Staying Strong - but for how long?

A follow up to the Staying Strong Guide produced by The National Forum of People with Learning Difficulties.
Staying Strong – but for how long?

This report has been written by the National Forum of People with Learning Difficulties.

It has information from more than 100 self advocacy groups.

The self advocacy groups are from the 9 Regional networks of the National Forum.

The information was collected from questions that were sent to self advocacy groups from May to September 2011.

This report was written to follow up Staying Strong which the National Forum wrote in January 2011.

Staying Strong is a Guide to help self advocacy groups to keep going in the future.

Staying Strong talked about the important work that self advocacy groups do.

It said that it was important to plan for the future because there could be less money for self advocacy from the Government.
It said self advocacy groups will need to work in new ways to keep going.

It had some ideas and information for groups.

The “Staying Strong –but for how long?” report has been produced to find out how self advocacy groups are doing now and what they think they will be like in the future.

It asked groups in 9 regions questions.

It asked about their money.

It asked about staff and members.

It asked about the work they were doing and what they planned to do in the future.

This report shows that self advocacy groups are worried about their immediate future.

Groups say -

“All the good work that has been done could be lost.”
What’s happening with money at the moment?

This year (2011) most groups say they have had the same money as in the past.

A few groups have had to close down because their funding has been cut.

Most groups do not know what will happen to their money after April 2012.

In the past many advocacy groups got all of their money to work from Local Authorities.

When Valuing People was happening funding was used by Local Authorities for self advocacy groups.

It came from the Learning Disability Development Fund or LDDF.

Now, everyone is being told to “think local”.
Local authorities have already given out less money to voluntary organisations like self advocacy groups.

There will probably be more cut backs from April 2012.

Groups say they that when funding is looked at they are lumped in with support agencies.

They think this means they are going to get less money.

Self advocacy groups now have to compete with other groups for smaller amounts of money.

Sometimes for contracts that join up lots of pieces of work such as Advocacy, Advice and Information.

“Staying Strong –but for how long?” found that self advocacy groups think Commissioners do not always understand their work.

It has found that groups need to be good at explaining and selling their work.
Smaller groups are worried about competition from larger groups who know how to get funding using forms.

Smaller groups do not always have the time or the skills to do this.

To manage on less money a lot of groups now have less paid workers

Some groups have fewer paid workers, working less hours.

Groups face less funding at a time when their work is most needed.

Self Advocacy is needed to support people with learning disabilities to cope with all the government cuts that affect them.

Groups say -

“If we had funding, we could support people to be listened to.”
The work that groups do

Self advocacy groups are still working on the Valuing People Now priorities:

- Health Self Assessments work
- Peer mentoring housing work
- Person Centred Planning work with people with complex needs.

Groups still support the work of local Partnership Boards.

- Making information easier to understand
- Hate Crime and Mate Crime
- Keeping Safe
- Training students and professionals
- Consultations
- Research
- Quality Checking

The Government says that it wants people with learning disabilities to find jobs.

Self advocacy groups can be very good employers.

They can give people training and work experience.
Groups need support from Government to be able offer people work.

It is important to employ people in a way that means they can come off of benefits.

Short term work or voluntary work helps with training.

It is the way to help people with learning disabilities to move onto real jobs with pay.

Groups say -

“Pay us for the things that we can do, and we will get people off benefits and into meaningful employment that will help and support other people.”
The information sent in by the National Forum’s 9 regions.
How many self advocacy groups replied?

- We heard from more than 100 self advocacy groups.
- We know there are many others not included here.
- Groups’ sizes go from small, to over 100 members.

**South West Region**
9 groups answered the questions.
3 groups were not sure how many members.
5 groups had more than 100 members.
1 group had 500 members.

**North West Region**
21 groups answered the questions.
The groups had 1,288 members between them.

**North East Region**
19 groups answered the questions.
The groups had 500 members between them.

**London Region**
18 groups answered the questions.
West Midlands Region
6 groups answered the questions.
Each group had between 12 and 80 members.

South East Region
9 groups replied.

East Midlands Region
10 groups answered the questions.

Yorkshire Region
7 Groups answered the questions.
4 Groups have between 10 – 65 members.
3 Groups have between 100 – 200 members.

Eastern Region
Groups from 10 of the 11 Local Authority areas in the region answered the questions.
3 areas had up to 30 members.
3 areas had between 50 and 60 members.
2 areas had more than 100 members.
How many paid workers and volunteers do groups have?

- More groups are giving jobs to part time workers and using volunteers.
- A lot of groups are giving jobs to people with learning disabilities.

**South West Region**
There are 58 paid workers in South West groups.

**Full time workers**
3 People with Learning Disabilities.
2 People without Learning Disabilities.

**Part time workers**
31 People with Learning Disabilities.
28 People without Learning Disabilities.

**Volunteers**
72 people are volunteers.

**North West Region**
- With LDs: 33
- Without LDs: 23

- FT: 12
- PT: 44

**Volunteers**
49 people are volunteers.

**North East Region**
Of the 19 Groups most had between 1 and 3 paid workers.

**Paid workers**
3 Groups had over 20 paid staff.

**Volunteers**
200 people are volunteers.
**London Region**

**Workers with Learning Disabilities**
8 Groups had 0.
5 Groups had 1 or 2.
5 Groups had between 9 and 15 (all Part-time).

**Workers without Learning Disabilities**
8 Groups had 1 to 4 Full time.
13 Groups had 1 to 3 Part time

**Volunteers with Learning Disabilities**
6 projects had 1 to 4 volunteers.
4 projects had 7 to 15 volunteers.
4 projects had 0 volunteers.

**Volunteers without Learning Disabilities**
4 projects had 1 to 4 volunteers.
2 projects had 35 to 50 volunteers.
5 projects had no volunteers.

---

**West Midlands Region**

Only 1 group had a full time worker.
Most groups had 1 or 2 part time people without Learning Disabilities.
All groups employed people with Learning Disabilities mainly on a freelance basis.

**Volunteers**
2 groups had between 0-2 volunteers.
2 groups had between 10-12 volunteers.

---

**South East Region**

It varies from group to group.
Some are run totally by volunteers with one person managing the organisation.
People with learning disabilities help to run some groups with support, and help to train other groups across the county.
**East Midlands Region**
4 groups have between 2-5 part time workers without learning disabilities.

**Yorkshire Region**
1 group had no workers.
6 groups had between 1 and 12 workers.

**Full time workers**
2 Workers with Learning disabilities.
Between 1 and 5 workers without learning disabilities

**Part time workers**
Between 5 and 10 workers with learning disabilities.
Between 1 and 5 workers without learning disabilities

**Volunteers**
2 groups had 0.
4 groups had between 3 -17.
1 group had 58 people with learning disabilities.

**Eastern Region**
31 paid workers 9 say they are learning disabled.

**Full time**
14 workers.

**Part time**
17 workers.
10 people with learning disabilities paid on a consultancy basis.

**Volunteers**
8 volunteers without learning disabilities.
57 volunteers with learning disabilities.
Where does self advocacy group money come from?

- Local Authorities and Councils are the main funding for self advocacy groups.
- There are other ways to get money.
- Groups earn some of their income from their work.

**South West Region**
- Adult Social Care.
- NHS.
- The County Council and Local Authority.
- The Lottery.

**North West Region**
- Charitable Trusts.
- Giving training to other groups and organisations.
- Health Authorities.
- Local Council.

**North East Region**
- Giving training to other groups and organisations.
- Local Councils (including different departments).
- NHS Commissions.

**London Region**
- Grants.
- Local Authorities.
- Trusts and London Trusts.
- The Lottery.
- 2 projects lost Local Authority funding had nothing.
West Midlands Region
- Local Councils.

South East Region
- Adult Social Care.
- Big Lottery.
- Learning Disability Development Fund (in the past).
- NHS.

East Midlands Region
- Lloyds TSB.
- Local Councils.
- Lottery.
- Funding to support people at Partnership Boards or in service based “Advocacy” groups.

Yorkshire Region
- Big Lottery.
- County and Borough Councils.
- Joint Commissioning.
- NHS Primary Care Trusts.
- 2 were Self-funding.
- Training to other groups and organisations.

Eastern Region
- Big Lottery.
- Local Authorities.
- NHS.
How much money will groups get this year 2011?

• Most groups are getting about the same money for 2011.
• Some groups are getting less money which will make a difference to the way that they work.

South West Region
• Most have the same.
• Some have less money.
• New groups with new funding (Gloucestershire and Swindon).

North West Region
• 4 groups are getting about 5 or 10% less from Council.
• 13 groups are getting about the same money.
• 4 groups are getting up to 5% more.
• 1 group had an extra £15,000 in council money and had won a charitable grant.

North East Region
• Most are getting less money this year. “They want more work for less money.”
• The funding is often given for short times. This is to give funders and commissioners time to make decisions about their future plans for core funding and contracts at a time of cuts. It is impossible to plan work.
London Region
• 10 projects have less funding than last year from a 10% cut to £70k less.
• 8 projects have about the same money.

West Midlands Region
• One group is losing all its funding.
• One has lost £25,000.
• One has had a 5% cut in its funding.

South East Region
• Most groups are getting less funding.

East Midlands Region
• Some groups have money for this year.
• Others are finding out now whether their funding will continue.

Yorkshire Region
• Some are getting the same money others less. A lot less money as “the grant pot has stopped”.
• Funding will be cut when a new Centre for Independent Living opens later this year.

Eastern Region
• 6 groups are getting less money than before between 2% and 65% cuts.
• 2 groups are getting the same.
• 3 groups don’t know what they will get.
What money will groups get after 2011?

- Most groups do not know what will happen.
- Local Authorities are making lots of cuts over the next 2 to 3 years and groups think this will include their money.

**South West Region**
- No one knows what happens after March 2012.
- Most think they will need to tender and be self funded.

**North West Region**
- No one knows what happens after March 2012.

**North East Region**
- No one knows what happens after March 2012.

**London Region**
- Only 1 project expects the same funding next year.
- 2 projects knew where some of their funding would be coming from.
- Most are applying for funding now.
- 25% of the groups that replied were expecting less Local Authority funding next year.
West Midlands Region
• 5 groups don’t know about funding after March 2012.
• 1 group has some funding agreed but not all.

South East Region
• Group is not sure about future funding and whether it will be able to carry on.

East Midlands Region
• An uncertain future!

Yorkshire Region
• 1 group thinks it will be ok until 2013.
• The rest don’t know.

Eastern Region
• 1 Group said it would get 3% less money.
• 1 Group said it would get the same as 2011.
• 7 Groups don’t know what their funding will be.
How are groups managing with less money?

• Not doing some pieces of work anymore.
• Making cuts in staff.
• Working with other groups.

South West Region
• Less staff and hours.
• Linking with other organisations.
• Developing new areas of work.

North West Region
• The majority are making the direct support of self advocates and their training a priority.
• One group have focussed on developing policies and getting a quality mark (to support future bids).
• Efficiency savings in office costs, use of technology, partnership working.
• 2 groups being asked by local council to form a user led organisation.

London Region
• Working less hours.
• Using volunteers more.
• No advocacy service.
• Less money on training, events, volunteer expenses.
West Midlands Region
- Reduced staff hours.
- Sharing office space; moved to cheaper offices.
- More fundraising.
- Watching every penny!

South East Region
- Using free venues, bring own lunch, share transport, no taxis.
- Cutting back working hours.
- Letting employees go.
- Projects have finished.
- Looking at new ways of working, supporting, projects to become social firms = self sustaining businesses.

East Midlands Region
- Reduced office hours.
- Closed local groups.

Yorkshire Region
- Smaller and fewer projects.
- No money to employ anyone with learning disabilities.
- Moved buildings.
- Workers part time or on a big pay cut.

Eastern Region
- Less hours for workers, less services provided.
- Less time to work on projects and campaigns.
- Organisation restructured, more volunteers recruited.
What sort of work are groups doing?

- Self advocacy work.
- Peer advocacy and friendship groups.
- Working on Valuing People Now and Partnership Board work.
- Keeping safe, Quality checking and training.
- Making information easier to read.

South West Region
- VPN Priorities Health, Housing, Jobs.
- Safeguarding, Hate Crime, Personal Safety.
- Quality Checking, Research, Training.
- Self Advocacy, Peer Advocacy.
- Friendship Clubs.
- Easy Read Information.
- People with high support needs.
- Offer placements to Social Work students.

West Midlands Region
- Running self advocacy groups.
- Keeping safe.
- Jobs.
- Health checker project.
- Partnership Board members support.
- Personalisation.
- Training on awareness raising.
South East Region
- Sharing Advocacy Sparks project work and follow up research with local groups.
- Training Health professionals.
- Healthy Walking scheme.

East Midlands Region
- 1 to 1 advocacy
- Support for groups of people within services - residential homes.
- Supporting people onto Partnership Boards.
- Friendship groups.

Yorkshire Region
- Self Advocacy work.
- Support to Partnership Boards.
- Mate Crime, Hate Crime and streetwise training.
- Making easy read guides.
- Training in colleges.

Eastern Region
- Supporting self advocacy groups.
- Learning Disability Partnership Board support work.
- Advocacy work 1 to1.
- Generic and Peer Advocacy.
- Training and raising awareness for people with learning disabilities.
New ways of working

- Getting more business-like.
- Working with other organisations.
- More time on fundraising.

**South West Region**
- Trying to network with local groups.
- Working and campaigning with other disability groups.
- More links with young people and their services
- More enquiries from local people as a result of service cuts.

**London Region**
- More publicity about our work – before, we just got on with it.
- More partnership working.
- Being more business like.
- Members have more say about the organisation.

**West Midlands Region**
- More time spent on fundraising.
- Working with other agencies.
- Focus on younger people.
South East Region
• Employing people specially to look at funding.
• Looking at specialising in just one area of work such as Transition, BME Communities, Prisons.
• More partnership working and community work.

Yorkshire Region
• Being clearer with funders about how we will work to support individuals.
• Now charging for the training we deliver.
• Connected to local “umbrella” user led organisation.
• Have updated our website.
• We constantly review the way we work and communicate with other organisations.

Eastern Region
• Advocacy Surgeries and Presentations.
• Getting more business-like charging for the extra things we do.
• Making funding bids together.
• Using texting and Skype more to communicate.
The role of Partnership Boards

- No one really knows what the ‘localism agenda’ means.
- Some Partnership Boards have been changed.

**South West Region**
- Not working on the “localism” agenda.
- Unclear about its status or work focus.
- “Better partnership working and positive outcomes.”

**North West Region**
- Some PBs are becoming more accessible, with more self advocates and family members, plus input from local Councillors re local issues.
- Nothing formally about “localism”.

**North East Region**
- They are really just “talking shops” a waste of people’s time. It is far better for groups to build relationships with bosses who commission services and councillors and chief officers who have the power to decide how to spend their budgets.
London Region
• Joining 3 boroughs’ Partnership Boards together.
• Accessible minutes, payments for representatives, no more lunches.
• Elected MPs (paid) to represent people with learning disabilities and run a citizen forum in the borough.

West Midlands Region
• Most focusing on Valuing People Now.
• Local and national policy.

South East Region
• One area no longer has a PB.
• Trying to work with local Health Watch.

Yorkshire Region
• 4 Partnership Boards have become 1 County Board.
• No real links to localism agenda.
• 1 mention of local Health Watch.
Eastern Region

- Most people don’t know what the Government’s “localism agenda” means.
- 1 Partnership Board is learning about how they will fit in to the new Health and Wellbeing Board.
- Including County Councillors on the Partnership Board is important.
- Valuing People Implementation Groups have been replaced by Locality Networks.
Using the Staying Strong Guide

- Most groups were pleased about the Staying Strong guide.
- Groups found it useful for different ideas and making plans for the future.

South West Region
All 9 Groups that responded have used the Guide
It has been useful for:
- Good at reminding us to look at all the options.
- Getting our paperwork in order.
- Campaigning.
- Looking for new ways to get funding.
- Linking up with other local voluntary organisations.
- Advertising our training and other services.

North West Region
- Most groups said –it’s a positive resource, which reinforces the work they are doing.
- Good info re possible sources of funding and efficiency.

North East Region
- It is accessible and well produced –“it told groups nothing new” most of the groups involved in the Regional Forum have been in business for decades and have loads of experience.
- Some groups will look at their long term funding and business strategy also ways to “play the system”.
London Region
• 6 out of 18 groups had used it.
• How to get hold of it?
• Good discussion about “being strong”.
• Helping us re planning for the future.

West Midlands Region
• Apply for and get grants.
• Making contacts.
• Focus their discussions.
• Tell others about their achievements.

South East Region
• Looking at joint funding bids.
• Good to meet with other groups to share information.

East Midlands Region
• Have sent the information about the Guide to groups that had not seen it.

Yorkshire Region
• To stay positive and give us new ideas.
• Work with local commissioners to identify our role.
• To make funding bids.
• Taking on students for social work and police.
Eastern Region

• Learning from it that we could do a lot more as an organisation.
• About the work we need to do to get the funding and plan for the future.
Other things we would like help with and want to say

- It is important that groups can still meet up and share information.
- Groups are still finding pieces of work that they want to do.
- Groups are worried about people losing support and being more at risk as a result of the cuts.

South West Region
- More information re working with people with complex needs.
- More ideas about funding for small, local groups
- More info about training for Management Committee members.
- More info /help with working closely with family carer groups especially re relationships/sexuality issues.

South East Region
- We can see already what’s happening now that there is no more LDDF money being spent.
- “Small organizations should make more use of local funding providers.”
- As they don’t have enough money in the bank. Keeping the Regional Forum going is really important.
North West Region

- More resources needed to make connections with other advocacy groups at all levels (locally, regionally, and nationally).
- Some groups said they needed longer term funding so they could plan ahead.
- Most groups are worried about benefit cuts plus Local Authority service cuts these affect their members.
- Hate Crime and abuse (Panorama programme).
- Groups believe that they could help services monitor quality better.

North East Region

- Loss (and reduction) of representational advocacy services at a time when people really need them.
- With getting less support; less help to use Personal Budgets.
- Transfer resources away from Partnership Boards to independently facilitated PCP and support planning. So that people can really use Personal Budgets.
- Pay for service-checking by people with learning disabilities (as experts by experience) and buddy schemes for people in residential care.
- Support peer advocacy.
London Region

• More information about how other (boroughs) groups are doing it visiting other groups to share ideas.
• Different ways of recruiting volunteers and increasing commitment to the group.

West Midlands Region

• Good to keep meeting up and sharing information.
• 2 groups specifically wanted the Regional Forum to continue.
• Our members will be more at risk if they don’t have the group to support them.

East Midlands Region

• The focus is on 1 to 1 advocacy or professionals running small advocacy groups within residential homes and day services.
• They seem to do self advocacy as part of an activity rather than as work like self advocacy groups do.
• There are hardly any self advocacy groups left. It seems to have become something that is funded by the Council, and they are not choosing self advocacy groups to run their advocacy services.
Yorkshire Region

- Independent funding not reliant on the Local Authorities.
- Help with making bids doing tenders (which need to be easier to read).
- Small, local groups feel at a big disadvantage to “big” organisations that come in and take over.
- Groups need to be more willing to work together; there is plenty of work for everyone if the funding was more available.
- We all need to be singing from the same song sheet.

Eastern Region

- The Eastern Region Forum to carry on
- More information given (accessibly) all round
- The money to do all the work that needs to happen.
- Self advocacy is “in crisis”.
What’s next for self advocacy groups?

- “We’re meant to be all about people first, but we’re not about the people, we’re about the money.”

- We want to support each other to get the money to do the work that WE want to be doing.

- We are committed to “Staying Strong – but for how long?”
Glossary of terms used
These pages tell you what some of the initials, letters and words in the report mean.

Numbers of paid workers/volunteers
FT = Full Time workers
PT = Part Time workers
w/LDs = with learning disabilities
without LDs = without learning disabilities
pwldls = people with learning disabilities

Funding information
NHS = National Health Service
LDDF = Learning Disability Development Fund
PCT = Primary Care Trust
“topped up” = extra money given

Different Groups
SSD = Social Services Department
LA = Local Authority
PBs = Partnership Boards
SA groups = Self Advocacy groups
Differences in how groups are organised
Self sustaining businesses = earning enough money to keep their organisations going.

The Work We do
VPN = Valuing People Now
PCP = Person Centred Planning

New Ways of Working
“umbrella” organisation = a bigger organisation that other local groups are linked in to.

Role of Partnership Boards
The Government’s “Localism” Agenda = Changing the focus from what central Government says should happen, to having decisions taken at a local level.

Using the “Staying Strong” Guide
Local Commissioners = the people that decide which organisations get funded to provide services.
Thank you to all 9 Regional Forums for their contributions to this report.

Thank you to John Hersov and Sarah Parker from Centrevents for the organisation and layout of the report.