

# Having a voice: advocacy for people with learning disabilities

## Easy read

This is a report about some work we did to find out what was happening with advocacy services for people with learning disabilities. We did the work because we wanted to find out:



- ☺ If the money problems in the country mean advocacy services are getting less money, and what this means for them.
- ☺ How advocacy services are working to get better health and health services for people.

## We looked at what other reports said about advocacy



- ☺ Valuing People (2001) and Valuing People Now (2009) said advocacy was important. This helped make advocacy stronger.



- ☺ There is a report called **Advocacy in a Cold Climate (2011)**. It says:
  - ☹ Many people with learning disabilities do not get the advocacy they need
  - ☹ Independent advocacy is very important



- ☺ There is a report called **Staying Strong: Taking advocacy into the future (2011)**. The report was written by the National Forum. It says::
  - ☹ How self advocacy groups can keep making a difference in peoples' lives with less money
  - ☹ Advocacy groups need to show people who buy services how they change peoples' lives, using numbers and stories
  - ☹ Groups need to find other ways of making money, like writing. Easy Read papers.

## We decided to ask advocacy groups and people who buy services (commissioners) some questions



- 😊 We asked advocacy groups and commissioners about the best questions to ask.
- 😊 We sent questions to commissioners of advocacy services (78 commissioners answered our questions))
- 😊 We sent questions to advocacy and self advocacy organisations (88 advocacy organisations answered our questions))
- 😊 We visited three advocacy organisations to find out more about what they were doing.

## What we asked about



- 😊 We asked advocacy organisations and commissioners about:
  - 😊 Types of advocacy work
  - 😊 The money they got
  - 😊 Why they thought advocacy was important
  - 😊 What made it difficult to provide advocacy services
  - 😊 Were some groups of people not getting advocacy
  - 😊 How to tell people about advocacy work
  - 😊 Good things that were happening.

## Who sent a reply?



- 😊 88 advocacy organisations replied
- 😊 Half did work just with people with learning disabilities
- 😊 Half did work with lots of people, including people with learning disabilities
- 😊 78 commissioners replied
- 😊 All from local authorities

## What different types of advocacy mean



- 😊 Self-advocacy is when a person with learning disabilities speaks up for themselves
- 😊 Citizen advocacy is when someone else helps someone with learning disabilities speak up for themselves
- 😊 Peer advocacy is when someone else with learning disabilities helps someone with learning disabilities speak up for themselves
- 😊 Professional or case based advocacy is provided by someone who is paid to work as an advocate

## What type of advocacy is provided?



- ☺ General advocacy groups are more likely to provide professional or case based advocacy for people with learning disabilities
- ☺ Advocacy groups working just with people with learning disabilities are more likely to provide self advocacy and group advocacy

## Why is advocacy important?



Advocacy organisations said:

- ☺ Giving people a voice, having a say
- ☺ Equality and rights
- ☺ Helping people be in control
- ☺ Choice and control
- ☺ Using and challenging services



Commissioners said:

- 😊 To give people with learning disabilities a voice
- 😊 To help people be part of making decisions
- 😊 To help people live good lives

## Money for advocacy



- 😊 The money for advocacy is still going up every year
- 😊 But money for advocacy organisations working just with people with learning disabilities is going down
- 😊 More money is going to bigger general advocacy organisations run by professionals

Some other things advocacy organisations said:

- 😊 Most advocacy organisations thought it will be more difficult to get money next year
- 😊 Organisations said less money would mean:
  - 😞 They couldn't do such a good job
  - 😞 They would reach less people.
  - 😞 Fewer staff or not so many hours work
  - 😞 More time spent trying to get money



# What makes it difficult to give good advocacy support



Advocacy organisations said:

- ☺ Lack of money
- ☺ Attitudes towards advocacy or people with learning disabilities
- ☺ Lack of understanding or knowledge about advocacy
- ☺ Lack of staff and lack of resources
- ☺ Being told only to work with people who were also using social services.



Commissioners said:

- ☺ Lack of money is the main problem to providing advocacy services
- ☺ People with learning disabilities who live independently may not know about advocacy services.

## Groups of people who are not getting advocacy



- 😊 Parents with learning disabilities
- 😊 Young people who are moving to adult services
- 😊 Lack of money means less advocacy
- 😊 People with mild or moderate learning disabilities
- 😊 People with complex needs
- 😊 People who have been in trouble with the police or in prison.
- 😊 People who are not using social services

## Advocacy for better health



- 😊 Most advocacy organisations said they were working to improve health services for people with learning disabilities. They did things like:
  - 😊 Involving people with learning disabilities in changes to services or mystery shopping
  - 😊 Events like conferences or Big Health Days
  - 😊 Training staff
  - 😊 Working with people with learning disabilities about better health
  - 😊 other events, conferences or workshops
  - 😊 Healthy living activities



# Summary



- 😊 Advocacy organisations and commissioners agree that advocacy is good
- 😊 They agree that less money will make it more difficult to give good advocacy support

- 😊 But:
  - 😞 Independent advocacy organisations led by and run for people with learning disabilities are getting less money
  - 😞 Big general professional advocacy organisations are getting the same or more money



- 😊 Danger that there will be less independent advocacy by and for people with learning disabilities
- 😊 Danger that commissioners may think advocacy is another professional 'service' to be delivered
- 😊 Danger that advocacy organisations will only be able to support those people with learning disabilities assessed as 'eligible' for services