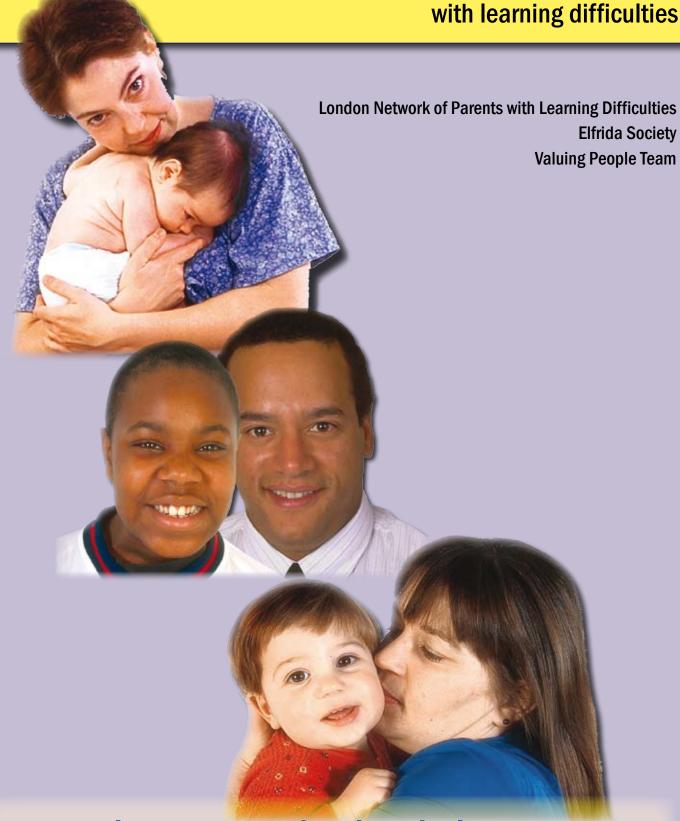


helping partnership boards meet the needs of people



supporting us to make the choices we want

## To get a copy of this Toolkit contact:

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# The Parenting Toolkit

#### **Foreword**

We are really pleased that the London Network of Parents with Learning Difficulties has written this toolkit for Partnership Boards in London.

Since Valuing People was written in 2001, we have been working towards people with learning disabilities leading ordinary lives and of course, this includes being parents.

We know that it is not easy for people to be parents with so much prejudice working against them and services not set up to give them high quality support. However, it is simply not acceptable for this situation to continue. Valuing People Now published in 2009, makes it very clear that the Government expects things to change. Services need to review the way they work, so that parents and their children receive the support they are entitled to.

Partnership Boards will need to make sure that all of their services, including mainstream services are supporting parents properly and they will need to regularly check that this is the case.

This toolkit will help Partnership Boards to know what the local situation is and to work out what needs to happen to make things better.

We would like to thank the London Network for all the hard work that went into writing the toolkit and we look forward to continuing to work with them.

#### **Debbie Robinson and Linda Jordan**

Valuing People Leads for London

## **Foreword**

It is Government policy that 'people with learning disabilities should have the choice to have relationships, become parents and continue to be parents' - and that they should be supported to do so.

That is what 'Valuing People Now' (the Government's new three year strategy for people with learning disabilities in England) says.

The Government has also produced Good Practice Guidance for professionals working with parents with learning disabilities on how they should support them.

The right support at the right time should mean that far fewer parents with learning disabilities have their children taken away from them. The right support should enable parents and their children to stay together safely as a family. This is their right under the Human Rights Act of 1998.

Sadly, there is still a long way to go before the right support is routinely available to parents with learning disabilities and their children. Last year's report from the Parliamentary Committee on Human Rights, 'A life like any other?', made that very clear.

But some positive changes are now taking place.

There is a free national Network for professionals and other people involved with parents with learning disabilities, which provides advice and support on how to do things better (1). There is a free Parents Network, run by and for parents themselves, which aims to help parents hold on to their children and give support to each other (2). There is a National Taskforce on supporting parents with learning disabilities, which brings together parents and people from key agencies, including government and voluntary organisations, to exchange ideas on good practice and press for change.

Equally important, there are now a number of publications for parents with learning disabilities, written in an easy read, illustrated, format which they can understand. Many of these have been produced by CHANGE, the organisation which runs the Parents Network (2).

Now there is this Parenting Toolkit, put together by parents in London, on the basis of their own experiences of what is needed by families where a parent has a learning disability. The Toolkit aims to help members of local Partnership Boards find out more about what they should be doing to ensure parents with learning disabilities in their area get the help they need - and to which they are entitled.

Let's hope that this Toolkit drives the issue of support to parents with learning disabilities up the agenda for Partnership Boards in London - and perhaps elsewhere in the country too. It is time that the right of parents with learning disabilities and their children to live together as a family - with the support they need to do this successfully - became a reality; not just in policy, but in practice too.

- (1) www.right-support.org.uk
- (2) www.changepeople.co.uk

#### **Professor Linda Ward**

Chair, National Taskforce on Supporting Parents with Learning Disabilities

# The Parenting Toolkit

# Helping partnership boards meet the needs of people with learning difficulties



In this Toolkit we use **learning difficulty** rather than **learning disability**. This is because this is the term the people in the London Network of Parents with Learning Difficulties prefer.

When we say **learning difficulties** we are talking about everyone who has a learning disability or a learning difficulty.

## What is the Toolkit and who is it for?

- This toolkit is to help services meet our needs as parents with learning difficulties.
- It has been made by the London Network of Parents with Learning Difficulties. This is a network of parents and workers.
- The Network has been meeting for about 6 years. It brings together parents with learning difficulties and workers working with them.
- The group shares our own stories, ideas and examples of good and bad ways of working.

## **Our Values**

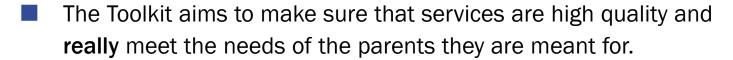
We believe that parents with learning difficulties:

- can be good parents
- deserve to be treated with respect
- deserve to be offered the support and services we need to be the best parents we can be
- should be able to be part of society



## What is the toolkit for?

- This Toolkit is for partnership boards
- The Toolkit helps partnership boards look at the support and services that are offered to parents with learning difficulties. It helps them to check how good they are.



## 'Valuing People' and the Toolkit

This Toolkit is based on the values and ideas about parents with learning difficulties that are in **Valuing People** (2001)



Valuing People says this;

"The number of people with learning disabilities who are forming relationships and having children has steadily increased over the last 20 years. Parents with learning disabilities are amongst the most socially and economically disadvantaged groups. They are more likely than other parents to make heavy demands on child welfare services and have their children looked after by the local authority.

"People with learning disabilities can be good parents and provide their children with a good start in life, but may require considerable help to do so. This requires children and adult social service teams to work closely together to develop a common approach. Social services departments have a duty to safeguard the welfare of children, and in some circumstances a parent with learning disabilities will not be able to meet their child's needs. However, we believe this should not be the result of agencies not arranging for appropriate and timely support."

Valuing People Now came out in 2009 and it says more about parents with learning disabilities. It says:



- People should have the choice to have relationships, become parents, continue to be parents and be supported to do so.
- Services need to support parents with learning disabilities.
  At the moment parents do not get the support they need and are therefore at risk of enforced separation.
- Adult and children's services need to work together effectively so that we have an integrated system to support people.
- People should receive good support from all mainstream family services, should have access to advocacy and the same level of information and advice as everyone else.
- Valuing People Now expects all partnership boards to make sure that parents with learning disabilities have accessible information and services and that individual budgets are used to support families.
- The Government has also written Good Practice Guidance on working with parents with learning disabilities (2007) for professionals.
- We have read Valuing People and Valuing People Now and thought about what the government is saying about parents with learning difficulties.

## The Government says:

Parents with learning difficulties are often hard up, and isolated.

## Parents say:

- The benefits system is too confusing.
- We might need advice to get the right benefits.
- If our benefits are cut, we need time to get used to **less money**.



- There should be more groups and clubs for parents with learning difficulties.
- We need groups with crèches.
- Groups have to fit in with picking our children up from school.
- We need groups that are local, or that have a minibus.
- We need groups to help us to be confident and speak up for ourselves.

## The government says:

People with learning difficulties can be good parents. They might need more support than other parents.



## Parents say:

- We agree, but it's hard to get the right support.
- Some of us want **more help** and can't get it. Some of us **don't** want help but are put under pressure to take it.
- Some parents are scared to ask for help, in case services think that we can't cope.

- Some of us need support before the baby is born.
- It's good to get support at the start, not when things are breaking down.
- Support should be there long term if we need it, not just for a couple of weeks.
- It's hard to get practical help because it costs money.
- Housing is a big issue. A housing support worker can help us get what we need.



## The government says:

Lots of parents with learning difficulties have their children taken into care. This should not be because they aren't getting the right support from services.

## Parents say:

- Some families don't get the right support from the start.
- Some parents are told they will get the services they need, if their child is on the 'at risk' register. They should get the help anyway.
- Being assessed to see if we have enough parenting skills can be very stressful. Assessments may look at all the bad things and not the good things we can do well. They should help us to learn the parenting skills we need.
- Assessment workers should know about the needs of parents with learning difficulties.
- Some workers are **prejudiced** about us. They think that people with learning difficulties can't be good parents.

- We want to be given the chance to prove that we can be good parents.
- We want to be clear about what we have to prove, and not keep having to prove more and more.
- We want to be sure that what we say is listened to and not taken the wrong way.

## The government says:

Support for parents with learning difficulties is not good enough everywhere yet. Services for the child and services for the adults don't always work together to help the family.

## Parents say:

Communication isn't good between the services. It might help if they shared the same office.



- Services need to sit down together around a table with the family.
- We want to choose what support we get.
- It's hard when you always get a duty social worker and it is a different worker each time.
- Some adults teams won't give you a service unless you have an intelligence test. Services should not have their heads stuck in the past.
- Some parents would like practical help, to read letters, or support to go on holiday.

## The government says:

- The government will give workers more training to make sure parents with learning difficulties get the help they need.
- The government will include the needs of parents with learning difficulties in all their future plans to make parenting better.

## Parents say:

- How can we make sure that the government makes things happen?
- They need to understand the different kinds of support parents with learning difficulties need.
- They need to be active, not reactive.
- The training should help them **understand** how to communicate with people who have learning difficulties.
- Use plain words with no jargon. Writing should have big print.
- Information should be on tapes and CDs as well as leaflets.
- Remember not all of us can read and write.
- Make sure we have enough time.
- School staff need this training too.
- Don't talk over parents' heads at meetings. Include us properly!



- In every borough the Head of Social Services will be in charge of making sure that services work together to support families.
- Partnership Boards will make sure that the right services are there for parents to use.



## Parents say:

We need to know more about Partnership Boards.



- Meetings should include us.
- They must remember that some people with learning difficulties are parents.
- Social Services should have people with learning difficulties working for them.
- We want to get away from labels like 'mentally handicapped'
   -we don't want to have to use our labels to get what we need.
- The Heads of Social Services should set up conferences to meet people with learning difficulties and listen to us more.
- This Toolkit is also based on the values and beliefs about parents with learning difficulties that are in the report Finding the Right Support (Norah Fry Research Centre, 2006).



## **Using the Toolkit**

- We want to make sure that this Toolkit is easy to use for as many people as possible.
- It has a picture of a **mountain** for each area so that people can say how well services are doing.
- Parents with learning difficulties have helped to make this Toolkit to make sure that it is accessible.
- Parents have been **paid** for the time they have spent on this toolkit, the same as workers.

## What's in the toolkit?

Each part is a different colour so that it is easy to find in the toolklit.

About us P 16

People and parents with learning difficulties in your borough



Thinking about a baby P 18

Choices, information, counselling and support



Pregnancy and birth P 22

Midwives, information, classes, father's involvement, birth plans and the birth



Health P 24

Health visitors, health information, breast feeding, our own health, doctors and contraception



Housing P 26

Getting on housing lists, supported housing, support in our own home, rent, housing benefits and repairs



## Money and benefits

P 30

Easy information on money, support to apply for benefits, independent advice, the right to appeal and help to get work



## **Getting out to groups**

P 32

Social groups, support for us to socialise, crèches, clubs for children



## Getting help and being assessed P 34

Getting help without stigma, saying no to services, training for workers, recognising our strengths as parents in assessments



## **Communication**

P 36

Communication plans, communication training, easy information, keeping in touch with workers, keeping workers accountable



## Listening to us

P 38

Advocacy, partnership boards and complaints.



## Mountain

P 40

Use the mountain to show how well services are doing



## About us

#### Our needs and wants



## We need:

- to know that all our needs are being met with different organisations working together
- the chance to have our say in meetings, groups and committees
- to know that organisations believe that people with learning difficulties can be good parents
- to know that organisations will respect us and listen to our views how we think children should be brought up

## **Questions**

- 1 How many people are there on the learning difficulties register?
- 2 How many on the register are parents?
- 3 How do you know that their needs are being met? (Person centred planning, regular meetings, life plans, other ways)

## About us

## Our needs and wants



- 4 How do you make sure that all the services for parents with learning difficulties work together?
  - (Partnership board meetings, subgroups, other ways)
- 5 What special groups or meetings are there to **bring together** the needs of people with learning difficulties?
- 6 How do you show you believe that people with learning difficulties can be good parents?
- 7 How do you make sure:
  - we are always respected
  - we are always offered choices about our lives
  - you accept that we know our children best?
- 8 How do you show your commitment to the idea that there are different ways of bringing up children?

## Choices about being a parent



## What people said

"I had pains. I didn't know I was in labour. I didn't know what was happening. I didn't know what to expect when I had a baby"

"It was useful to have leaflets from the clinic"

"Sometimes I don't feel listened to. I had the injection to stop me getting pregnant, but I didn't like the side effects"

"It would be good to involve men more, to have more information aimed at men, not just women. For example - contraceptives, planning a baby etc"

"It was good to have a choice. I could go to a mother and baby unit or a foster placement. I chose a foster placement and stayed there when I was pregnant and until my baby was 13 months old. It was good being in a family and I could learn useful things"

"It's good to get the support package sorted out before the baby comes along".



## Choices about being a parent



#### We need:

- support to have the same choices as everyone else about pregnancy, having a baby, abortion or adoption
- to have the option of counselling and easy information to help our choices
- advice and easy information about contraception and the chance to get contraceptives (birth control) when we need them
- support and advice about adoption without pressure to have a child adopted
- long term support if we decide to have a baby.



Choices about being a parent



## **Questions**

- 1 If someone is pregnant, how do you make sure we are supported to make **our own choices** about:
  - having a baby
  - adoption
  - abortion?

What Counselling services are there for us?

2 Is support available from:

An advocate	
A counsellor	
A support worker	
A community nurse	
Family planning	
A GP (Doctor)	
A social worker (Learning Disability Team)	
A social worker (Child and Family Team)	

- 3 What easy information is there about these choices?
- 4 How do you encourage **men** to use services which provide information on contraceptives (birth control) and parenting?

## Choices about being a parent



- 5 How do you make sure we can make our own choices about contraceptives (birth control)?
- 6 What easy information do you have on contraceptives (birth control)?
- 7 How can we **get** contraceptives (birth control)?
- If we are pregnant and want to keep the baby, what **long term** support can we get (**not** just for a few weeks)?
- 9 How do you make sure that a support package is set up **before** a baby is born?
- 10 Can we get support from the beginning of the pregnancy (not just when things break down)?
- 11 What services do you have to help if we are thinking of adoption (counselling, information etc)?
- 12 How do you make sure that a decision to keep, or have a child adopted is ours and we are not put under pressure?

# Pregnancy and birth

## **Getting ready for the baby**



#### We need:

- Support before the baby is born
- Regular checkups in pregnancy and extra help to understand what is going on
- The same midwife through the whole pregnancy
- Antenatal classes that we can understand
- Information about pregnancy which is easy to understand
- Support to write our own birth plan
- Easy information and advice on painkillers, home birth and breastfeeding

## **Questions**

What support can we get before the baby is born?
What support is there to learn practical skills?
How many people get this support?

# Pregnancy and birth

## **Getting ready for the baby**



- 2 How often can we get midwife checkups through pregnancy?
  What special support is there at checkups? (Extra time, easy information, trained staff)
- 3 How do you make sure we have the **same midwife** through pregnancy?
- 4 What **antenatal classes** do you offer, and do you offer **easy information** on pregnancy and birth?
- 5 How do you include fathers in your care and support?
- 6 What help do you offer us to write a birth plan?
- 7 What choices do you offer about home birth and pain killers?
- 8 What easy information do you offer about these?
- 9 What choice do you offer us as **new parents**? (Support worker, adult placement scheme, parent and baby units)

## Health

## Looking after our children and ourselves



#### We need:

- Easy information and advice about our children's health diet, development, first aid, vaccination and safety
- Access to trained staff, including health visitors, who understand our needs and explain things without jargon
- The chance to see the same health professionals each time
- Support and extra time at health checkups to understand what is going on and to ask the things we want
- Advice and support about our health including contraception

## **Questions**

- 1 What easy information do you offer about:
  - breastfeeding
  - changing feeding from milk to solid food
  - healthy eating
  - how our children develop and learn
  - first aid for our children
  - injections the benefits and the dangers
  - keeping children safe

## Health

## Looking after our children and ourselves



- What training do staff have to explain things to us in ways we understand without jargon?
- 3 How can we get a **health visitor** if we need one?
- 4 What **special support** is there at health checkups? (Extra time, easy information and trained staff)
- 5 How can you make sure we can we see the **same** health visitor every time?
- 6 How much **training** do health visitors get to work with people with learning difficulties?
- 7 What can our doctor offer to support for our health? (Longer appointments, training to work with us, easy information, extra support)
- 8 What support and advice to you offer on **contraception** once our child is born?



## Finding a place to live and staying independent



## What people said

"It's taking a long time to find out about housing and I don't know what is happening ...."

"I have a social worker to help me find somewhere to live and to get help with things like my money as I don't know how to pay the bills and stuff"

"Having more children meant our two bedroom flat was far too small for the number of people. It could be difficult phoning up to get a bigger home. You were told that you would have to transfer and exchange with another family if you wanted to move. There didn't seem to be any other options"

"I found it useful to have choices of the type of accommodation I had, such as the area I wanted to live in and what floor I wanted to live on if I were offered a flat".



## Finding a place to live and staying independent



#### We need:

- Supported housing to help us be independent
- The chance of moving into, and be supported in our own home
- Support to find a home that is right for us and our children
- Easy to understand information about housing and benefits with support with filling out forms and housing interviews
- Independent advice if we cannot get the help we need
- Support with shopping, money and cleaning to stay living independently



## Finding a place to live and staying independent



## **Questions**

- 1 How many people with learning difficulties are there on the Council housing waiting list?
- 2 How many of these have **children**?
- 3 How many parents with learning difficulties live in their **own** home?
- 4 How many are **temporary** and how many **permanent**?
- 5 How many **supported housing places** are there for people with learning difficulties?
- 6 How many supported housing places do you have that accommodate parents and their children?
- 7 How many support workers are there all together?
- 8 What information and support is there for our housing choices?

## Finding a place to live and staying independent



- 9 In supported housing, what support do you offer if a resident gets **pregnant**?
- 10 What support do you give parents living in their own home? (Help with shopping, money, cleaning etc)
- 11 When we move, How do you make sure our support moves too?
- 12 What **support** is there for us to apply for more suitable housing?
- 13 What easy information do you offer about:
  - getting on the housing list
  - help with rent and mortgages
  - council tax benefits
  - grants and housing repairs
- 14 How can we talk to someone about all these things together so we don't have to talk to separate people.
- 15 How much support to you offer people at housing interviews?

  (More time at interviews, staff trained to meet our needs, help with forms or a support/advocacy person to help us)

## Money and benefits

## Managing money and work



#### We need:

- A benefits check and easy information which tell us about all the benefits we are entitled to.
- Up to date information about benefits to do with children and parents (Maternity Grant, Child benefit, Child tax Credits etc)
- Help to fill in benefits forms and someone to go with us to benefits interviews
- Independent advice if we can't get the benefits we think we are entitled to
- Help without pressure if we want to find work when we become parents

## **Questions**

- 1 How do you set up a benefits check for us?
- What easy information about benefits do you offer?

## Money and benefits

## Managing money and work



- 3 What help is there in filling in benefits forms?
- 4 What extra support is there for us at meetings about our money? (Staff trained to know about our needs, extra time, a support worker to go with us)
- 5 What support do you have for us to talk to someone about:
  - Maternity Grant
  - Income Support and Job Seekers Allowance
  - Child benefit
  - Child Trust Fund
  - Housing Benefit and Council Tax Benefit
  - Child Tax Credits and Working Tax Credits
  - Incapacity Benefit
  - Disability Living Allowance
  - Carers allowance
  - Attendance Allowance
  - Other things like Freedom Passes and Milk Tokens Is there someone who can help us with all these together?
- 6 What **independent advice** do you offer if we **don't agree** with a decision about our money or benefits?
- 7 What extra support do you offer to help parents to find work?

# **Groups and getting out**

Meeting other people for us and our children



#### We need:

- A choice of clubs and groups for us to go to with crèches for our children
- Groups around the borough with transport to get to them
- Support to join the same groups as everyone else
- Support to help our children go to clubs and play schemes
- Help with other things like going out for the day and going on holiday

"It would be good to have a group where parents could talk socially to each other, not just to learn about parenting. This could be a support when things are not so good where other people may have had similar experiences. It would be good to know I am not the only one"

# **Groups and getting out**

## Meeting other people for us and our children



## **Questions**

- How many social clubs and groups are there that offer support and the chance of getting to know other people?
  What are the names of the clubs and groups?
  Is there a limit on places?
  How many places for people in all?
- 2 Are there crèches at the clubs and groups?
  Is there a limit to the number of crèche places? How many?
- 3 Are there clubs and groups meeting all over the borough?

  Do they have a minibus to get us there?
- 4 How do you **support** us to find and join **clubs and groups** for **parents**?
- 5 How do you support us to find out about clubs and play schemes for children?
- 6 Do you have a **list of services and charities** that support families?
- 7 Can we get help to do things like read letters or go on holiday?

# Getting help and being assessed



#### We need:

- Help on our terms not having to sit tests
- Help without our children having to be seen as 'at risk' first
- To be able to get help without people thinking we can't cope
- To be able to say **no** to services
- To be assessed by workers who have had **training** to understand our needs
- To be assessed for the **good things** we do and to be given time to show the things we **can** do

## **Questions**

- 1 How can we get help even if our children don't have a child protection plan?
- 2 Can we get services without having to sit an intelligence test?
- 3 Can we ask for help without services thinking we can't cope?

# Getting help and being assessed

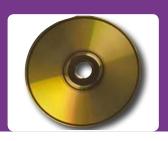


- 4 Do we have a **choice** between different services?
- 5 How can you help us see the **same** social worker or case worker every time?
- 6 What **training** do the workers assessing us have to know about **our** needs?
- 7 When we are assessed, do you ask about what we are **good** at?
- 8 How do you make sure any assessment of us is **fair**? (given that we have learning difficulties)
- 9 How do you explain to the children's workers that we may need more time?



## Communication

## Keeping in touch and getting clear information



#### We need:

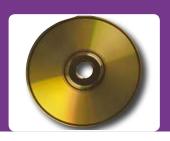
- A clear commitment for organisations to communicate with us in the ways that help us
- Easy information about all important choices like breastfeeding, health, money, and housing
- Staff training to support us and the chance for us to get extra time and support in health checks, meetings and consultations
- Easy ways for us to contact workers when we need to and make sure they do what is needed

## **Questions**

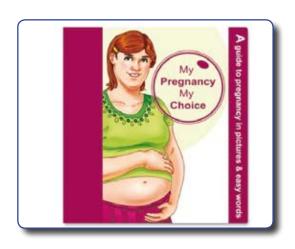
- 1 What sort of communications plan do you have?
- 2 What easy information do you offer:
  - Easy leaflets
  - Big writing
  - Pictures and symbols tapes, CDs, videos and DVDs. On what **subjects**? (Health, contraceptives/birth control, parenting, housing, money, support etc)

## Communication

## Keeping in touch and getting clear information



- 3 Do workers get training to:
  - use easy words
  - making meetings easier to understand
  - use tapes and CD's not just writing
  - use symbols and signing
  - give us extra time
  - help us have our say in meetings not talk over our heads.
- 4 What easy ways are there for us to get in touch with workers?
- 5 How do you make sure we can see someone when we need to?
- 6 How do you make sure workers do what they've been asked?
- 7 Do you send copies of all **letters and notes** about meetings to parents?



# Listening to us

## Having our say about services and support



#### We need:

- Advocacy services which are funded and which support us to have our say
- Meetings which support us to have our say which don't use jargon and which use easy information
- People with learning difficulties to be working in the organisations which support us
- The chance to complain easily when we are not happy without worrying about getting in trouble

## **Questions**

- What advocacy services do you offer for parents with learning difficulties, so we can have our say?
  Are places limited? How many places?
- How do Partnership Boards meetings include people with learning difficulties?How many people with learning difficulties go to meetings?

# Listening to us

## Having our say about services and support



- 3 Do your Partnership Boards have:
  - A rule not to use jargon
  - Easy minutes and agenda
  - Tapes and CDs of all the information
  - The chance for **people with learning difficulties** to have their say
  - The chance for **parents with learning difficulties** to have their say and ask questions?
- 4 What **other ways** do you get **feedback** from people with learning difficulties?
- 5 How easy is it to complain if we're not happy with services?
- 6 How many people with learning difficulties do social services have working for them?



## How to use the Mountain

## Checking how good services are



On the opposite page there is a picture of a **mountain**.

In the pack there are **10 people stickers**; in each of the colours used in this pack.

You can **photocopy the mountain 10 times** and write the name of each area (like **Housing** or **Listening to us**) on a copy.

Then you can stick the figure on the mountain to show how your partnership board is doing in each area.

If it is doing **well**, you can stick the figure **higher up** the mountain. If you think it is **not doing well**, then you can put the figure **lower down** the mountain.

This will help you **feedback** on how well your partnership board is doing.





Write the name of each area (Like health or communication) on the line above.

## **Notes**

## **Notes**

## Thank you to those who took part:

## Kath & 'Our Group' - Parents and Co., Elfrida Rathbone Camden

Corina

Diana

**Jackie** 

Jill

Kevin

Marie

Sandy

## **Susan & Islington Parents Group - Elfrida Society**

Abiola

**Alex** 

Celia

Dawn

George

Mahmuda

Miriam

Nabeel

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