council a long long time ago and then it stopped and they're funding advocacy but they're only funding advocacy where it's absolutely necessary …so they're funding advocacy so it's when someone's having a mental health issue and it's serious they fund it then, so they only fund it when it's a matter of life and death maybe.

(Self-advocate, Group 7)

Understanding of local authority drivers and sophisticated use of language was something larger groups emphasised.

Staff member: *…what the council want to pay for is to know what people with*

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learning disabilities think about things ... So we still do consultations where we have a worker who goes round but actually we still make sure we support self-advocacy groups in order to make sure that we've got spaces for people with learning disabilities to talk about things and think about things. The council wouldn't say they fund self-advocacy groups, they would say they fund engagement activity and consultations... So the funding has changed in that whilst our delivery hasn't changed massively, that's because we've designed it to fit in how the funders want – their wording.

(Staff member, Group 3)

"Fit with their needs – their requirements of their ... sometimes you have to word it in a way that they will give you that funding."

SELF-ADVOCATE, GROUP 3

we might get wind of some funding that the NHS or CCGs have ... because they have to hit their targets they would have a specific job to do and sometimes they put that out to tender but also with how that would benefit people and obviously self-advocacy groups are all about benefiting people ... we specifically choose the work to go for that we think actually would be supportive of our self-advocacy groups.

(Staff member, Group 4)

Piggy backing on project funding to pay for self-advocacy was a variation on this:

... if there's other projects that we know we can look to apply for then we always try to think of a spin around how can we actually support self-advocacy as part of this so we're kind of like also thinking of as part of this can we take some money from that to do this...

(Staff member Group 4)

Two groups described times when self-advocacy has been run on 'good will' (staff volunteering) or members paying subs.

Because before it was like tagged onto other people's jobs and some people were let's just say some people were still willing to still do it and some maybe weren't so much.

(Self-advocate, Group 4)

Several groups had diversified their sources of funding. Group 5 for example is funded from:

- Grants from utilities companies to support people to use electricity safely, install SMART meters etc.
- Working with local Universities to gain research funding.
- Charitable Foundation funding, including one major grant providing 25% of its income over several years.
- Lottery funding to provide Walking Bubbles, where a self-advocate supports someone with mental health problems to get out for a walk, particularly important during COVID.
- Training
- Easy Read services

4.6 RELATIONSHIPS WITH COMMISSIONERS

Building an understanding of local authority priorities and structures is greatly assisted when groups know their commissioners. Some groups have very weak relationships with commissioners. Others described good relationships with and/or experience of commissioners.

Good commissioners are active, engaged, skilled at talking to people and supportive of self-advocacy.

> it's good if commissioners are good at talking to people, x

Others were sceptical about the motives of their commissioners:

> they're not looking for organisations to be represented there (Partnership Board). They would probably say that they are interested in having self-advocates there but not necessarily self-advocacy organisations. I think it might be because there's a funding implication there...

(Staff member, Group 7)

Their view is that the Council is not engaging with people:

> That used to happen before quite a lot and I don't know if the lockdown has been an excuse for them to disengage but there isn't much user involvement that goes on...

(Staff member, Group 7)

Groups, like Group 3 which had a good understanding of the way to press local authority buttons for funding, also knew how to challenge. This group does not believe it is constrained by local authority funding (for advocacy and projects) in criticising, but would always tread carefully and, initially, privately in airing concerns.

One group expressed concern that they could be used by local authorities as cover for unpopular changes.

> When people say 'oh can we come and consult a group of people with learning disabilities?' and we have to be very careful about that because what's the intention behind it and sometimes it can rather cynically be that they

> need to tick some boxes to say that they've asked people with learning disabilities this question. ... I just got an email saying oh can you ask your weekly zoom group what activities people want to do and blah blah blah and this is all linked to the fact that the council have recently had to make cuts and they're changing the way they're changing the day services.

(Staff member, Group 8)

4.7 EVIDENCING OUTCOMES

Although the priority for local authorities has shifted to statutory advocacy, 3 groups argued that investing in self-advocacy would reduce the need for statutory advocacy in the long run.

> And there was a project a couple of years ago as well and it was called reshaping advocacy so again we were able to get some money across not just us this was other groups ... so they put money into looking at different ways to kind of do that and reshape advocacy that all the statutory advocacy all the money goes into statutory advocacy but actually if commissioners look to fund the self-advocacy then a lot of that actually might negate the need for statutory advocacy at the end of it...

(Staff member, Group 4)

We think more research is needed if we are to evidence this important argument.

Local authorities require evidence of outcomes which might run counter to self-advocacy.

> Yes, so for us it means things like in our contract it's typically things like we will aim to talk to so many services to make their services better or we will train

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so many services around the needs of people with learning disabilities. Now that's quite different to self-advocacy which is about people really setting their own agendas so what we do is sort of with the council funding we have these groups where people kind of have control over their groups but we have to make sure this other activity goes on around that to please the council basically. So it used to be a lot more round self-advocacy – this is what the self-advocates say, this is what they want to do. That still happens internally but externally there is a lot of – we have to tick boxes around doing consultations or around – not tick boxes, that makes it sound like it's meaningless and it's not but it's not – it doesn't come without quite a lot of targets that are externally set really.

(Staff member, Group 3)

4.8 PROS AND CONS OF DIFFERENT TYPES OF FUNDING

The groups reflected on the relative benefits and disadvantages of different forms of funding and how this impacts on their work.

4.8.1 FUNDED AS A SERVICE PROVIDER VIA MEMBERS' DIRECT PAYMENTS

This type of funding is stable, but requires sophisticated networking and promotion.

It is difficult to expand the group and extend support to those who do not meet the requirements for direct payments.

4.8.2 LOCAL AUTHORITY FUNDING

The universal message was that you cannot rely on local authority funding. Even highly committed Councils struggle to find money for non-statutory functions, and funding was decreasing.

Two groups have core costs funded by their local authority, both regarded this as unstable and likely to decrease.

The more successful groups recognised the importance of understanding local authority structures and priorities, and to 'tick the boxes' when applying for funding e.g. self-advocacy nested under 'engagement', 'consultations', supporting a Partnership Board to function rather than funded in its own right.

COVID actually led to increased local authority funding for 2 groups. Local authority funding is often short term, usually only one year, can be longer for specific projects. One staff member argued that working to local authority agendas can distort their work:

I mean the problem is it depends on whether you're talking about self-advocacy or you're talking about influencing the council because they're two quite different things ... the groups that come out where they go no we want to do something about that, we want to do something about long stay institutions or whatever and we support people to take action and the other is a bit more like at times pulling teeth.

(Staff member, Group 3)

Some feel constrained by local authority funding, and unable to criticise.

I would prefer it if we were completely independent from the council because we could be a lot more critical and have a lot more impact.

(Staff member, Group 7)

On the other hand, most recognised that relationships with the local authority were important:

it would make sense for us to have a good relationship or a good dialogue because I've seen what happens when – some advocates can be very aggressive or heavy handed and then what tends to happen is that people don't want to talk

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to them because they're too 'bloody' to talk to.

(Staff member, Group 8)

As described in section 4.6 groups were aware they need to take care not to be used by local authorities to provide cover for unpopular cuts like changes to day services.

One group reported that stop start funding is demotivating and means they cannot offer paid employment to their members, and they have become more like a social group.

4.8.3 CHARITABLE FOUNDATIONS

Many charitable foundations resist funding core costs like office and support worker employment.

Most funding is short term, which does not permit medium to longer term planning. Some exceptions were highlighted, such as The Henry Smith Charity for 9 years.

National Lottery funding was described as a preferred funder used by 6 of the 8 groups, not only for its willingness to fund core costs, but also because its reporting is flexible – willing to accept a film or Easy Read report for example. Its sustainability is, however, an issue because there is not continuous funding. Not being able to apply again for Lottery funding for 2/3 years is a limiting factor.

Inaccessible funding applications mean self-advocates are excluded: Some are readily accessible, others almost impossible to co-produce with concepts like 'weighting' hard to explain.However, the National Lottery and some others were praised for accepting video and visual reports.

Some charities have heavy and time-consuming monitoring requirements for small amounts of money. For example, group 2 cited a grant of £1000 which requires an hour each week to be spent on a monthly evaluation form– out of a 21 hour a week job.

4.9 SUMMARY

Local authority funding has a place in the repertoire of groups looking for funding, but it requires quite a sophisticated understanding of how they work, what language to use, who to talk to. Some groups had this. Local authority funding has tapered over time and is not to be relied upon. Groups need a diversity of funding strategies.

Successful groups combine different approaches to funding, e.g. selling services, charitable foundations, specific local authority projects, understanding of how local authorities are structured and what words to use.

Groups can feel constrained to criticise local authorities if receiving funding from them. Professional fund raising can have a role. Funders need to recognise that when working with small voluntary organisations, like self-advocacy groups, a light touch is required in applications and monitoring to support self-advocates to be involved and to reduce burden on staff who are already stretched.

"we are absolutely inclusive here but there are some things that to be inclusive it would take us weeks and weeks of time and everyone would be yawning."

STAFF MEMBER, GROUP 6

5. REFLECTIONS FROM COMMISSIONERS

We interviewed 6 commissioners from 5 different local authorities. Their experience as commissioners ranged from 18 months to 9 years. Given the way commissioners were recruited – through our advisory group – it is probable that the sample is biased towards people who know about and have a favourable view of self-advocacy. It is also notable that 4 of the 5 local authorities have functioning Partnership Board. This may bias them towards funding self-advocacy as a means of recruiting members to the Boards.

5.1. THE MEANING OF SELF-ADVOCACY

As discussed in section 4.1, the term 'self-advocacy' has multiple meanings. The list below summarises what self-advocacy means for the commissioners we interviewed.

What self-advocacy means for commissioners:
Self-advocacy should be user led (not professional or carer led).
Self-advocacy is about engagement, coproduction and hearing the voices of people with learning disabilities: 'listening to what people want' to improve and plan services and to inform the decisions that local authorities take.
Self-advocacy is distinct from statutory or Care Act advocacy.
Self-advocacy is not a legal requirement for local authorities but a 'duty' and 'the right thing to do'. It is provided on a 'voluntary basis'.
Self-advocacy groups should represent the views and experiences of people with learning disabilities generally.
Self-advocacy is about empowerment.
Self-advocacy should challenge local authorities (this is necessary to improve services).

Despite sometimes making clear distinctions, commissioners often used 'advocacy' and 'self-advocacy' as interchangeable terms and were less consistent in their definition of self-advocacy than staff and members of self-advocacy groups.

Five commissioners made a clear distinction between 'statutory', 'required' and 'Care Act' advocacy which local authorities are legally required to provide, and self-advocacy which, though described as valuable, vital, 'a duty' and 'the right thing to do' is not a legal requirement. Statutory or Care Act advocacy is 'a service for those people who need it' and self-advocacy supports people to 'have their own voice in their engagement with public society'.

> Self-advocacy I think is a right, everyone has the right to have their own voice and be supported to have their own voice in their engagement with public society, whatever that looks like. Doesn't mean you have a right to have it funded because we live in a financially constrained world but nonetheless you have a right to have your voice heard and some people need support with that.

(Commissioner 1)

> I think advocacy as described in the Care Act is a service and I'm saying that very distinctly. There are a set of things that are called advocacy in the Care Act, they are very distinctly a service that we should be providing to people. I personally think that self- and peer advocacy is a right and I'm going to distinguish the two.

(Commissioner 1)

All six commissioners drew a distinction between advocacy services provided by voluntary/charitable organisations that are not service user led and services 'delivered by user controlled or self-advocacy groups'.

> I would want to look for advocacy providers … who have self-advocates as part of their structure as standard and are not just saying we're going to employ people as self-advocates or something vague you know. Where in your structure are

people with disabilities, learning disabilities, black and minority ethnic groups, autistic people, where in your structure are those people and what action have you taken to make sure they are there and visible and heard and just part of your DNA?

(Commissioner 3)

Advocacy which was not user led included organisations which did not have trustees with learning disabilities and whose work was guided primarily by professionals, volunteers and parents/family members who do not have learning disabilities. In contrast, self-advocacy was described as peer led. User led self-advocacy was described by commissioners as preferable if not vital when making commissioning decisions. This was sometimes described as 'true' or 'real' self-advocacy.

5.2. CHANGE OVER TIME

Like self-advocacy groups, commissioners recognised that funding of self-advocacy had changed over time.

5.2.1. THE SQUEEZE ON LOCAL AUTHORITIES FINANCES

There was broad agreement that the funding available for self-advocacy in local authorities had declined over time, particularly since the 2008 financial crash.

The requirement to deliver Care Act advocacy (professional advocacy mandated by the 2014 Care Act) had, for this commissioner, tended to push self-advocacy to the margins:

we spend £193,000 a year on advocacy …. All of that money goes on Care Act specific required advocacy. None of it goes on broadly defined user voice self-advocacy that type of thing and that Care Act required advocacy has consumed that space that used to be occupied by a lot of different types of advocacy.

(Commissioner 1)

However, it is important to note that this was the only Commissioner who did not fund self-advocacy in any form – and the principal reason was that there were no suitable organisations locally. This was linked to a broad decline in self-advocacy groups across his Region, in the previous decade.

I have a pot of money, we want to fund self-advocacy, we cannot find a sensible group that is local enough to us to fund so we said right, we won't go out to tender, we'll look to give somebody a grant who's doing self-advocacy... in [local authority 1], there isn't anybody.

(Commissioner 1)

One interviewee commented that the local group they work with had diversified its funding sources, which made it more secure. They recognised the precarity of local authority funding.

(local self-advocacy group) has managed to get funding from the police and crime commissioner, they did work with the safeguarding board, they've worked with NHS England so the thing that was worrying me the most is that they were quite dependent on the council's funding and the council's funding was very precarious but I think they're in a much stronger position now because they've got contracts from lots of different organisations which I think means that there's less threat from reduction in budgets in one area because they've got a kind of mixed model.

(Commissioner 4)

5.2.2. PARTNERSHIP BOARDS

The Partnership Boards set up under Valuing People in 2002/3 had driven the need for a user voice. Since the Valuing People programme ended in 2012, it has been difficult to find data that confirms the precise number of active Partnership Boards in England. We do know that many areas have maintained Partnership Boards since 2012, and other areas resurrected them after a period of inactivity.

Our sample of commissioners may not have been representative of all local authorities. In four of the five areas where we interviewed commissioners the Partnership Board was active and supported the need to fund self-advocacy. Partnership Boards were changing to include more 'neurodiverse' people including autistic people in some areas, but this was not a consistent picture.

In order to improve effectiveness and in response to reductions in funding and staffing levels, one local authority had combined multiple separate partnership boards (e.g. learning disability, physical disability and mental health) into one co-production board.

The interviewees were unanimous that Partnership Boards were valuable. One commented that it needed to be better integrated into decision making in the Council.

Commissioner 3 ascribed the flourishing of the Partnership Board in the area to two committed Local Authority employees who had continued to invest in it.

We've been lucky to have …. two really key people who kept that board going for years and they've both gone now they moved on and retired but it only takes a couple of people with that dedication and that commitment to keep something going and that's really stood us in good stead. If we didn't have that we'd have to pump loads of money in to bring it back…

(Commissioner 3)

5.2.3. COMBINED HEALTH AND SOCIAL CARE COMMISSIONING

In two areas the commissioning of learning disability has developed over time to become shared with health and social care commissioning.

…at the moment we've got a legal agreement that says … that the NHS clinical commissioning group and local authority will work together to commission services and that started off just for learning disability … which basically means we Frakensteined our learning disability community team and mental health learning disabilities team and our social workers, our learning disability social workers together under the umbrella of one service.

(Commissioner 3)

This was acknowledged to open more funding doors and to potentially provide protection from changes to local authority funding priorities.

"…so if you've got to prioritise statutory or non-statutory services when you've got a very limited budget I suppose that is the thing that would stop you from doing it (commissioning self-advocacy) but because we are an integrated commissioning team …. we commission self-advocacy both in the local authority capacity and in our health capacity as well."

COMMISSIONER 4

5.2.4. DECLINE IN NUMBER OF SELF-ADVOCACY GROUPS

Commissioner 1, who had experience of commissioning a self-advocacy group in a previous job, noted that they would like to commission a group, but there was no suitable local group, and it would take more time and money than they had to set one up from scratch:

> *So you saw a big flowering of self-advocacy user led groups in the 2000s through to the early 2010s, most of those groups have gone throughout the country.*

> *twenty/thirty grand a year is not a lot of money for a group. It's enough to sustain a group if it exists and most of its members are volunteers, it's not enough to get a group off the ground and that for us is the challenge.*

(Commissioner 1)

5.3. WHY DO COMMISSIONERS FUND SELF-ADVOCACY?

5.3.1. HEARING THE 'USER' VOICE

All commissioners said self-advocacy plays a part in enabling local authorities to hear the 'user voice', 'listening to what people want', 'engagement' and 'coproduction' to develop and improve the quality of services:

> *…you can't have services that meet the needs of people unless you are prepared to listen to what people want and self-advocacy is one of the core parts of delivering that.*

(Commissioner 1)

> *the advocacy process is absolutely key …. in order for us to provide the best services, to achieve the best outcomes and enable people, self-advocacy has to be a central part of it. If we don't have that voice we're failing organisationally.*

(Commissioner 2a)

5.3.2. TO SUSTAIN PARTNERSHIP BOARDS AS EFFECTIVE FORUMS

Some commissioners argued that self-advocacy is about engaging, empowering and representing people with learning disabilities in relation to local authority services and decision-making:

> *… we have representation of service users with learning disabilities on the board and obviously they're funded for their engagement work that they kind of do and that's around the partnership board but they also do a number of engagements throughout the year around various topics that we will agree with them and then they report that back to the partnership board and they're really keen in terms of that kind of communication with adults with learning disabilities.*

(Commissioner 5)

5.3.3. TO SAVE MONEY BY GETTING IT RIGHT FIRST TIME

Three commissioners argued that working alongside self-advocates actually saves money:

> *…coming from a perspective of where I've got statutory duties but also financial responsibilities, if we listen to people before we start the planning we're gonna do it right first time and it's cheaper. It just makes common sense, you ask people what they want and you respond to that and it's cheaper than giving them the wrong thing multiple times.*

(Commissioner 2a)

> *In terms of value for money, it cost us nothing extra to save people's lives by offering that vaccination …. if that's not an example of good value for money self-advocacy*

organisations being part of the make up of decision making and understanding .... then I don't know what is because I think it was brilliant.

(Commissioner 3)

5.3.4. TO BE HELD TO ACCOUNT

Three commissioners said that self-advocacy should challenge local authorities. This is noteworthy given the concerns expressed by some of the self-advocates and staff that challenging local authorities could threaten their funding (see section 5.2.).

> *advocacy has to be painful for the organisation ... it has to be enlightening, it has to be a learning experience for the organisation and the vast majority of organisations that I've worked with can be resistant to that. So you have to be open to the challenge, you have to be open to feeling the difficulty and the challenge coming through the advocacy group otherwise it's a pointless and empty process. All partnership boards should be where x and I are held to account and given - yeah hauled across the coals by the customer base, otherwise it's meaningless.*

(Commissioner 2a)

> *I'm very clear that organisations will steam roller everybody and anything given the opportunity to just to continue to do what we've just always done, that's what institutions do. What we have to be very clear is that the advocacy group are able to stop that happening and the value for money is I hate to use the term being pulled over the coals but sometimes that's what it feels like but that's right and proper that that's what happens and that's where we're getting value for*

money that the investment that we've putting into [charity name] to support the x group to hold us to account is well worth the cost and that alone I think is a really strong model in terms of the benefits of the advocacy programme.

(Commissioner 2b)

There is, however, a caveat. One commented how difficult it is for elected members to be seen to fund people who criticise them:

> *to be seen to be funding a group which is campaigning against elected members, however understandable that campaign is, is really difficult.*

(Commissioner 1)

5.3.5. COVID 19 EMERGENCY

COVID had highlighted for some the value of self-advocacy.

Commissioner 4 gave this description:

> *as well as the work they normally do they were also phoning around people checking they were okay they were doing the translating the partnership bulletins into easy read, we asked them if they would set up a covid accessible website and they did that, they've been absolutely fantastic so yeah we've never had any bad experience I don't think. I think because we're all motivated for the same reasons and we try to be supportive and reasonable in what we ask and it's a constant conversation to understand each other's perspectives.*

(Commissioner 4)

Commissioner 3 stated that they had introduced vaccines earlier than mandated in early 2021 because of evidence from the Partnership Board that people were dying disproportionately:

"...*we made the decision to vaccinate people with learning disabilities and we started that in January because we looked at the information in December from LeDeR where essentially there was at least one person every day with a learning disability dying being reported to the programme from Covid. We made that recommendation, we'd already done the ground work ... and that meant that we had people saying we need the vaccination, we want the vaccination, make it accessible and so we were able to respond.*"

COMMISSIONER 3

5.3.6. SUMMARY OF MOTIVATIONS FOR FUNDING

Below we set out all the reasons that commissioners gave for funding self-advocacy:

Motivations for funding and increasing funding for self-advocacy described by commissioners:
• Commissioners are motivated to fund self-advocacy if they are part of a local authority that has a good understanding of the value of self-advocacy/hearing the voices of service users.
• The value of/need to hear the voices of people with learning disabilities to improve existing services or develop good new services (engagement, co-production, user voice). This includes being challenged by self-advocates/ service users.
• If funding is available.
• Increased demand.
• There is a legal reason to commission services for people with learning disabilities.
• To ensure Partnership Boards work well.
• The importance of advocating for people who can't advocate for themselves.
• The importance of working with an organisation independent from the council with the skills, abilities around advocacy and knowledge of the individuals.
• Local authorities need services they can refer people to for advocacy.
• Cost, quality and outcomes for people with learning disabilities.

Sometimes commissioners want to fund a specific organisation.
Here are the reasons why:

Motivations to fund a specific self-advocacy organisations:
• The work of a specific organisation fits in with the local authority's 'strategic intentions'.
• The group represents people with learning disabilities and is truly user (rather than professional or parent) led.
• If service users view the group positively and the group is advocating for people with learning disabilities.
• If the group is providing choice and control for people with learning disabilities and is empowering.
• The group provides self-advocacy/advocacy that is challenging, constructive and empowering.
• Confidence that the organisation can deliver the work that is needed.
• A group is willing to learn, change and adapt to future needs.

5.4. WHAT DETERS COMMISSIONERS FROM FUNDING SELF-ADVOCACY?

5.4.1. FUNDING

Funding is one major reason. It is not entirely straightforward though. One commissioner explained that because self-advocacy is categorised under the broader heading of advocacy, 'advocacy' appears sufficiently funded.

> *... if you send me an FOI saying do I fund advocacy you'll get an answer that says 'yes we spend £193,000 a year on advocacy, thank you very much we definitely don't need to spend any more'. All of that money goes on Care Act specific required advocacy.... That means that other stuff that's called advocacy doesn't get funded ... making the argument is tricky.*

> **(Commissioner 1)**

5.4.2. NOT AN OBVIOUS PRIORITY FOR LOCAL AUTHORITIES

Performance has to be measured according to local authority Key Performance Indicators – and self-advocacy is not one of these.

The absence of specific guidance from bodies like CQC also makes arguing to fund self-advocacy difficult:

> *If it was something that was statutory or regulated or – we would have to follow CQC guidance or things like that.*

> **(Commissioner 4)**

5.4.3. ABSENCE OF A SUITABLE GROUP TO FUND

This was the major reason for Commissioner 1. Conversely, Commissioners 3 and 4 were convinced that their local groups were immensely valuable and would be costly to start from scratch. It is important not to underestimate this aspect.

"So mostly ... where I've been in a situation to give grants to self-advocacy groups it's not been just for self-advocacy it's also been for service delivery. So, our key performance indicators would tend to focus on the delivery of the activities rather than on the self-advocacy in itself."

COMMISSIONER 1

5.4.4. SUMMARY OF BARRIERS TO FUNDING SELF-ADVOCACY

Below we summarise the reasons that may make it difficult
for commissioners to fund self-advocacy:

Barriers/deterrents to funding self-advocacy described by commissioners:
• Absence of good 'user led' self-advocacy groups in some regions.
• Financial constraints.
• The need to prioritise Care Act advocacy.
• Austerity/cuts in services.
• Reluctance to fund politically aligned lobbying groups.
• Lack of funds, local government cuts, e.g. lack of staff to run learning disability partnership boards.
• When service users no longer need advocacy services.
• When defined under the umbrella term of 'advocacy'.
• Competition/lack of cooperation between different service user groups.
• No legal or regulatory incentives.

Here, we outline the reasons commissioners gave for why
they might need to stop funding self-advocacy:

What might stop funding of specific self-advocacy groups:
• If the group weren't 'advocating' or representing people with learning disabilities.
• 'poor performance against the contract targets'.
• Organisations who don't challenge local authorities.

5.5.   POCKETS OF BRILLIANCE

All commissioners gave examples of the value of working with self-advocacy groups/self-advocates:

- Expert by experience inspections of supported living and residential care.
- Day service redesign.
- Challenging and holding local authorities to account to prevent the mindset 'continue to do what we've just always done'.
- Being on job interview panels;
- Development of learning disability strategy.
- Learning Disability Partnership Board involvement including highlighting inequalities e.g., to prioritise Covid vaccinations for people with learning disabilities.

Positive outcomes from working with/ commissioning self-advocacy included:

- Improved quality of services, making a substantial difference to the outcomes that people receive from using services.
- Involvement in how services are provided and what services are provided , which is more than a description of experience of services.
- Raising the confidence of self-advocates, empowering people with learning disabilities to share their views and opinions.
- Informing an early decision to offer the Covid vaccine to people with learning disabilities.
- Reports and feedback to inform priorities within strategies, including identifying gaps.
- Supporting people throughout the pandemic and providing valuable intelligence on the impact of Covid.
- Developing good relationships, being supportive and understanding each other's perspective.

5.6.   SUMMARY

Our research highlights that local authorities have moved towards viewing 'advocacy' as Care Act advocacy rather than self-advocacy. Although commissioners made it clear that they placed a high value on self-advocacy and described it as 'a right', four commissioners said that funding self-advocacy may not be a priority. They expect self-advocacy groups to help with 'engagement', 'consultation', Partnership Boards and 'user voice', and are more likely to fund these activities than self-advocacy groups per se. The absence of a suitable group to fund locally prevents some commissioners from funding self-advocacy groups.

6 THE POTENTIAL FOR SELF-ADVOCACY

6.1. COMMISSIONERS

Commissioners described their plans for future work with self-advocacy groups, including plans to coproduce a new learning disability strategy, to move towards a model of neurodiversity for partnership boards and to ensure that work done with self-advocates has an impact on decision making.

> *Yeah, do people pay attention to it that's the thing and that's where we're lucky enough to be able to move it on from so like yes we've got a partnership board and that's great but now we want to make it so that people pay attention to it so that it's part of the understanding and decision making and move it on.*
>
> **(Commissioner 3)**

Commissioner 1, who works in a local authority that does not currently commission self-advocacy expressed an intention to fund self-advocacy in the future.

> *…at the moment we do not currently give grants for self-advocacy. We fund advocacy services and we fund some organisations that deliver self-advocacy as part of their – but we don't – it's a gap but we don't fund user voice or self-advocacy groups. It's something we want to do and something we're moving towards and I personally and I have in other commissioning roles funded self-advocacy groups because I think they are essential to the proper functioning of social care…*
>
> **(Commissioner 1)**

6.2. SELF-ADVOCACY GROUPS

In answer to the question what they would do if funding was unlimited most self-advocacy groups could see enormous potential:

- Reaching out to more people, including people with higher support needs and people who are harder to reach.
- A town centre base with more accessible and attractive facilities.

> *If we had a kitchen we could help people learn to cook healthy food.*
>
> **(Staff member, Group 1)**

> *We would run a drop in in the City Centre for care homes so more people learn about us.*
>
> **(Self-advocate, Group 2)**

- Supporting people to use technology, including training staff to support people.
- Provide formal qualifications for employees and volunteers with learning disabilities:

> *I would get some way of getting some sort of official certification for people at x who've got skills so for people like x and x and myself we've got people looking at paper work looking at other jobs so we can get other jobs.*
>
> **(Self-advocate, Group 6)**

- Train more volunteers to run meetings and conferences so the work is shared around more.
- Hold an Open Day to promote the group and increase awareness of autism and learning disabilities.
- Offer jobs to more people with learning disabilities.
- Train people to respond better to people with learning disabilities – NHS 111 and GPs were mentioned by Group 6 self-advocates.
- Increase digital presence – podcasts, Facebook Live.
- Get our voices heard.
- Employ another work to share ideas.

7   CONCLUSION

In 2012 the National Forum of People with Learning Disabilities, in their Staying Strong but for How Much Longer report, was pessimistic about the future for self-advocacy as local authority funding tapered. This report shows that self-advocacy groups are worried about their immediate future. One group argued that the achievements of self-advocacy risked being lost.

It was a question also posed by Simone Aspis in 1997 (Aspis, 1997). In some respects, this research, carried out 10 years later, underlines that message. Local authority funding has diminished and is not to be relied upon. And yet this research also indicates that, despite funding constraints and few external drivers from Government or regulators, self-advocacy has survived in some places, and performs a valuable role, recognised by commissioners.

The very term self-advocacy is problematic. It is not self-explanatory, not a term in widespread use outside the sector, and too easily confused with advocacy.

There is a market for self-advocacy. Local authorities need self-advocacy to meet KPIs like 'engagement', 'consultation', and to improve the quality of services.

COVID underlined the value of self-advocacy groups which could respond in very practical ways to the emergency.

Self-advocacy groups needs to be nimble, to seek funding from a range of sources, to understand but not be slavishly driven by local authority priorities and language.

Commissioners recognise that self-advocacy groups should criticise them, though acknowledge that this can present difficulties.

There are many ways to sustain a self-advocacy group. This report points to the incredible inventiveness of the sector.

Commissioners may benefit from more information about self-advocacy and how it is distinguished from advocacy.

Self-advocacy undoubtedly has a future. This report indicates ways in which it can be sustained.

8 FUNDING THE GAP RECOMMENDATIONS: WHAT NEEDS TO HAPPEN NEXT?

8.1. RECOMMENDATIONS TO ALL STAKEHOLDERS

- Work with LDE and its members to improve knowledge of the role and potential of self-advocacy.

8.2. RECOMMENDATIONS TO LEARNING DISABILITY ENGLAND

- Continue the good work in bringing groups together to share ideas.
- Launch an information campaign in partnership with self-advocacy members to explain what self-advocacy is.
- Offer opportunities for leaders of self-advocacy to learn how to write good funding bids.

8.3. RECOMMENDATIONS TO COMMISSIONERS IN LOCAL AUTHORITIES AND HEALTH

- Invest in self-advocacy! There are many reasons why you should invest in self-advocacy. For example:
  - » It helps people with learning disabilities to live good a life, be active citizens and rely less on expensive services.
  - » It can prevent ill health and loneliness, and promote wellbeing for people with learning disabilities.
  - » It builds social connections, and provides opportunities for paid and voluntary work.
  - » It can help you save money by getting services right first time.
  - » It can help reduce health and social inequalities.
  - » It helps you meet your commitments and KPIs on co-production, meaningful engagement and consultation with people with learning disabilities.
- Self-advocacy and statutory Care Act advocacy go hand in hand. But they also have distinct and different aims and outcomes. Self-advocacy can help to reduce the need for expensive advocacy services in the longer term.
- Support for self-advocacy is not only financial. You can help self-advocacy groups in other ways, for example, by:
  - » Signposting them to alternative sources of support or funding.
  - » Building a relationship with your local self-advocacy organisation, ensuring they are involved in local initiatives and consultations for people with learning disabilities.
  - » Identifying training opportunities which might help self-advocacy leaders.
- If you cannot identify a group to fund in your area, Learning Disability England can help you find one.

8.4. RECOMMENDATIONS TO SELF-ADVOCACY GROUPS

- Be confident – you do an important job which your members and many commissioners value.
- There is a market for self-advocacy. Local authorities and Clinical Commissioning Groups need self-advocacy to meet KPIs like 'engagement', 'consultation', and to improve the quality of services.
- You need to understand local authority and Clinical Commissioning Group language and priorities to get money from them.
- Be professional, serious, reliable, friendly and focused – make people want to work with you.
- Invest time in telling the world how good you are – blogs, articles, local radio.
- Build positive relationships with Leaders in the Council (Cabinet) and local MPs.
- Use every way possible to develop the skills of writing good funding bids.
- It is important to maintain independence and the freedom to be critical of services. You are not doing your job if you hold your tongue when your members meet difficulties.
- Don't rely on one source of funding.

8.5.   RECOMMENDATIONS
TO THOSE WHO FUND SELF-ADVOCACY

- Make your application process as simple as you can: is the process accessible so that people with learning disabilities can be meaningfully involved?
- Longer term (3 years plus) funding is more valuable.
- Don't make progress monitoring too onerous: is it realistic monitoring, and is what you're asking achievable?
- Recognise that outcomes may change: self-advocacy organisations are responsive to their members' needs, and these needs may change.
- For reporting purposes, consider asking groups to produce material in accessible formats, like video or Easy Read documents.
- Remember, core running costs are essential.

8.6.   RECOMMENDATIONS
TO THOSE WHO FUND RESEARCH

- Prioritise the funding of more research that can help us understand what makes self-advocacy 'not just survive...but thrive'.
- Make sure that research about self-advocacy includes paid researchers with learning disabilities.
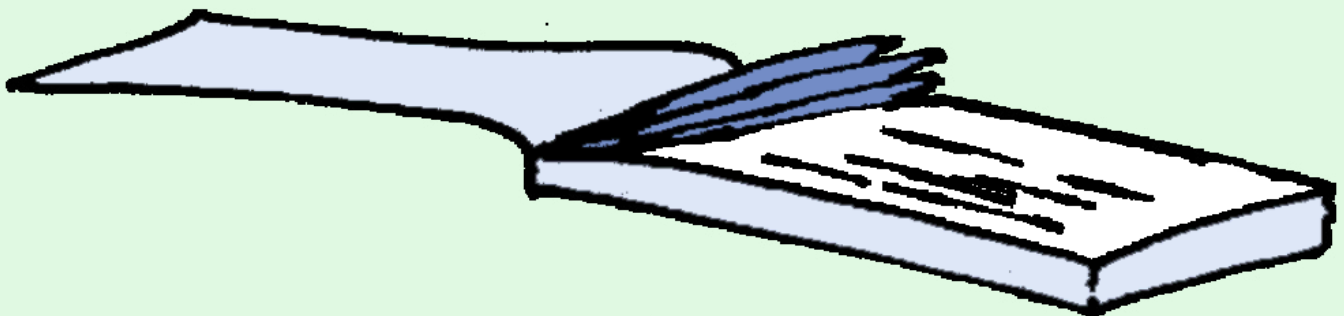
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