# Funding the gap



# Helping Self-advocacy Grow

Lorna Rouse, Liz Tilley, Jan Walmsley and Shaun Picken





### The Main Messages



Self-advocacy really matters to people with learning disabilities.



The commissioners we spoke to understand self-advocacy and want to fund it.



But we know from our Advisory Group that some commissioners are less sure.



It is important that self-advocacy groups learn from each other's experiences of getting funding.

## The main points for self-advocacy groups



Show people that self-advocacy works.



Use the same words as funders use so they understand you.



Remember to tell funders what you have done.



Have more than one source of funding

# This report



What we wanted to know.



How we did it.



What we found out about funding self-advocacy groups.



What we found out about the Commissioners.

(people who decide what is funded)



What self-advocacy groups would do if they had the money.



What we think should happen next:



1 – For commissioners



2 - For self-advocacy groups



3 – For funders.



#### What we wanted to know



Why do some self-advocacy groups get money, but others don't?







Where does funding come from if a local council does not fund it?



What are the pros and cons of different types of funding?

#### How we did it



We had an advisory group to help us.



They told us who to talk to and what questions to ask.



We talked to 8 self-advocacy groups in England.



We talked to 6 people who make decisions about funding (commissioners).



#### What we found out about self-advocacy



It is harder to get money for selfadvocacy now.

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 ... they only fund it when it's a matter of life and death maybe.





People don't agree what self-advocacy is.

Self-advocacy is about people with learning disability having a voice and empowerment.

Self-advocacy groups are there to enable people with learning disabilities 'to get their full rights'.



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.

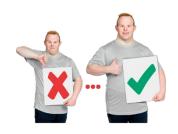




## People agreed that



Self-advocacy should challenge local authorities.



So the council improves services.

# What we found out about self-advocacy groups



Some get funding from local authorities or health.



Others don't want funding from local authorities.

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.











Some groups sell services to raise money.









Some funders make it difficult to get money:



• They ask difficult questions



• They want reports with lots of words.



Some funders make it much easier to get funding:



• They ask simple questions



 They let groups send an Easy Read report or a video summary.



Some groups told us about good experiences with charitable funders.



#### What is difficult for groups:



• Often, funding is short term



Groups worry about funding ending



• This makes it difficult to plan.



#### What helps groups to be successful:



• Have several funding sources



Have staff that are good at funding applications



 Use the same words that the funder uses.

#### What we found out about commissioners





They value self-advocacy because it can:

1st time



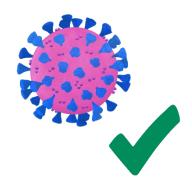
 Help them get services right first time



 Help make consultation more meaningful



• Help with coproduction



 Helps councils to do their job properly.



But



They don't have to fund self-advocacy, even though they do have to fund advocacy.



They can't fund self-advocacy if there isn't a member-led group.



They find it hard when groups campaign.



#### Good examples of self-advocacy



Inspections of supported living and residential care.



Helping appoint staff.



Being on a partnership board.



Holding local authorities to account.



Developing a learning disability plan.



Designing new day services.

# What we found out about what groups could do!



Reach out to more people:





• Who live further away



• Who have high support needs.



Be more accessible – like in the town centre.



Help people to use technology.



Train supporters to help people.



Give qualifications to employees and volunteers.



Train more people so the work is shared out.



Offer paid work to people with learning disabilities.



Hold an open day to tell people about learning disabilities and autism.



Train professionals so they can help us better.



Get online.



Have more workers.

# What we think should happen next



We all need to tell people about self-advocacy:



• Help them know what it is



• Help them know why it matters



• How it can help.



#### 1 – For commissioners



Invest in self-advocacy because it:



• Helps people have a good life



• Helps people use less services



• Builds social connections



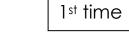
• Helps people get jobs



Prevents ill health



• Prevents Ioneliness





Helps get services right first time



• Helps avoid advocacy services.



You need self-advocacy to do:



Good co-production



• Meaningful consultation.



Commissioners can help self-advocacy grow by:



Providing money (funding)



Providing advice and support



 Helping self-advocacy groups to network.





Learning Disability England can help you find a group.





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#### 2 – For self-advocacy groups



Be confident – self-advocacy is important!



Be professional and business like.





Don't rely on one funder.





Make people want to work with you!





Get to know people in your Local
Authority and Clinical Commissioning
Group:



• What words do they use?



• What are their priorities?



• Tell them what you do



• Tell them why they need you.

# £££



Get better at writing funding bids:



Do training



• Ask for help.



Tell the world how good you are, by using:



• Radio – get on air



Internet – use blogs and social media



• Local paper – give them a story.



#### 3 – For funders

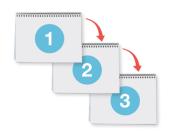




To make it possible for self-advocates to be involved in funding, you should:



 Make your application process simple



Make your reporting process simple



 Allow video and other forms of report.



To help self-advocacy groups grow and keep going you should:



 Give funding that lasts 3 years or more





• Include core running costs.





We need funding to do research on what makes self-advocacy groups work well.



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# AN INVESTIGATION INTO THE FUNDING OF SELF-ADVOCACY GROUPS

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