Staying Strong
Taking self advocacy into the future

How to find more money for your group
Advice on fundraising and saving money

Self advocacy is changing
Find out why. Learn how your group can stay one step ahead!

Survive and thrive
Lots of top tips to help your group plan for the future
The Office of the National Director asked the National Forum to produce this guide. It is to help self advocacy groups to adapt and change their ways of working. It will help them to make sure they have a plan for their future.

The National Forum did a survey of self advocacy groups in England to find out how they work now and what plans they have. We have used the information that 80 groups from all 9 regions across the country gave us to write this report.

We hope it will help all groups to plan for the future and Stay Strong!

These people were on the project team who wrote this report.
Index

4  Self advocacy - an introduction

6  Things self advocacy groups do well

9  All self advocacy groups are different

12 Including everyone

17 Managing your group

20 Working with supporters and staff

23 Show that you can make a difference

26 Where will the money come from?

31 Staying strong

36 Information and useful contacts
Self advocacy

Valuing People Now says that “self advocacy is people coming together to speak up for themselves”.

Self advocacy groups are led by people with learning disabilities. Working together helps self advocates to become more confident. Then they can then have their say about things in their lives.

Lots of people with learning disabilities are involved in self advocacy. There are hundreds of self advocacy groups in England.

Groups work in their local areas and regions to make sure that people with learning disabilities are treated fairly.

Some groups also work nationally to make sure that the Government hears their voices.
In the future the Government will have less money to spend on services for people with learning disabilities.

This means that self advocacy groups are even more important now. They need to make sure that people still get the services they need.

In our local groups we can support each other and stand up for our rights.

But there will be less money around to run our groups.

This report looks at how we can Stay Strong, so that our self advocacy groups can keep making a difference.
Things self advocacy groups do well

- Good work has been done as part of “Valuing People Now”
- Self advocacy groups are good at working with people from different backgrounds
- Groups are also good at research and training which they can get paid for
- Groups make resources for others
- Self advocacy groups create jobs for people
Skills and experience

We are great at:
- Speaking up for ourselves and others
- Listening to each other

Good for our community:
- We run events and conferences
- We challenge services about charges and cuts
- We employ people with learning disabilities
- We tell other people about our work, especially how being involved in self advocacy has changed people’s lives
- We work with people who have high support needs

And good for us too:
- We find new ways of learning
- We support other group members, such as parents with learning disabilities
- We help members with skills like spelling, writing, using the phone and the computer
- We help our members to get jobs

“We are good at training people about our needs and how to treat us with respect”

“We when feel good about ourselves, we can help others and grow in confidence”
Things we do

- Talk to people about what people with learning disabilities can do. We use local papers, TV & radio, posters and the internet to do this.

- Talk to MPs and our local authorities about things that are important to us.

- Go to local disability and equality forums, advocacy networks and talk to local organisations.

- Take part in the work of “Valuing People Now”. This means going to Partnership Boards, Sub Groups, Regional Forums and the National Forum.

- Run learning disability parliaments. For example, in Devon and Lewisham.

- Help people to speak up using “1 to 1” advocacy. Sometimes this advocacy is done by other people with learning disabilities and is known as “peer advocacy”.

- Look at the quality of local services: Quality Checkers and Health Checkers.

- Consultations (asking people what they think) and research.

- Training for professional people (doctors, nurses, social workers) and students.

Communication

We include people by using symbols and pictures.

We make things easy to understand:

- Leaflets
- Newsletters
- Reports
- DVDs
- Meetings

These things help other groups of people too.
All self advocacy groups are different

- Groups value their individuality and independence
- Their members should be in charge
- Groups are all at different stages of development
People First Merseyside

Some groups start off in a small way and grow or change over time. This story about People First Merseyside shows how this often happens.

The group started as Liverpool Self Advocacy in 1988 with 6 members.

Social services paid them to do some consultation in day centres. They rented an office and employed 3 support staff to help them do the work.

The group got bigger and changed its name to People First Liverpool. They got paid to train hospital staff and moved to a bigger office.

In 1999 they helped people in Sefton, (another part of Liverpool) to set up a self advocacy group.

Both groups worked well in their own areas. In 2004 they joined together to make an official limited company called People First Merseyside.

They now have 2 offices and employ 7 staff. Their board of directors are all people with learning disabilities. They make all the big decisions about how the company is run.
Some advice for all groups, big or small

Be clear!
- What do you do?
- Why do you do it?
- What are your plans for the future?

Be “User Led”
Your members should make the decisions about what the group does and how it is run.

Support your members
Members need to give and get good quality support.

Take time to think
In these difficult times, groups will first have to get enough money to keep going, while they decide what they are going to focus on.

Don’t be pushed around
Local authorities may try to tell groups what to do. One group told us: “They are trying to turn us into service providers”.

Work with other groups
Contact Inclusion North to find out about other self advocacy groups in your area. Also think about joining up with other local organisations. You could save money and have a stronger voice as a result.
Including Everyone

- Groups want to be able to include everyone with a learning disability.

- It’s good to use different ways to connect with different groups, for example people with:
  - Complex needs
  - Autism
  - Black, Asian and Minority Ethnic communities
  - Mental health problems
  - Parents with learning disabilities
  - People who find it difficult to come to meetings
People First Independent Advocacy, Cumbria. “Voices of the Voiceless” project

We found out how to include people with complex needs without them having to come to big meetings.

Now people tell us what they think in lots of different ways.

The self advocacy group now go into care homes. They work with staff, helping them to think about the people first when writing plans about care or services.

**Complex needs.**
If someone is described as having complex needs, they are likely to need a lot of support with things like getting around, their health and communication.
A group of young Asian women left their local day centre to set up their own group. They got some funding to help them get started. They called themselves Nayi Zindagi, the “New Life” group.

They went to a Citizenship course run by Speakup and were offered a room in Speakup’s building to meet in.

A good partnership is developing with the Self Advocacy organisation. The 2 groups are working well together on joint projects.

Before the New Life group came along Speakup did not work with many people from ethnic communities. Now they have regular links with volunteers from the local community.

Asian
The people in this story are Asian. This means that either the women themselves, or their families, are from a country in Asia.

Ethnic Communities
are groups of people who share the languages, customs, festivals or beliefs of the country they or their families come from.

Some may be more comfortable getting some or all their support from their own community.
Advocacy in Greenwich
Parents’ Project

We work with parents who have a learning disability and live in Greenwich, London.

We help parents to find the support they want to care for their children.

We support parents to speak up and be heard particularly when there are child protection or court cases.

As well as offering one to one advocacy, we support a parents self advocacy group.

We think that through our group we will be able to make changes for parents with a learning disability in Greenwich.

We have delivered training for social workers and other professionals to help them support us better.

We would like to get more parents to come to our meetings and join up with other parents with a learning disability in London and across the country.

Here are some of the things members of the Greenwich Parents Self Advocacy group said:

"Everyone was friendly and I didn't feel judged."

"I was nervous about coming to the group but when I came I felt comfortable."

"Everyone is lovely - we get good support from each other."

"Everyone was friendly and I didn't feel judged."

"I was nervous about coming to the group but when I came I felt comfortable."

"Everyone is lovely - we get good support from each other."
Warrington Speak Up

“Speak Up on the Road” project

Warrington Speak Up have found ways to work with people who find it hard to get to meetings. They run workshops in places like day centres and gardening projects.

They got 'Grassroots Grant' funding for their project. This was a funding scheme to help all kinds of local community groups.

They visited 5 groups for 6-8 weeks. People in these places became more confident during the project. They wanted to be listened to by their friends.

One person who cannot speak was able to tell us that they did not like having to spend long periods of time each day on an uncomfortable bus. They did this using gesture and facial expressions. The group found out who to tell so that different transport could be organised.

This project helped to tell more people about the group. 60 people went to their “Big Issues” conference in the summer.
Managing your group

- You need a strong management committee

- A good manager will give your group direction and help everyone to work together

- There is training available to help your group to think about how it is managed, organised and led
Management

Management means getting people together to achieve the things that are important for your group.

This is done by:

- Planning
- Organising
- Finding and looking after staff
- Leading
- Keeping good records

Management Committee

You may need a management committee to do some of these jobs. It is a way of members having their say about how the organisation is run and making sure that the work gets done.

It is important that all members of the committee understand their roles and responsibilities and get good training and support to help them do their jobs well.

Your committee should include people with learning disabilities.

Many groups also like to involve a mixture of people from different backgrounds.
A manager

“You need a really good manager with business skills to get money into your group, or you are too dependent on the commissioners and public money.”

Your manager might do these jobs:

- Fundraising
- Keep in touch with funders
- Support staff
- Make a business plan
- Look at **policies and procedures**. It is often harder for smaller organisations to keep their policies and procedures complete and up to date.

Some groups are managed by other organisations who provide the management support for staff and volunteers.

**Policies and procedures**

A policy is a rule that you follow or something you believe in. For example “we want to include everyone”. Procedures are the practical things you will do to make your policies happen.

**Training**

There is training available to help your group, committee members and staff to develop their skills in business, organising your group and leadership.

Look at the information on page 45 for some examples.
Working with supporters and staff

- You need to be a good employer and follow employment laws
- Workers need the right personal qualities and skills to do the job
- You need to give your staff good support
- Volunteers could be very good for your group too
Good support

People need support that suits their different needs. Talk to your group members to find out what they think good support is. Here are some of the things people told us:

- "Listen and don’t try to take over"
- "Be committed to the ideals of self advocacy"
- "Treat us equally and with respect"
- "Know how to explain complicated information in a simple way"
- "Have knowledge and skills to help us run our organisation"
- "Get people’s voices heard at meetings"
- "Work hard together as a team"
- "Be committed to the ideals of self advocacy"

Don’t tell us what to do!

One group told us that they had a problem with supporters taking over. They needed good advice and support to help them through this. Another group does a yearly survey of the members to find out what they think about their supporters.

"What’s in it for them?"

Groups need to think about how to value and support their own supporters.

Looking after your staff

Keeping your supporters for a long time builds up trust and respect.

People First Cumbria have developed “co-working”.

This means having a person with and without learning disabilities doing each job.

“We are playing to our strengths not just giving someone a title like “Treasurer” when they can’t do the job well. It’s more equal now. We work together.”
Empiring staff

Groups need to look for staff who get on well with people. They also need the right values and skills, especially in business.

You need to make sure you are a good, responsible employer. Here is a short list of things which will help you and your staff:

- **Good policies and procedures** (see page 23 for what this means)
- **Induction** training (helps new staff members to get to know your group and how it works)
- **Supervision and appraisals** (regular meetings with staff to make sure that everyone is okay, listened to, and working well)
- **Training**, so that staff can learn new skills and get better at their jobs

Volunteers

Speakeasy NOW in Worcestershire have 15 volunteers.

They help with meetings, training and a “Health Checkers” project. Some of the volunteers are trustees.

They find volunteers through their local Volunteer Centres, and from the “Do-It” website: **www.do-it.org.uk**

“Volunteers are an extra pair of hands. Our meetings would not run as well as they do without them.”

**Things to think about before you look for volunteers:**
- CRB checks
- Induction
- Information packs
- Training
- References

Volunteers can help to run meetings, become trustees, help with transport or do office work.
Show that you can make a difference

- Groups need to show commissioners that they are doing a good job and that they give value for money.
- Local connections and regional networks can be very useful.
- Make sure your local community knows about the good work you do and that working in partnership will make everyone stronger.
Commissioners are important people for many self advocacy groups. They give out public money. Commissioners often work for the NHS or for your local council. You need to let them know how brilliant your self advocacy group is!

Lots of self advocacy groups rely on money given to them by commissioners. Some groups have said that commissioners do not always understand what self advocacy is all about.

Commissioners told us that groups need to show clearly, using numbers and stories, how they change people’s lives.

There is a project in the Yorkshire and Humber region to train commissioners. They are taught about self advocacy and why it is important. You can contact Speak Up in Rotherham if you would like to find out more.
5 top tips

• Show that people will use services less as a result of your work. This might be because group members don’t go to a day centre any more because they are working for you. Or it may be that your support for people stops small problems turning into big ones.

• Record the number of people you help. This could be the number of members you have, how many people come to your events, or the number of people you go out and talk to.

• Tell everyone about what you do. Newsletters, emails and websites are good ways to do this.

• Use people’s stories. Give examples of people getting more confident and independent.

• Show that you are an important part of your local community. This may help you to show that you can do the job better than a larger national organisation.

Dorset People First invited members to ‘Tell us Your Story’ days. ‘We found out about the difference people thought we have made to their lives. Then we made a booklet to show what people said’
Where will the money come from?

- You will have to find new and different ways of working and getting money.

- Groups already have skills which they could use to get paid work.

- Be creative. Look at developing new links and partnerships beyond the learning disability world.

- Look at ways to spend less and make sure you keep good records.

- You need to be able to give funders the information that they ask for.
Ways to earn money

Self advocacy groups told us about the places they are looking for funding.

You may find some ideas here:

- Contracts with Local Authorities and Health Services
- Charity funders
  Examples: Big Lottery and Comic Relief
- Sponsorship by businesses
  Examples: Northern Rock and Sainsburys
- The European Social Fund
- Fundraising events
- Quality Checking
- Use Direct Payments and Individual Budgets
- Charge for membership
- Training - for people like social care staff, the police and NHS staff
- Find out what people think of services (consultation)
- Make “Easy Read” documents and films
- Advocacy service for individuals
- Student placements, for social work, the police and nursing

People said:

“The biggest worry is that self advocacy groups do not know how much money they are going to be able to get or where it will come from.”

“We used to get most of our money from the Valuing People LDDF fund.”

“We now have to look for new places to get money.”

To stay strong and plan for the future, groups are changing the way they work. They are thinking about the best and cheapest ways to do things.
Help and support

Talk to your local council’s Community Development Officers and Council for Voluntary Services (CVS).

They should be able to give your group advice and support about funding and organising yourselves.

Think about what your group is good at and then look for ways to earn money with those skills.

Look back at the red section of this book: “Things self advocacy groups do well” for some ideas.

Talk to other community and support groups in your area to see if you can work together on getting money for joint projects.

Use Easy Read and consultation skills to work with other groups on big changes to services, such as personal budgets.

Save money where you can

“We use SKYPE to make free telephone calls between our 3 offices to keep our bills down”

People First Cumbria
"It is easy to find money for exciting new projects. But what about our regular meetings? Without these we would not exist!"

'Some groups have told us that advocacy contracts have been going to big organisations, because they have more experience and time to write funding bids.

In the North West, local authorities have put in money to fund a workshop for advocacy group members and managers to learn how to apply for large amounts of money from people who are used to putting bids in.

Try this! - some more ideas

<table>
<thead>
<tr>
<th>Keep good records</th>
<th>Cut costs</th>
<th>Talk to your local council</th>
</tr>
</thead>
<tbody>
<tr>
<td>Record how much money your group has and how you spend it. This will make sure that you are not wasting money, and will show funders that you are reliable.</td>
<td>There are lots of ways to cut costs. Maybe you could look at your transport costs. Dorset People First gave some members travel training, which cut their taxi bill.</td>
<td>They need to find ways to include people with learning disabilities in their plans for services. Self advocacy groups are good at this and are good value for money.</td>
</tr>
</tbody>
</table>
Fundraising Top Tips!

Be organised
When you are applying for money, you must show that you are properly organised. You need to have a constitution. This will tell funders about the work that you do and the rules that you follow.

Your status
It can help if you are a registered charity and a limited company. You can find more information on this at www.volresource.org.uk.

Paperwork: do it well, and on time
Keep a record of all the money you receive and spend. Write your project reports on time.

Communicate
Keep talking to your funders about your projects so there are no surprises! Give them any information they ask for. This might mean filling in forms about your contracts. They will need to know that you have spent their money wisely.

Tell funders how good you are!
Let them know about the work you have done and how it has made a difference. Have a look at Action for Advocacy’s 'Quality Standards for Advocacy Schemes'. You can find it using an internet search (like Google).
Staying Strong

- Use your existing contacts and networks
- Look at the work you want to do, then work out how to pay for it
- Be prepared to work differently and with other groups
- Think about what services you could provide
Get ready for change

Your group may not be able to do exactly what you want to if you still want to get public money.

Some self advocacy groups don’t want to be “service providers”, but may need to think more about this in order to survive.

The rules to apply for money will change for all voluntary groups. There will probably be fewer grants and more contracts.

Self advocacy groups will need to be able to do all the work described in these contracts.

Portsmouth Self Advocacy Group have started up a “Friends Group”. The number of college places has been cut so this group helps the people who might have gone to college instead.

This is a good example of how to provide a service. Your local authority might also be looking for schemes like this one, to help people out when services are cut.

Contract

A contract is a legal agreement between people. You must do the work that you have promised to do in your contract. As well as doing the project work, you will probably also have to have meetings with your funders and write reports.
Back to basics?

In the future there will be less money around for self advocacy groups.

It may be time to look at what you spend your money on and where your money comes from at the moment.

Then ask yourselves some questions.

• How much do you spend on things like rent and staff?
• Do you really need an office?
• Could you meet somewhere for free?
• What work would you ideally like to do?
• Could you use things like Facebook and Skype more to keep in touch and tell people about your work?
• Find out what needs doing in your local area. Apply to do these projects.
• Use the contacts you may have already built up. For example, people you have met at Partnership Board meetings.
• You could ask local businesses to help “in kind, not with money”. This could mean them donating equipment, office space or their staff’s time.

Talk to the people who give you funding. Tell them what your group has been doing and about the value of self advocacy.

You can make a difference. Tell your funders what difference your group has made to people and to their lives.

Tell them what you can do. For example, training for staff and GPs, or reporting on what is happening about health care.

Watch out for other self advocacy groups. Help each other out. Use local networks, like the Regional Forums to keep in touch. In the South West region they have started up “Group Watch” to help struggling groups survive.
Becoming a Social Enterprise instead of a charity can be easier. There are fewer rules. It can be easier to get support and funding. You could do things like training, Quality Checking and “Easy Read” information design. You could then earn money for doing things that your group is already doing!

People First Cumbria support a social enterprise called Jupiter Quality. They work with providers, commissioners and regulators of services to check that they are doing their job properly and listening to what people want.

Things to watch out for

Work to improve Health, Housing and Jobs is still important.
More ideas for paid work

- Personal Budgets
- Training for GPs and health professionals
- New GP commissioning groups (this is sometimes called a Consortium)
- NHS Health Watch groups
- The Big Society
- Help local councils and the NHS to do work that they have to do by law
- Tell local councils about how cuts to services and benefits are affecting people’s lives

Taking Part Shropshire are being paid to help people with learning disabilities, local authority staff and carers to make personal budget support plans for people with high support needs.

Working with others

Look around your local community for people to work with. Here are some ideas:

- Library
- Housing Associations
- GP Surgery
- Police and Criminal Justice Agencies
- Theatre
- Leisure centres
Using the guide

This guide is full of ideas, suggestions and information from the 80 groups that took part in this project. Choose the bits that will work best for your group to help you think about where you are now and what you want to do in the future.

You could:

• Talk to your group's trustees and management about the best ways to use the guide

• Organise a workshop for your members and think about which good ideas could work for your group

• Use it to help write a plan for the future

• Use it to keep strong using new ways of working

Tell us your ideas

Tell us how you are using this guide. Have you any ideas or resources you can share?

Please get in touch and let us know by going to the National Forum website: www.nationalforum.co.uk

From the Home page click on:

Campaigns  ➔  Advocacy  ➔  Submit feedback
Information

Most of these websites are not in an “Easy Read” format, but they do have useful information. If you know of any other good websites, please let us know.

Funding, management, setting up groups
• www.supportforgroups.org.uk
• www.ncvo-vol.org.uk
• www.volresource.org.uk

Recruiting and using volunteers
• www.volunteering.org.uk
• www.do-it.org.uk
• www.vinspired.com (for volunteers age 16-25)

Training courses
• www.dsc.org.uk
• www.peoplefirstltd.com/training-for-groups.php
• www.bild.org.uk - “Stronger Together”
• www.inclusionnorth.org - “Tomorrow’s Leaders”

Social Enterprises
• www.socialenterprise.org.uk
• www.jupiterquality.co.uk
• www.pathwaysassociates.co.uk

List of GP commissioning groups (Consortia)
• www.dh.gov.uk/en/Aboutus/Features/DH_122384#_8
Useful contacts

Advocacy in Greenwich:
www.gcap.org.uk

Dorset People First:
www.dorsetpeoplefirst.co.uk

Devon Learning Disability Parliament:
www.devonpeoplefirst.org.uk

Inclusion North:
www.inclusionnorth.org

Jupiter Quality:
www.jupiterquality.co.uk

Lewisham People's Parliament:
www.lsup.org.uk

People First Independent Advocacy:
www.peoplefirstcumbria.co.uk

People First Merseyside:
www.peoplefirstmerseyside.com
More Useful Contacts

National Forum:
www.nationalforum.co.uk

Portsmouth Self Advocacy Group:
www.pldpb.com/Our-Friends.html

Speakeasy NOW:
www.speakeasynow.org.uk

Speakup Self Advocacy Rotherham:
www.speakup.org.uk

Taking Part Shropshire:
www.takingpart.co.uk

Valuing People Now:
www.valuingpeoplenow.dh.gov.uk

Warrington Speak Up:
www.thespeakupgroup.org.uk

York People First:
www.peoplefirstltd.com/members-yorkshire-york.php