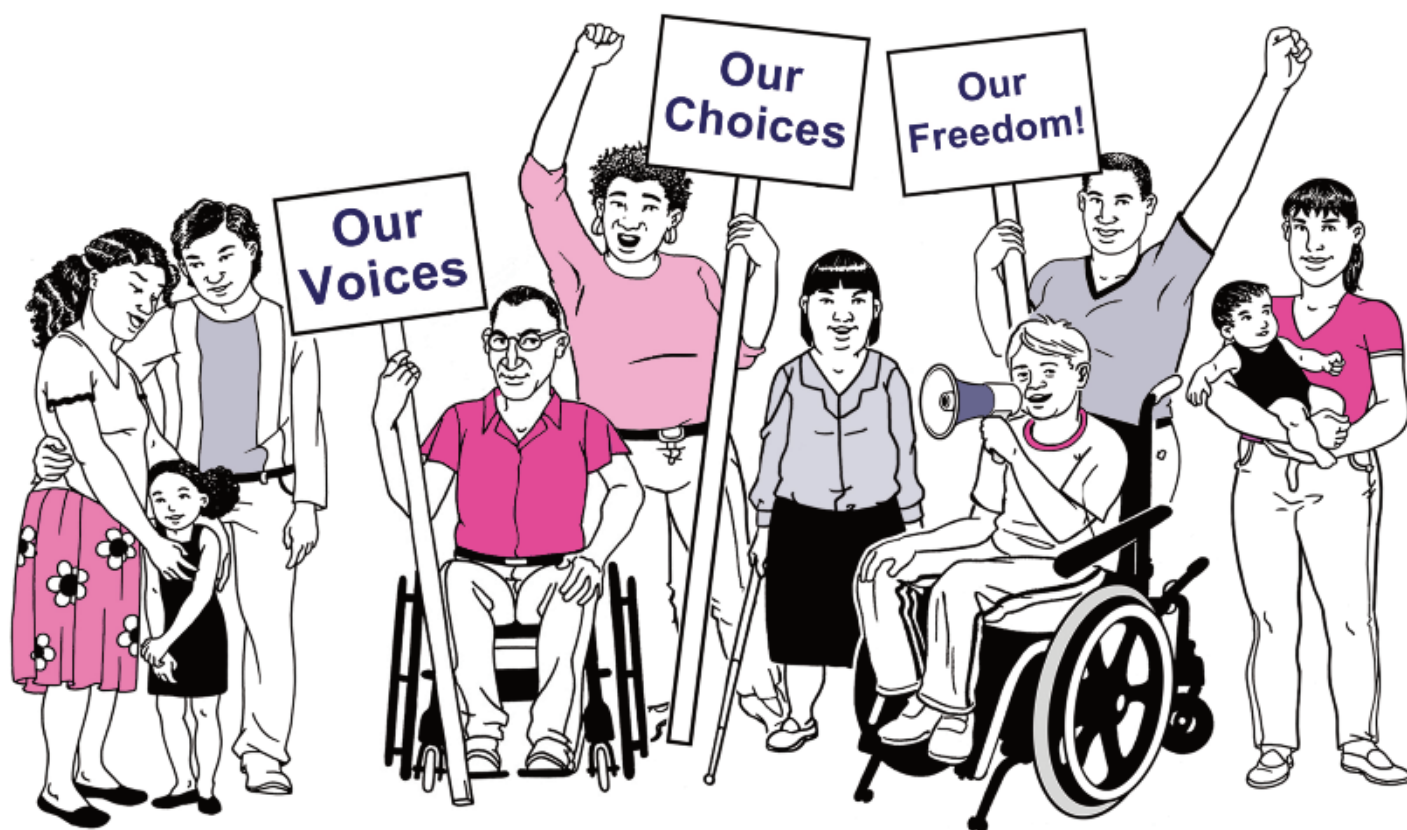
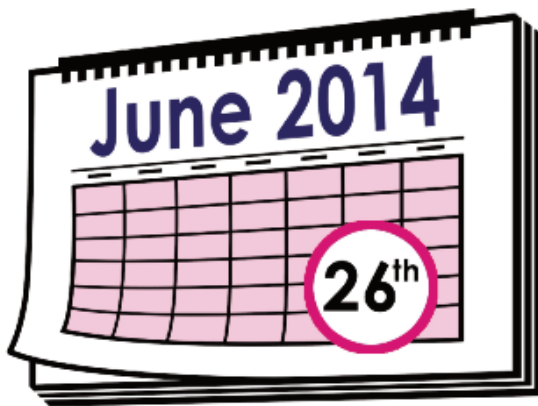


Our Voices, Our Choices, Our Freedom

National Event - 26 June 2014



Report



Our Voices, Our Choices, Our Freedom

A National Event was held in Leeds. 100 people with learning disabilities came together to close institutions.

The Event took place on Thursday 26 June 2014 in Leeds.

It was jointly organised by CHANGE and Lumos.

This Event was led **by** people with learning disabilities **for** people with learning disabilities. People came from across the country.



1. Opening Remarks by Co-Chairs

Gavin Harding - A person with learning disabilities, a member of the Winterbourne View Joint Improvement Board, Deputy Mayor of Selby.

Catherine Carter - A parent with learning disabilities, employed as a Trainer at CHANGE. Catherine delivers training on:

- Better communication
- Good support
- Parenting
- Sex and relationships.

2. Key Messages of the Day



- This Event is the **first** time people with learning disabilities have come together with a **collective voice** to campaign for the closure of institutions
- Free people with learning disabilities.
- Close institutions.



- We will decide on what we want the Government to do.



- We will vote on our Proposals.



- CHANGE will support us to take our voices, the voices of people with learning disabilities to the Government.



The Event was attended by **Zawar Patel**, the Learning Disability Lead within the Department of Health, on behalf of Norman Lamb, Minister of State for Care and Support.

3. Speak Out Session



We shared our experiences of living in institutions and care homes in the UK and in Europe.

“I was told last minute about the institution closing”.

“Children’s voices are very important. We want **you** to listen to **us**”.

“They made me have my hair cut – I used to hide under the bed when the Sisters came”.

“I didn’t know the institution was closing – nobody told me, I just moved”.

“When I go into meetings at this place I don’t understand what they’re saying half the time”.

“We are all different. We are all important”.

“I could not put pictures up on the wall of my family”.

“The staff on one shift are very good but on the other one there’s a different approach which is when the problems started”.

“I did not like that we had to share dormitories – there was one lady who used to bang on the door – this was quite upsetting and scary”.

“I could not talk about my worries with the staff”.

“I don’t get the chance to do things I like in here. The doors are locked”.

“What would make life better is having a flat of my own that’s close to the shops”.

“All of us have the right to continue studying, get a job and to be the same as everyone else. We are not second-class people, we are the same. We should have equal rights”.

“Living in my new home was something different, it was better and I felt safe. I felt I could do everything I wanted, I felt more independent”.

“Any young person with disabilities has the right and need to have contact with so-called 'ordinary' people. We are good for each other”.

“You can’t see what a place is like until you live there and then it’s too late”.

“The worst thing about where I am living now is being far away from my home and family.

“You can ask other people about our difficulties but we can say best what we need”.



4. Presentations

Daniel Doherty

I am a person with learning disabilities. I am an expert by experience.

I lived with a foster family and then moved to an institution without being told. I was treated worse than an animal in the institution. I now live independently in my own flat. I have come to this Event to share my story.

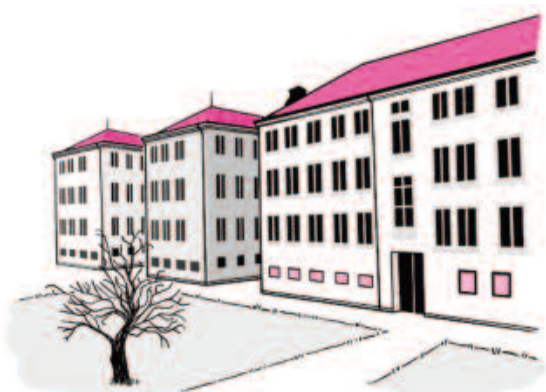
Video from Norman Lamb

Minister of State for Care and Support

As he was not able to attend the event, Mr. Lamb sent a video with some messages that he wanted to share with the participants.

One of the most important things Norman Lamb said is that he would:

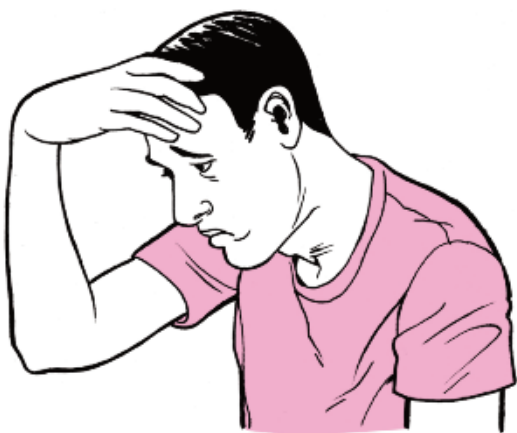
support the collective voice of people with learning disabilities.





Shaun Webster

I am a person with learning disabilities. I am the European Project Co-ordinator at CHANGE



I had no confidence. I could not live independently and I lacked the power to take control of my life.



With the right support, I was able to build my skills, gain confidence, get a paid job I enjoyed and I learned to live independently.



I am a role model for children, young people and adults with learning disabilities.

5. Table-top discussions to plan question for Zavar Patel, Learning Disability Policy Lead attending on behalf of Norman Lamb



Questions from the tables:

“Why can’t people with learning disabilities live in the community?”

“Why are they still building institutions when they are supposed to be closing them?”

“Why does it keep happening again and again? – Winterbourne View and now elderly people?”

“The 1st June deadline for people with learning disabilities to leave treatment and assessment units has failed. Is there a new deadline date for when this will happen?”

“Why is there not a better top standard for all social care?”

“Why are there not more opportunities for us to feel safe in the community?”

“We spend lots of money on hospitals and institutions – but in the community, we don’t get the support we need – how do we get government to make sure people with learning disabilities get the money and support we need?”

“We want more learning disabilities nurses in hospitals GPs surgeries and elsewhere – are you going to increase the numbers?”

“What can we do to close institutions?”

“Have lessons from Winterbourne View really been learnt? – How are people with disabilities going to be included?”

“Are we going to have some guarantees about money and funding to live in community? We are scared of losing support!”



Zawar Patel - Learning Disability Policy Lead, Department of Health

Dominic Slowie - National Clinical Director for Learning Disability, NHS England.



Bill Mumford, Director of the Post Winterbourne View Joint Improvement Programme.

All answered questions that came from the tables.



Zawar said that this Event is the **start** of a conversation, a dialogue, and it is **not** a one-off Event. Any unanswered questions can be sent to CHANGE for follow up.

The questions were answered as follows:

“Why does it keep happening again and again? – Winterbourne View and now elderly people?”

Zawar Patel: There are many reasons why some people don’t treat people with learning disabilities and their families and carers the way they should – it is to do with a lack of respect and a lack of personal attachment.

There is work that is happening to try and change culture and we will continue to make sure that people with learning disabilities are respected for who they are. We are trying not to just keep using the same big words but to **really** change things.

“We spend lots of money on hospitals and institutions – but in the community, we don’t get the support we need – how do we get government to make sure people with learning disabilities get the money and support we need?”

Dominic Slowie: there are two main things that can make a difference: **Your voice as a collective group – the**

energy and passion is brimming over – this group can have much more impact – keep together and keep saying the things you need to say!

The way things are set up the Government gives instructions to Health, this is called the **Mandate**. The **Mandate** has everything in it, it is no secret. There is **not** a lot in it about people with learning disabilities. What you can do is:

- Tell the Government to write in the **Mandate** some clear direction regarding what Health Services should be doing regarding people with learning disabilities.
- The NHS, in Leeds and in London can't tell each Clinical



Commissioning Group (CCG) directly what they need to do. They have to decide locally. **The local CCGs need to hear your voice – they are spending the money on your behalf.**

If you need them to close institutions and move money to the community, you must tell the CCGs in your local areas.

Dominic Slowie said that he would support these things.

“Why can’t people with learning disabilities live in the community?”

“Have lessons from Winterbourne View really been learnt? – How are people with disabilities going to be included?”

“What can we do to close institutions?”

“The 1st June deadline for people with learning disabilities to leave treatment and assessment units has failed. Is there a new deadline date for when this will happen?”

Bill Mumford: Before I was involved in this role, I have been trying to move people out of institutions all my

working life – what is really different now, is that the **voice** of people with learning disabilities is much stronger –

children with learning disabilities will benefit from the work you are doing.

Talking about Winterbourne View at the end of last year, there were about 3000 adults with learning disabilities still living in institutional settings across England. This is far too many and we want to make this number smaller. If you do need to stay in hospital because you are poorly or have problems, we want this to be for a shorter stay and closer to home and whilst you are there, that you have a good experience not a bad one.

It is not just about closing institutions, but also changing the experiences people have when they need care.

We hoped we would be further along in achieving our goals. We are not far enough. It is taking too long. There are some positive stories, we get reports of people moving out and starting good lives – **but it is not enough**. We are



also hearing stories of people in crisis and needing hospitalisation – **what we have at the moment is not good enough**.

The challenge is, **there is too much talk and not enough action**. There is too much talk at the top in central London and **not** in your local areas. We want to go person by person, area by area, to try and get the talking and the action in your local area. **We want a local Winterbourne View Action Plan for each area**, with local



professionals, people with learning disabilities and families involved. We want to support all to be involved and find out better ways that you can talk; to find out what we can do to stop institutions in local areas and see what support is available locally.

“We want more learning disabilities nurses in hospitals GPs surgeries and elsewhere – are you going to increase the numbers?”.

Zawar Patel: In the “**Transforming Care**” document, The government signed up to say that people

would be properly trained. Health Education England was given the responsibility to do this, it is written into their instructions.

We will have to hold them to account to make sure it happens.

To look at the document click here: <http://tiny.cc/64ihkx>

Dominic Slowie: We know that in 2008 the “**Healthcare for All**” document said that every hospital should have a Learning Disability Nurse. However, **policy on it’s own does not help**. I have spoken to the Chief Inspector of Hospitals and Chief Inspector of GPs and both have agreed to do something to: **measure the quality of services for people with learning disabilities.**

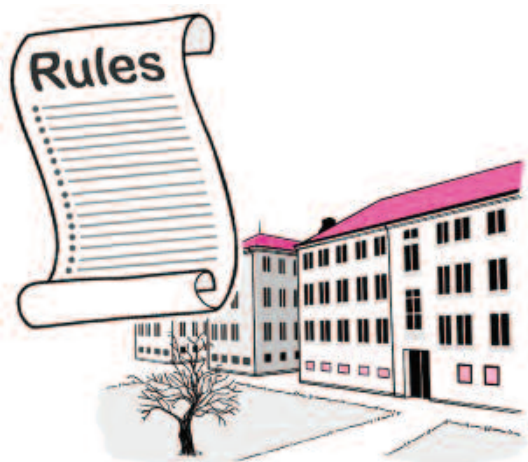
Hospitals are being inspected on this. Questions will be asked in inspections about:

- Where are the Learning Disability Liaison Nurses?
- Are they producing high quality accessible information?

Hopefully, the process of inspection will help them to make their services better.

To see the "Healthcare For All" document click here: <http://tiny.cc/86ihkx>





6. Presentations

Georgette Mulheir

Chief Executive, Lumos.

Georgette shared that Lumos was set up by JK Rowling (the author of Harry Potter) because she saw children being kept in cages in Europe. She set up Lumos to bring light to show everyone what the problem is and help bring back children to where they are supposed to be - in their families.

Georgette explained that institutions are usually buildings with strict rules and people have to do what the institution tells them.

Georgette explained how living in institutions hurts children and keeps them away from their families, and that it is important to work to close institutions and set up services in the community instead.



She added that when institutions are closing it is important to involve the children and adults living there. This is what Lumos does for children in Europe. Georgette showed a film where young people shared their views about what was wrong with institutions.

7. Questions to the Question and Answer Panel: Shaun Webster, Bill Mumford, Gavin Harding, Georgette Mulheir

“Why don’t people listen to us?”

“Why don’t the parents believe the children with learning disabilities?”

“Is there going to be more funding to support us?”

“There is no respect, services are about business and making money; how can we get more advocacy and transparency?”

“Why are people in institutions in the first place?”

“I don’t think children should be locked up in cages – I have two children living with me and they are at school today – more children should be living with their families – how can we make this happen?”

“How can we get together across the world to improve things?”

“How can people get the care and support they need?”



Gavin Harding: If you are a parent, you are going to trust the organisations that you are told will support your daughter; it is hard for the parents because they don’t think that abuse is going to happen. Parents think it is the right thing to do.

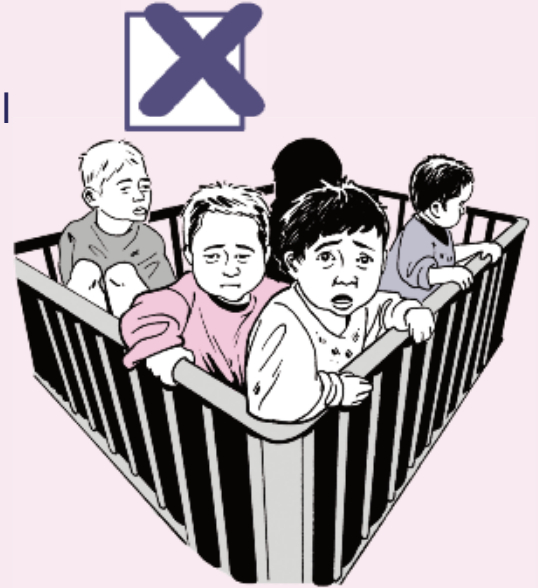


Bill Mumford: I don’t think that there are that many parents who want their children to go into an institution – but also as a parent, it is a really hard job, I know what years of not having sleep feels like – many parents and carers start to become ill themselves – they want to continue to care – it’s about supporting them – only as a last resort does a parent choose an institution.



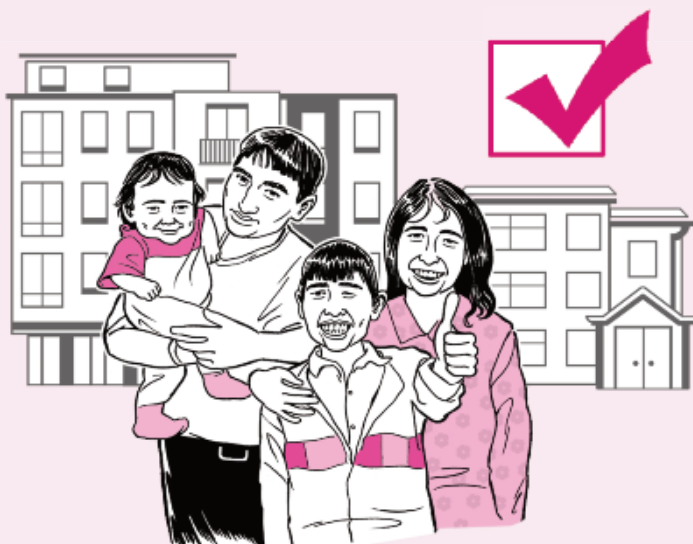
Georgette Mulheir: Children should not be in cages – we all agree – but for children with behavioural problems, it still happens – in some countries

they got rid of cages but use drugs instead – we need to make sure we get the right solutions. It is poor children, those with disabilities, ethnic minorities, old people with mental health problems – as a society those are the ones we don't want and we hide them away.



We get into habits, if you are a doctor in Bulgaria, you are in the habit of saying to a parent - you don't know how to care for this child, and we know better, we will look after your child for you in an institution. It is a habit from over hundreds of years. Getting them to do it in a different way is hard – it is a big ship to turn around.

Having the right housing is important: at Lumos we help Governments know how much they spend on institutions and help them move the

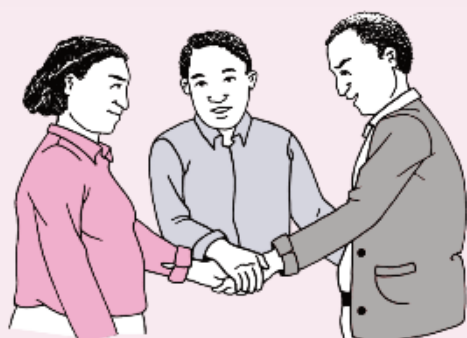


money. It is cheaper to keep children with families. When Governments say there is not enough money, you have to ask them **how much money have you spent on institutions where children are abused and put in a cage?**



Shaun Webster: One way to support people to move out of institutions is to provide Peer-to-Peer

Support. I train young people with learning disabilities to be advocacy workers so that if one person with a learning disability struggles, we can support them to be more independent. People with learning disabilities have a lot of skills to support each other.



The Government must give jobs to people with learning disabilities so that we can support each other.



Georgette Mulheir:

We should say to the Government: You can't take people out of institutions to save

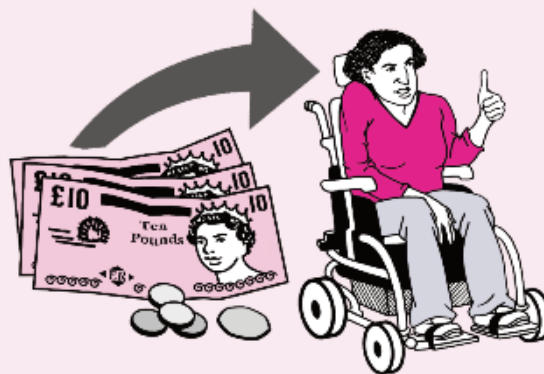
money. You need to use that money to provide all the things that are needed.

Self advocates are important. We don't want them to cut their budget. We want them to spend it on something better.





Shaun Webster: Put money in place to support people with learning disabilities to be independent!



Bill Mumford: There is a lot that people here can do to help find a solution in the future, too. It does take money. When meeting with the Minister ask: **How does the government and local areas support self-advocacy?** It is money well spent!



Where we are asking local areas to close hospitals we also need to ask: **Why people are going to institutions in the first place?**

We need to build up support. It is essential to talk to family groups and self-advocacy groups. There is a lot we can do to support local areas.

Ask the CCG's to say **how** they are talking to families and people with learning disabilities. Is it tokenistic? Is it real?
This is really important!



What people who have been in Assessment Units want when they leave is to have a life. This is something more than just finding services. We need to think about how we support people in the long term.



When leaving hospitals, people might not know or might want to change their minds about what they want. We want to reduce the chances of having to go back to institutions again so support has to be reviewed and talked about with the person concerned.



In Sunderland, people with learning disabilities wrote a letter to everyone in hospital, “When you come out of hospital, we are here, we have links, we can help you rebuild your lives.” This is a fantastic idea – a real reach out of friendship.



Gavin Harding is doing some work to write some easy read guidance on leaving hospital, 10 top tips on how to do well when leaving hospital.

8. Workshops



Workshop One:

Closing Institutions. Why is this important? How can People with Learning Disabilities get involved?

Led by Skills for People.

Main points discussed:

- The law isn't tough enough on people who abuse people with learning disabilities
- We seem to be tougher on people who commit other crimes, but damaging people with learning disabilities – people get away with it.
- The physical environment needs to support people to be involved in their own communities.
- We put homes for people with learning disabilities in the middle of very poor areas where people don't feel safe.
- Why are health and local authorities still paying for people to live in residential homes that abuse people?
- Is it more expensive to pay for people to live in residential care than it is to support people to live in communities?
- Social workers need to listen to us and be our advocate to support us - they **have to** speak up when things are wrong.
- Why do people with learning disabilities have to pay more for things like paying for your carer to go out with you?
- If we are closing institutions down why are they building more?

- Children need to be in family environments and homes, not put in to institutions.
- We put people into categories and label them.
- Doctors and Nurses are sending people to live in places that don't understand their needs or can care for them properly
- Question for the Government: **Why are more institutions being built when the money should be used to support people in the community?**
- We want training on the Mental Capacity Act including understanding of the need to include peoples Circles of Support.



Group Proposals:

1. The Government **MUST** make things change – not just publish reports.
2. People with learning disabilities **MUST** be **properly** employed to work in care settings.



3. STOP building institutions. Use the money to support people in the community.



4. People in power **MUST** involve people and their Circles of Support in planning and providing care and support.



5. Everyone working with people in care roles **MUST** sign up to a **Code of Conduct** which **must** be made into easy read and which we need training on.



6. CQC's **MUST** work with people to inspect and regulate care settings – they should publish which setting have had a user-led inspection.



Workshop Two:
Replacing Institutions. How can we work together to make sure services are good?

Led by Nabeel & Elfrida Society.

Discussion focussed on ‘What Does Good Look Like?’

The group felt that the following points were important:

- Having a voice and being able to join your voice with others so that we can **all** be heard.
- People with learning disabilities **must** be included in things right from the beginning in **everything** that happens.
- People with learning disabilities **must** be listened to and taken seriously.
- People with learning disabilities **must** have choices.
- Making sure that parents have a voice and there are groups they can go to.
- Having good communication so people with learning disabilities know what is going on and people are working together.
- The rights of people with learning disabilities are respected and we are treated equally as citizens. We want stability, consistency and good communication skills in staff who support us.
- That people with learning disabilities who can't speak for themselves have someone who can do that for them so that they can be heard. This can be Peer-to-Peer Support from a more independent person with learning disabilities.
- Staff who are paid well.

Discussion moved on to Empowerment:

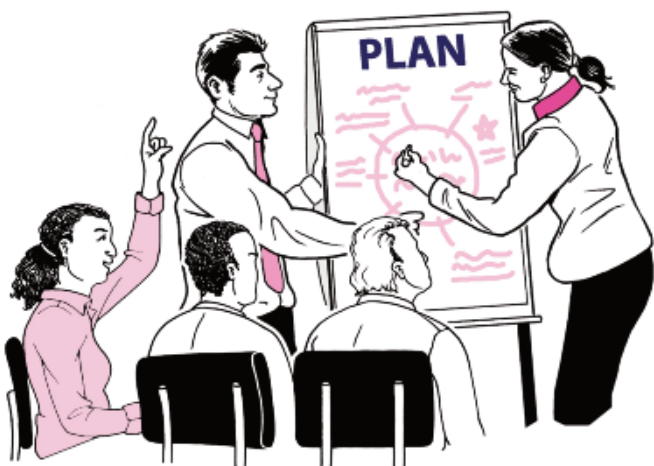
- **Sometimes** Partnership Boards are really helpful in supporting people to be empowered.
- Some areas don't have these.
- It is good when Partnership Boards have local leaders on them and make the changes that people want to see.
- People with learning disabilities should be heard by the people who commission and provide services such as Councils and Clinical Commissioning Groups, Social Workers, Police, Health Watch and Third Sector Groups and self advocate groups. These people should have the training and support from people with learning disabilities who are paid to deliver the training so that they can listen and understand our needs properly.



Group Proposals:

1. People with learning disabilities should meet with senior leaders in their areas regularly, so that our voices are heard.

2. People with learning disabilities should be involved at the beginning of things.





3. People with learning disabilities should have the chance to inspect services.

People with learning disabilities should have the right to regular training, and the right support to do this. Inspectors of services should be properly paid jobs for people with learning disabilities.



Workshop Three: Right Staff. Right Attitude. How can we work together to achieve this?

Led by Danny & Grapevine

Staff – the good stuff:

- Experience, Patience, Listening Skills, Trustworthy.
- Understands the disability of person being supported.
- Don't bring own problems with them.
- Positive attitude towards the person they are supporting.

- Support – do NOT take over. Do not tell the person being supported what to do.
- Sense of humour – get on well.
- Keep things confidential. Do not put it on Facebook or twitter.
- Fun and encourages person being supported to do new things and supports them to go out.
- Stand up for and with the person they are supporting.
- Supports the person to talk about their problems if they want to.
- No personal questions unless needed.
- Gives support to keep flat of person being supported a good place to live.
- Gives support with filling in forms & writing letters, bills and computers.
- Gives support with personal care.
- Explain to the person being supported how they can complain if they need to.

Staff – not so good stuff:

- Sometimes they choose for you.
- Not a lot of staff to do what I want to.
- Problems with money – sometimes staff take control.
- Staff who think they know best.
- They need too much time in advance to make arrangements.
- They don't sort out transport in the way that I want.



Group Proposals:

1. Understanding – know someone, respect our needs, ask what we enjoy.
2. Support us to build our confidence – try new things and support me to stand up for myself.
3. Stand up for and with me. Respect me – when I am not able to myself – build our relationship – keep things private.





Workshop Four: Making Ourselves Heard! How can we make this work better?

Led by Sabrina - a person with learning disabilities and Opening Doors.

- Sabrina said she is not afraid to say to people what she thinks. Opening Doors does training by people with learning disabilities so that staff know how to support people with learning disabilities in the right way. Her support worker is a fantastic friend and genuinely cares.
- It is important to have a voice!
- We need a better Customer Service Group.
- Being involved in local Partnership Boards can sometimes increase our confidence.
- Confidence building and employing us is important in supporting people with learning disabilities to have a strong voice.
- Working with patient's forums can result in changes that patients request.
- It is important that people with learning disabilities have access to Advocacy services in the community.
- Some people with learning disabilities living in institutions can be worried about moving out. It's useful to know about things like the Facebook site "Close Institutions Now".
- People with learning disabilities are treated really awfully at times.
- Inspecting services can give people with learning disabilities a voice.

- Some people with learning disabilities have harmed themselves because they did not like the services they get and no one listens to us.
- Very expensive homes are being built and they fill them with lots of people with learning disabilities – the Government should stop this.
- In some places, like Salford for example, some good work is being done to stop the private providers – through the local planning of the council.
- We often don't like to live with lots of other people.



Group Proposals:

1. Do not allow big residential homes to be built, people want normal homes – don't let it past the planner!
2. Everybody should have access to Advocacy & self advocacy.



3. We *must* be paid to deliver training to all Health and Social Care professionals. We want to be paid a proper salary to deliver this training.



**Workshop Five:
Where are our Role Models?
Bringing together adults with
learning disabilities with young
people.**

Led by Salford Being Heard.

The workshop started with a discussion around what makes a good role model? Words that came up included kind, respectful, honest, and truthful.

A couple with a learning disability who have two small children gave a presentation about the challenges and barriers they face and how they overcome these to stay together as a family. When they had their first child, they were worried that the baby would be removed from them, particularly following a conversation with their first Health Visitor. With the right support from public and voluntary sector services and a strong family network they have managed to keep their children. They were proud to be role models for other couples in a similar situation.



Group Proposals:

1. We want more parents with learning disabilities to be supported to be role models to support other parents with learning disabilities, especially when having a first baby.
2. • We want social services to leave us alone!
 - Do not judge us.
 - Support us.



Workshop Six: Making Space for us in the community.

Led by CHANGE.

Aim of workshop: To discuss equal opportunities for people with learning disabilities living in the community.

Discussion about what changes need to happen and identify three proposals to bring to the plenary session.

The group divided into two smaller groups to discuss and share

experiences about living in the community. They were asked to talk about, write or draw about negative experiences on the topics - housing, education, justice, employment, health, and transport.

The group then came together to discuss what changes need to happen and which three proposals they would like to take to government.

There was a lot of discussion and people were happy to share personal experiences. In particular topics on hate crime (bullying) and education. People spoke about their experiences of being bullied in the community.

Most people lived independently and had mixed experiences in receiving good support.



Group Proposals:

1. Make things more accessible.
2. People need to listen to us and not assume everything is OK.



3. We need support and an accessible service to report hate crime and tougher punishment for the bullies

9. Final Session – presenting workshops and voting



Led by **Kerry Hall** from Lumos and **Nada Heyari** from CHANGE.



Similar Group Proposals were grouped together this meant that people with learning disabilities could vote more easily.



The following are the four main proposals that came out from all the workshops combined:



Proposal One:

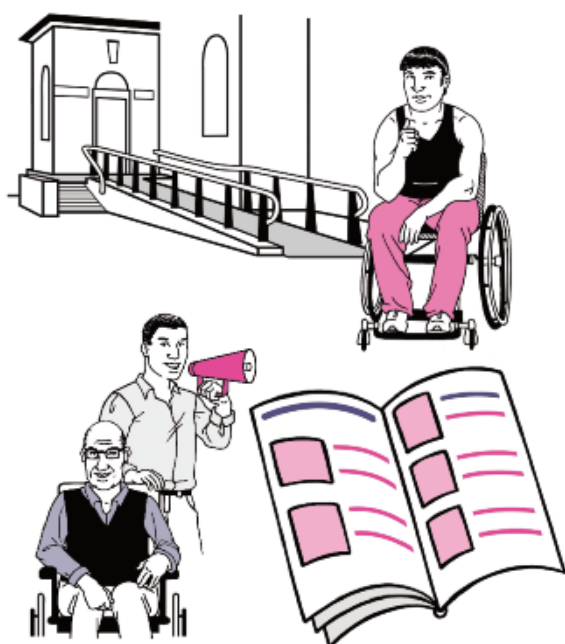
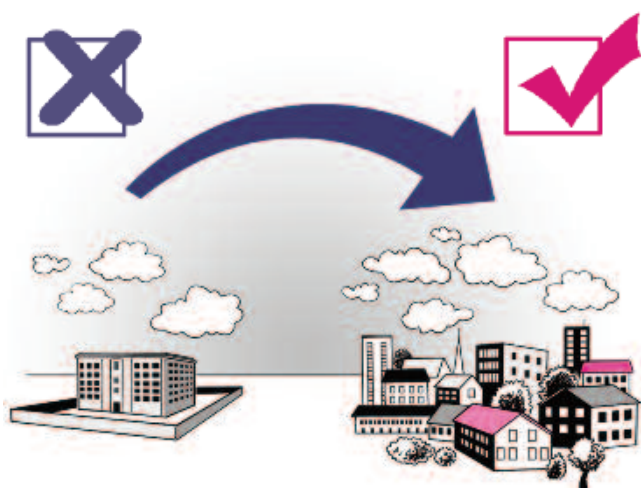
Institutions should not be allowed to be built in the first place - resources should be used in building the support people with learning disabilities need to live successfully in the community.



Proposal Two:

People with learning disabilities want to play an active part in making this happen, as employees in care, employment and advocacy services. Our voices and choices can shape a more successful way of doing things.





Proposal Three:

To successfully move from institutions to living in the community we need the opportunity to build our self-confidence individually and collectively through:

- Self-advocacy
- Peer-to-Peer support
- Role models – including parents with learning disabilities.

This needs investment and support.

Proposal Four:

Living successfully in the community also requires accessibility. **This means high quality easy read information,** mobility, and access to advocates and self-advocates.

All the proposals were met with an equal amount of enthusiastic applause!



10. Closing statements

This is the start of a movement for change.

We can feel the power in the room and it is breathtaking.

Everyone is making a difference.

We are taking our Proposals to a Summit meeting with the Government and with people with the power to change things.

Together we can change things for people with learning disabilities.

Our event was mentioned on twitter 1.3 million times!

We will not give up.

Together we can make the biggest difference.

Work with us and listen to us.

We have the experience and we know best what we need.



This document was produced by CHANGE
www.changepeople.org



