Minutes: 5 to 6 Dec 2012

In the chair: Karen Flood, Gavin Harding (5 Dec)
Supporters: Paula Camborne, Lyn Gregory

Vice-chair: Craig Hart with supporter Kered Roskill

People at the meeting:

North West:
Jonathan Hurley with supporter Dermot Hurley

North East:
Harry Longmoor with supporter Adam Brown

Yorkshire & Humber:
Alison Owen with supporter Kat Taylor

West Midlands:
Ruby Walker with supporter Phil Sawburton

Eastern:
Carole Lee MBE with supporter Alex Morris

London:
Karen McCaffrey with supporter Vicky Tantony

South East:
Dawn Johnson with supporter Gill Cross

South West:
Kerry Martin with supporter Sally Scott

Complex Needs:
Christian Raphael with supporters Vicki Raphael, Matt Clark and Lynn Herbert

VoiceAbility:
Paula Briley (5 Dec), Lyn Griffiths, Imogen Ridler, John Woodhouse
Day 1

- Gavin started the meeting by welcoming everyone. Everyone introduced themselves. New to the meeting: Carole Lee, Harry Longmoor, Lyn Griffiths (new National Forum Coordinator).

- Craig went through the housekeeping. Gavin introduced the washing line for any questions or queries. Lyn Griffiths went through the Ground Rules for the meeting.

- Karen F and Gavin went through the agenda for the next 2 days.
Feedback & Updates

CQC ADVISORY GROUP:
Gavin

• Research:
  ➢ CQC is going to do a study of people’s experiences in acute hospital settings. Acute hospitals are where people usually stay for a short time for medical care.
  ➢ They will tender for someone to do this work by 13 January 2013. This means organisations will tell CQC how they would do the study.
  ➢ CQC expects that the organisation which gets the job will consult with experts by experience.

• Next Stage:
  ➢ This will start once the final Winterbourne Report is published on 10 December.
  ➢ The next meeting of the advisory group will look at whether CQC is moving in the right direction.

• Winterbourne View Concordat:
  ➢ CQC will sign up to this once the final version has been agreed.

• Count Me In:
  ➢ ‘Count Me In’ is the ‘National Mental Health and Learning Disability Ethnicity Census’. It looks at how many in-patients there are in all mental health and learning disability hospitals in England and Wales.
  ➢ This information helps to show when Black and Minority Ethnic patients are not getting good care.
  ➢ Its report with information from 2006 –2012 will be published at the same time as the Winterbourne Report.
  ➢ Some of the information has already been reported wrongly.

• Partnership
  ➢ CQC and the Dept of Health will continue to work in partnership with other organisations.
PROGRAMME BOARD:

Gavin

- **Message from Norman Lamb, the new Minister for Care and Support:**
  - People with learning disabilities and their carers are important and must be involved in the process of care.
  - People must be listened to by the system.
  - Cultural attitudes must change!
  - People with learning disabilities have the same rights as everyone else. They must not be treated in a worse way than other people.

- **Winterbourne View:**
  - The final report was first promised at the end of November. Norman Lamb felt it was not strong enough, so he decided it should come out on 10 December. This was to give enough time to get it right.
  - There will be a statement in Parliament and the press.

- **Winterbourne View Concordat:**
  - It is important that all 49 organisations sign this.
  - The organisations all promise to make the care of people with learning disabilities better in the future.

- **Reports from National Forum and National Valuing Families Forum (NVFF):**
  - Norman Lamb liked the sound bites presented. He was also given a copy of the minutes from the National Forum’s September meeting.
  - The NVFF gave the structure of their links to families through national, regional and local involvement.
  - The NVFF asked how they and the National Forum will stay involved after Winterbourne. They also asked how we will be included in the work plan.
  - Norman Lamb said both forums will be involved through partnership working.
  - We asked that all government departments make the information they send out accessible.

  - Gavin raised an issue about parents with learning disabilities not getting enough support. Norman Lamb said he would look into this.
Request from Karen F:
- At meetings like the CQC Advisory Group and Programme BoardKaren F and Gavin are often asked to make quick decisions on the National Forum’s behalf. Karen F asked for permission from reps to do this when it is needed.

HEALTH NEWS
Dawn

1. All Parliamentary Group on Learning Disability:
- This meeting took place on 23 October in the Committee Room of the Houses of Parliament.
- It was about making the health of people with learning disabilities better.
- It was a very big meeting with lots of people from different organisations.
- It was chaired by Tom Clarke MP.
- There were a number of speakers who reported back to the Parliamentary Group on health issues.

- The first to speak was Siraaj Nadet. He said:
  o Not enough is known about people’s health issues.
  o Things had got better but there is still a long way to go.
  o We need more action at national level.
  o Recommendations from the Winterbourne View Report will need to be adopted and written into new care contracts.

- Dr Pauline Heslop leads on the Confidential Inquiry into the deaths of people with learning disabilities. She has been looking at lots of reports and said:
  o There is a need to identify factors that can lead to changes in the health service. This is so that what has been reported in ‘Death by Indifference’ does not keep happening.
  o For more information on Dr Heslop’s reports, there is her quarterly report: Confidential Inquiry into the Deaths of People with Learning Disabilities, September 2012. This is in easy read here: www.improvinghealthlives.org.uk
Gyles Glover, Co-Director of the Learning Disability Public Observatory and Professor in Mental Health said:

- Out of 58 people in hospital at any one time, there will be 1 person with a learning disability.
- Main health issues for people with learning disabilities are:
  - Mental health problems.
  - Epilepsy.
  - Swallowing.
  - Diabetes.
- They have seen 48 health reports.
- The National Census counts the number of people in the country, but it does not record the number of people with learning disabilities.
- There has been no special health survey in England concerning people with learning disabilities.
- Hospitals may not even know that a patient has learning disabilities.

Eric Emerson, Co-Director of the Learning Disability Public Observatory and Professor of Disability and Health Research, said:

- There is a lack of awareness in health services of the needs of people with learning disabilities.
- This failure in health services to understand the needs of people with learning disabilities can lead to institutional discrimination. This means an organisation is working in such a way that people who belong to a particular group get treated badly.

Rob Grieg, Chief Executive of the National Development Team for Inclusion (NDTi) said there is a need:

- To translate research into health actions. For example, health checks and health reports should go to local areas to help them understand better what services they need to provide.
- To provide practical health advice for family carers, carers and the NHS.
- For a website which provides advocacy peer learning, for example about health checks for advocacy groups.
Professor Peter Fleming, expert in premature deaths in children and infants, explained his current research. This will include children with learning disabilities.

Panel Discussion. Some of the things that were said:

- There is a need for training for NHS staff in learning disability, and for improvements in communication.
- More hospital learning disability liaison nurses are needed.
- There is a need to get the right information to commissioners. This is very important as 85% of commissioners are new and often have other responsibilities.

Date of next All Parliamentary Group on Learning Disability meeting: 18 Dec 2012.

- This meeting will discuss lessons learnt from Winterbourne.
- Norman Lamb will present the Government Strategy.

2. The Monitoring and Evaluation Group (MEG)

- This meeting took place on 12 November at Wellington House in London.

- It was about the Learning Disability Public Health Observatory (LDPHO) and the Confidential Inquiry. They were reporting back to MEG on the quarterly reports (reports which are written 4 times each year).

- What we did in the meeting:
  - Looked at previous minutes from the meeting on 9 May.
  - Had a project update from Zawar (Project Leader for MEG).
  - Looked at the timetable for all the work to be done and what could happen if it is not done.
The LDPHO was then invited to join the meeting to present its second quarterly report for 2012/13 (July-Oct). Some of the work the LDPHO has been doing:

- Looking at all the Learning Disability Partnership Board reports to gather information about what is happening in different areas with Autism and Health Checks. They have found out useful information about who has and who has not had health checks, and where.
- They did a survey on how many people are using the Improving Health and Lives website. They found that 65% of people using this website had found the information on it useful.

- The Confidential Inquiry then presented its second quarterly report. Some of the things it has done:
  - Checking that people with learning disabilities are safe when they are in hospital and are cared for properly.
  - They have 27 investigators looking into the care that 239 people with learning disabilities received before they died in the 2 years up to March 2012.
  - They have been talking to many different people, including carers, family members and professionals who were involved with each individual.
  - Only 3 of the 239 people were from an ethnic background. There is concern that this does not show a true picture of the situation. Siraaj Nadet felt strongly about this when he was the National Forum rep on MEG.
  - Dr Heslop finished by saying that it is important the final report focuses on what needs to be done. MEG will continue to pull all the information together for the final report by March 2013. This work has taken 3 years.
3. The Learning Disability Professional Senate

- This meeting took place on 13 November at the Royal College of Psychiatrists. The Senate is for reps from professional organisations who work with people with learning disabilities.

- There were presentations and workshops on the new guidance for Clinical Commissioning Groups (CCGs) on the health needs of people with learning disabilities. These groups will be responsible for the planning and buying of healthcare in their area. They will be starting work in 2013.

- Sue Turner, who works for the National Development Team, talked about the new guidance she and others have been working on.

- Sue asked for comments on the draft CCG guidance. She has already done this with GPs and nurses. She wants to get as many professional groups as possible to sign up to the guidance. When she has got all the comments, she will finish the guidance and send it out.

- In small groups we talked about what is important for people with learning disabilities who use community or in-patient mental health services. This is what I fed back from my group as being most important:
  - Feeling safe when using mental health services.
  - Access to an advocate / self advocate organisation for support. Making sure that people from Black and Minority Ethnic groups have this access.
  - Information and meetings that are easy to understand.
SPECIAL EDUCATIONAL NEEDS (SEN) STAKEHOLDER MEETING

Alison

- This meeting took place on 6 November at the Department for Education in London. It was to talk about the SEN Code of Practice.

- The code is a guide to help local authorities, schools and early education settings think about how they can support disabled children and young people in education. It was written in 2002.

- The Department for Education wants to update the code. At the moment it only covers children and young people aged 0-16. The new plans will cover people from 0-25. The department will work to update the code over the next year. They want to hear your views.

- At the meeting people said:
  - The current code means a lot to parents and organisations.
  - If the code is going to include people up to the age of 25, it needs to look at employment and transition.
  - It should be Person Centred planning. This means real co-production, not just asking for people’s views.
  - It should sign-post to the Equality Act and other duties for schools around SEN and disabilities.

- If anyone, or any region, has any comments about the SEN Code of Practice, please let Alison know. Her email is: alison.o@speakup.org.uk She will then give this information to the Department for Education, so they can add it to their plans.
• **Good Practice Board**  
  **Kerry**

- Kerry explained that her role in the group has not really started yet. She will have more to report at the next National Forum meeting.

- People should have seen the sheets asking for good practice examples.

- The Department of Health and National Valuing Families Forum have already done a lot of work to make sure the information that comes in is useful.

- The board will make a list of which good practice projects could be good to visit before the whole group meets up just after Christmas.

- The board hopes that by sharing the good work people are doing that it will happen in other places too. This will show the government what quality looks like.

- There will be a big launch for the Good Practice project in April. The minister will attend this.

• **People with Complex Needs**  
  **Christian**

- Christian has attended 2 meetings of Cambridgeshire High Support Needs Committee:

  1. Meeting in September - Focus on **health**:
     - People shared their experiences of using healthcare services, including hospitals and GP practices. The group discussed how well improvements are working in practice such as:
       - Hospital Passports.
       - Annual Health Checks.
       - Hospital flagging systems for people with learning disabilities.
o Claire Kelly talked to the group. She has done a research project into the experiences of people with learning disabilities who have used Addenbrookes Hospital in Cambridge. Her research found:
- Hospital admissions were patchy. This means people are not treated in the same way by all staff.
- Different groups of staff view learning disability in different ways.
- There is still a lot of confusion and misunderstanding among hospital staff about equal access to services, and about reasonable adjustments.

2. Meeting in October – Focus on housing:
o People who live in different kinds of housing talked about their experiences. Some people live in their own home, others have a council house or flat, or are in supported living. They discussed how where they live affects them and other things in their lives.

- In September the Midlands and East of England Strategic Health Authority conducted their Self Assessment and Improvement Plan panels:
  - These panels look at the services provided by local authorities for people with learning disabilities.
  - Local Authorities have to look at how they are responding to the needs of people with complex needs. This means it is important that people with complex needs are on the panels, and give presentations.
  - Christian did this on the panels for 2 of the local authorities in the Midlands and East of England.

- In October Mencap organised a ‘flush mob’ protest in Trafalgar Square. This was to make people aware that there is still a need for more Changing Places toilets for people with complex needs in public places. There were about 200 people who raised toilet brushes in the air.

- In November SeeAbility held a one-day workshop and conference in Huntingdon for people with learning disabilities, their supporters and carers. It was a fun day with lots of information given in an accessible way. There were breaks at the right time and practical activities. Go to a SeeAbility event if you can.
On 25 October Christian represented the National Forum at a conference for the Association of Directors of Adult Social Services (ADASS). This was the National Children and Adult Services Conference.

- The conference was about what needs to be done after Winterbourne View. These things were discussed:
  - Key findings
  - Challenges
  - Next steps

- Christian was the only person with a learning disability at the conference. He took part in a Challenging Behaviour Foundation (CBF) workshop. His presentation was called ‘Real Lives’.

- **Department of Health Review of Winterbourne View – Project on Advocacy**

  - Craig

  - This meeting was held on 26 November at the Department of Health (DoH). People who were there:
    - Sheila Evans and Pam Nixon from the DoH.
    - Craig representing the National Forum.
    - People from VoiceAbility, Action for Advocacy and Inclusion North.
    - Andrea Pope-Smith from ADASS.
    - Geoff Baines from South of England NHS.

  - Everyone agreed that what happened at Winterbourne was terrible. Everyone wants to take action to stop it happening again at another hospital.

  - Everyone agreed how important good advocacy is. This includes self-advocacy. After Winterbourne the Department of Health wants good advocacy for everyone with learning disabilities. It can help people to move out of hospital and into community living.
This is what people at the meeting said they will do:

**Action for Advocacy:**
- They will update their Quality Performance Mark. This is for advocacy organisations. It makes sure they are good.
- They will also update their Code of Practice. This tells advocates how to do their job well.

**Inclusion North:**
- They are looking at what is needed for people with learning disabilities in hospitals in the North East.
- They will let the group know how they can do this for the whole country.

**VoiceAbility:**
- The group talked about making a list of the most important things about good advocacy.
- Jonathan Senker, Chief Executive at VoiceAbility, is interested in helping with this work.
- The other group members will also join in with this.

Andrea Pope-Smith told us about her work in Dudley local authority:
- She is working with advocacy groups and people who buy advocacy to make it better.
- She will work with Action for Advocacy, VoiceAbility and Inclusion North on this work.

No one knows yet what money there will be for this advocacy project. The Department of Health will let everyone know what money there is.

Everyone agreed the meeting had been useful. Pam Nixon will let everyone at the meeting know when the next meeting is.
Regional Updates:

East:

- **Benefits** was the issue talked about the most: There are big worries about benefit changes and this is affecting people’s health. Universal Credit will only be given if applied for on-line. Many people with learning disabilities do not have internet access. What was said at the meeting has been given to Gavin and Karen. This may help with thinking up questions for the next National Forum meeting when the Department for Work and Pensions will be there.

- **Transport** including taxis and buses: The issue of CRB checks for taxi drivers was raised by the Eastern region at the last National Forum meeting. Support from the National Forum was asked for to look at the new rules about CRB checks for taxi drivers. Is the National Forum able to do this?

- **Making it Real**: Some people thought their councils had signed up to ‘Making it Real’. On the website it turned out that only 4 of the 11 local authorities in the region have signed up: Norfolk, Cambridgeshire, Hertfordshire and Southend. Not signed up in the eastern region: Peterborough, Bedford Borough, Luton, Central Beds, Essex, Thurrock, Suffolk.

A letter from Scotland People First was discussed. It had an invitation to a meeting to talk about a United People First for the whole of the UK.

Yorkshire & Humber:

- **Winterbourne agreement**: This was discussed at the regional forum. People appreciate the work that has been done. It was felt the agreement is a good idea and a way forward to getting better care and outcomes for people in residential care. Before signing it, details of actions, timescales and responsibilities are needed. This is so the forum can check organisations are doing what they should do.
• **NHS Reforms**: Workshops were held to talk about these. We asked these questions:
  o How many people know if their GP surgery has a Patient Participation Group?
  o How many people know if there has been any contact with their local Health & Wellbeing Board to make sure it represents the needs of people with learning disabilities?
  o How many people know if there has been any local contact with a learning disability organisation to talk about Local Healthwatch?

**West Midlands:**

• **Working in partnership with the National Forum:**
  o The region would like to see outcomes from National Forum meetings. It is important that the National Forum take action about issues.
  o The West Midlands wants regional forums to be more involved.
  o It is not good that there have been 3 coordinators in 10 months.
  o There has been no direction from the National Forum since late last year.
  o There is no one from Black Minority Ethnic communities on the National Forum – this is wrong!
  o The West Midlands would like to see a copy of the contract to run the National Forum. People want to know what the government says has to be done and how this is going to be checked.
  o People with learning disabilities should be monitoring how VoiceAbility is performing against their contract.
  o The National Forum should sign up to ‘Making it Real’.
  o How can a regional forum member with no internet access learn about the National Forum?

• Tony Johnson from Mencap gave a presentation about Personal Independence Payments and other changes.
• **Making It Real – Think Local Act Personal (TLAP)**

  o Not many groups knew about TLAP. Birmingham Council is using some issues on the checklist to check how well their services are doing. They are asking other organisations to sign up too.
  o Dudley, Sandwell and Wolverhampton have had consultation events. Dudley has a Making It Real board which is making an Action Plan.
  o Worcestershire and Warwick have not signed up. The regional forum should show councils why it is so important that they sign up to the checklist.

  o It was decided these actions could be taken:
    ✓ Get local MPs on board.
    ✓ Ask partnerships boards how they will get involved.
    ✓ Work with other local groups of disabled people to speak to councils about TLAP.
    ✓ Write to ADASS saying not all areas in the region have signed up.
    ✓ People to check if their own areas have signed up.

• **UK People First:** Some members want to go to the meeting in April about a People First for the whole of the UK.

**South East:**

• **Housing:**
  o Living with older family carers means some people never get to the top of the priority housing list.
  o People in shared housing who want to move find there are not enough houses available.
  o It is hard for people who have moved away from their family and friends and who cannot get the support they need.

• **Transport:**
  o Most buses run until 9pm. This means people cannot go out late and if they do they are forced to use taxis.
  o In Kent some buses finish at 7pm. The forum is going to meet bus companies to discuss this.
**People who have been in care:**
- People from the Kent Speaking Up Network have been talking about their experiences in mental health units in long stay hospitals and foster homes. They are going to write about this.
- People say that it is not just in Winterbourne but other places too that bad things happen and continue to happen. They feel things have just not moved on.
- They are going to present their stories to the Kent Learning Disability Partnership Board and Cabinet.

**North West:**

- The 3 main issues are still:
  - Hate and mate crime.
  - Access to public transport.
  - Valuing People.

- The North West conference will be held in February 2013. The 3 main issues for the year will be chosen.

- Jonathan has been trying to find out how many people with a learning disability are employed by advocacy groups. This is being discussed at the regional employment group. Jonathan is trying to get some questions sent to all advocacy groups.

**London:**

- There has not been a meeting since September.

- Richard, the second London rep, gave a presentation on behalf of the National Forum about hate crime at Learning Disability Today. In some places the police have signed up to a promise to act on hate crime. Not all police forces have done this.

- There is a People’s Parliament in Greenwich. Elections have just been held for 5 MPs with a learning disability to attend the partnership board, run Citizen Forums and surgeries. The 5 MPs each have a priority area: Housing, Health, Choice and Control, Jobs and Moving On. The MPs are paid for this work.
South West:

- There has been no meeting since September but there has been contact with groups.

- The forum lobbied candidates in the Police Commissioner elections to get hate crime on the agenda. Because of this the Dorset force has signed up to the ‘Stand By Me’ charter.

- It was very difficult to get easy read information from the Electoral Commission. They said they had new rules and would not send groups lots of booklets. They would only send them to people who asked for them as individuals. This change means that people with learning difficulties will not get the information they need. This may need to be challenged before the next general election.

- The next big meeting will be a celebration of the work that is being done in the region. Good work will be shared and awards given to projects that have made a difference, to self-advocates and people in the community who make life better. This is being done because people are feeling alone and worried about the future.

- Cornwall People First are now running the Quality Checkers network. It is one of the most powerful tools to make sure services are doing what they should. We have heard good stories about change happening. The people who buy services are now very keen to have independent checks made by local groups.

- Work on safeguarding training is being shared between groups. One thing that must happen after Winterbourne is to make sure people with learning disabilities know:
  - What abuse is.
  - What it might look like.
  - What they should do about it.
This should be part of the Concordat.
North East:

- A big commissioning event was held in November about people getting more choice and control over the support they use. Self advocacy groups, local councils and the local NHS mental health trust were there. A task group will be set up to come up with an action plan to make things better.

- Many groups in the north east are concerned about cuts in the support that people use. Many people had reviews of their support which has now been cut.

- The North East Regional Forum is concerned about changes to the benefit system, particularly housing benefit. Some people look likely to be forced to move out of their home because they have more space than the new system thinks they should.

East Midlands:

- In Derby some day and respite services may close. People are not being told what is happening.

- A number of people said they still do not understand how personal budgets work. After people have been assessed for personal budgets they do not have enough money to do everything they want. One person said: “I have lost a day at the centre.”

- People are being left by themselves as there is not enough money to pay for services. Changes to people’s support hours are confusing. There have been lots of changes within social services.

- There are not enough social opportunities.

- People find it hard to get to meetings. The day services in Lincolnshire no longer have transport, so people cannot get to the regional forum.

- Changes to benefits – DLA, Personal Independence Payment, Income Support. It is all very confusing.
Karen talked about some of the work she has been asked to do on behalf of the National Forum:

- She was invited to Learning Disability Today to talk about abuse. She feels the National Forum should take the lead on this issue and campaign on it, as in her opinion the sentences given to the staff at Winterbourne were “a joke”. 5 people spoke out at the conference for the first time about abuse. One of them disclosed being raped.

- Fiona Ritchie from Turning Point has asked Karen and Gavin to take the lead on some work she wants to set up. This is paid work with expenses (including support). Anyone interested should tell Karen or Gavin and they will let Fiona know.

NHS Commissioning Board meeting – 13 Dec

- This is a new organisation that is being set up. Their letter: “We would like to talk with you about how we can work together and improve the quality of care given to people with learning disabilities or autism. This is very important to us, in particular after the terrible things that happened to the people at Winterbourne View Hospital. We want to hear what we could do to make things better for people with learning disabilities.”

- Reps were asked who would like to go. Christian is going, but not to represent the National Forum.

Summary of Actions from Day 1

1. All reps to make a list of the skills they can offer the National Forum. This is so that reps can get more involved in other meetings. It will also show the minister and others in government what the National Forum can offer. Government departments ask for reps on consultation groups - they want to get the right people for each job. It will also show why they should pay people to get involved.

2. Reps to let Lyn know if they want to go to the NHS Commissioning Board.
Day 2

- Minutes from the last forum meeting were discussed:
  - The North West commented that some of the questions about the PIP presentation by the Department of Work and Pensions (DWP) have not been answered.
  - Claire de Banke, who gave the presentation, took questions away, saying she would send in answers. This has not happened.
  - Karen F said someone from the DWP is coming to talk about PIP at the March forum meeting.

- Queries raised by the West Midlands yesterday were answered by Lyn Griffiths and Karen F:
  1. **We would like to see outcomes from National Forum meetings:**
     It is up to reps to bring issues from the regions. Chairs will then take them to government. West Midlands said that actions used to be sent to the regions after the National Forum meetings, but this is not happening now.
  
  2. **We want regional forums to be more involved:**
     In what way do you want to be more involved? West Midlands said this relates to issues not going back to regional forums. This is why regional forums feel isolated and not involved.

  3. **Having 3 National Forum coordinators in 10 months is not good:**
     West Midlands just want it understood how frustrated people are with the situation. Karen F: “It’s down to us to keep on track and keep the Forum going.”

  4. **No direction from National Forum since late last year:**
     Karen F said that this will get better.

22
5. No one from Black Minority Ethnic communities on the National Forum: 
Reps need to go back to their regions and find out why. Who exactly is the National Forum reaching? Who does it represent? How do we get more involvement?

6. We would like to see a copy of the contract to run the National Forum: 
This can be arranged. Under the contract VoiceAbility does basic admin, a little management and organises National Forum meetings and representation at the National Programme Board.

7. We suggest that the National Forum signs up to ‘Making It Real’: 
The National Forum has already signed up to Making It Real.

8. How do I learn about the National Forum as a Regional Forum member if I don’t have internet access? 
Give Lyn the contact details of anyone who wants information, and she will send it to them by post.
World Café 1

How can we influence Local Authorities (LAs)?
(East & South West)

1. Find the right people:
   - It might be their job.
   - They might be a ‘champion’.
   - Know what everyone does – what their areas of responsibility are.
   - It’s not just about social care and health!

2. Work out how to work with them:
   - Be politically aware.
   - Make friends with Big Bosses.
   - Figure out how to ‘work’ with them:
     ✓ Make them think it was their idea.
     ✓ Let them know you will go further.
     ✓ Make them feel important!
   - Work hard and earn respect.
   - Be brave.
   - Have solutions, not just problems.

3. Keep on and on and on! Never forget!
3. Make contact with your local MP:
   - Identify an issue you want to campaign about.
   - Create a petition and give it to the right person.

2. Use people who are skilled in talking to the media and who are sympathetic to the campaign being launched:
   - Look for backing from the National Forum.
   - Use the internet:
     - For example - internet campaigns reach a wider audience. Then more people can be involved and sign up.

1. Index of local groups in all regions:
   - Then groups can know about each other and work together.
1. Reps were asked to feed back about the Winterbourne Concordat (agreement):
   - We did not have enough time (2 days).
   - Reps need time to meet and talk with groups in the regions.
   - This can take 2 months to do properly.

2. CQC inspectors need to be experienced:
   - They should be trained by people with a learning disability.
   - Inspections should always include a person with a learning disability.
   - People with a learning disability should be on the scrutiny panel.
   - Scrutiny panel minutes and information must be in easy read. This is good practice and, for example, happens in Rotherham.

3. Make it a law, not just an agreement, about how long people stay in assessment and treatment centres:
   - People stay in these centres too long.
Craig Hart: Why I would be a good rep on the Co-production Group

- **Why I am the best person for the job:**
  - I am very flexible and can do the work as soon as possible.
  - I am a good listener as I bring back people’s answers from meetings.
  - I always turn up for meetings on time and never turn anything down.
  - I am a fast learner and good at speaking up for other people’s views.
  - I am good at making things happen and put other people first before myself.
  - I will keep to the same way of working, following in Janet’s footsteps. (Janet was the last rep for the group.)

- **My skills:**
  - I have good computer skills.
  - I am a good listener.
  - I deliver people’s views across to the right person.

- **Work I have done in the past:**
  - Research on people with learning disabilities and their backgrounds.
  - I am flexible and do lots of meetings: National Forum, Regional Forum and Partnership Board meetings.

**Question:**
Will Janet do a handover with you?

**Answer:**
Janet is still attending the Co-production Group meetings. This means a handover can take place.
• NHS Commissioning Board meeting on 13 Dec:
  - Dawn is not able to attend this meeting. No volunteer came forward to take her place.
  - Reps agreed they were happy for Siraaj to attend on behalf of the National Forum. He used to be the National Forum’s Health Rep before Dawn.
  - After the meeting, Siraaj will link in with Dawn, so that she can feed back to the National Forum.

• Discussion about the National Forum’s response to Winterbourne View:
  - Reps agreed to set up a group to take forward actions following Winterbourne View.
  - Karen F feels that the sentences given to the Winterbourne staff should be challenged.
  - Vicki R said that more difficult things will be coming out in March. This is when the findings of the Confidential Inquiry into premature deaths of people with learning disabilities are published. It will therefore be good to have a group to deal with the issues raised.
  - The South West will set up a Skype group with Karen McC, Alison, Kerry and Carole:
    - The Skype group will discuss setting up the group to take forward actions following Winterbourne.
    - They will also discuss writing a press release to respond to the final report about Winterbourne on 10 December.
Andrea Pope-Smith
The Association of Directors of Adult Social Care Services

- Andrea is the Director of Adult Services, Communities and Housing at Dudley Council. In this job she is directly responsible for the safety of adult social care services in Dudley.

- Andrea also chairs the West Midlands regional group of the Directors of Adult Social Services (ADASS). ADASS brings together directors across the country. She is on the National Executive of ADASS, and is the joint lead on learning disability services in this group. This means she is a champion, who challenges and promotes issues about learning disability and autistic spectrum conditions.

- After the Panorama programme about Winterbourne, Andrea became the lead to work with other people to make sure we move forward from the most terrible example of care and support we can imagine.

- Andrea told the National Forum that being involved in the Winterbourne work means she has seen, heard and learnt things she never wanted to hear. This has made her angry and sad. At the same time it has been a privilege for her to work with other groups to get to point where they are now. At the heart of all the work are people with learning disabilities and family carers.

- Andrea has a lot of confidence that after the Winterbourne report comes out things will get better.

Questions:

**Question 1:** Will you support us with our new group to look at what happened at Winterbourne and how we can get justice? We also want to make sure that the people affected get counselling.

**Answer:** I can’t get directly involved but I can give advice about how to raise issues from Winterbourne and other places. I have a list of questions for people to ask Health & Wellbeing Boards, Partnership Boards and Safeguarding Adult Boards.
These questions include:

- What do you know about what is happening to people with learning disabilities in your area?
- How are you holding people to account? (This means: How are you making sure people are doing their jobs properly?)
- How do the 3 boards come together to make sure abuse does not happen?

Andrea will send the complete list of questions to the National Forum. She explained that she is going to a meeting with the 3 boards in her area. This is the first time they will all have sat in one room together. She will give them her questions and find out how much they know, so that there is an improvement plan in Dudley. She sees this as the start of a change.

**Question 2: How can we influence Local Authorities?**

**Answer:**

- Make sure you have representation on all partnership boards. As a result of Winterbourne they will have new life.

- Ask adult safeguarding boards exactly what they are doing about learning disability and safeguarding. What part can people with learning disabilities and carers play?

- Write to the Chief Executive Office (CEO) of every Local Authority and Clinical Commissioning Group. Ask what role people with learning disabilities and family carers will have on Health & Well-Being Boards (these were PCTs). This could have real impact.

**Question 3:**

In supported housing scheme when there is a problem, why does nothing get done until an advocate gets involved? Why doesn’t it happen with support workers?

**Answer:** You don’t want to hear the answer – it just shouldn’t happen like this.
Question 4:
I have asked about having people with learning disabilities on Health and Wellbeing Boards. What do you think about this?

Answer:
It all depends on how strong the representation of people with learning disabilities is on your Partnership Board.

Question 5:
Are authorities doing enough to make sure that the model of assessment and treatment centres (private hospitals) is not necessary?

Answer:
The Winterbourne report doesn’t go far enough, but it has gone a lot further than was ever thought possible. There is a strong degree of hope that it will open the door.

Question 6:
Where can we get these questions from to ask the boards?

Answer:
Andrea will send them to Lyn, who will send them out on the National Forum network.

Question 7:
What will happen to hospitals like Winterbourne? Will they be closed? Can we ask the directors of Adult Social Services?

Answer:
There will be review of all people in those services and a programme to close them. People will be moved out into community settings.

Question 8:
Does Winterbourne still have its CQC registration? Castlebeck, the company which ran it, is still in business!

Answer:
Write to CQC and ask.
Question 9:
Why is CQC not out in public, rather than in an office and behind a telephone?

Answer:
Since Winterbourne we have seen a big change in the way CQC has responded. People did come out from behind their desks to say that mistakes were made. David Behan, the new Chief Executive, is already making very big changes. There has been some improvement. Andrea suggested the National Forum asks for a meeting with David Behan. He used to be a director of adult social services like Andrea.

Question 10:
Will people who have been punished go on a register, so they cannot work with vulnerable people in future?

Answer:
Yes.

General comments made:

- CQC needs to inspect more.
- David Behan has put together plan.
- There are lots of important questions the Forum needs to ask and consultation it needs to do. There is not enough support for people to do this.
- Andrea:
The Winterbourne report says a lot about the National Programme Board holding people to account (making sure they take responsibility for doing their jobs properly).
Before March it would be good to ask the minister, Norman Lamb, how people will be supported to do this. The government will be talking about a plan, and the money available to put the plan in place. The National Forum should ask how much money will come to people with learning disabilities and family carers so that they can get involved.
National Forum meeting in March

- **Norman Lamb – Minister for Care and Support:**
  - He is looking forward to meeting the National Forum team. People feel he is easy to deal with. He is the first Minister for Care and Support who has wanted to come to the Forum. The National Forum needs to work out what it wants from him. Reps should ask their regions what they would like the Forum to say to the minister.
  - **London:** He needs to listen to us and not ignore us. He has to help people with learning disabilities.

- **Issues for the March meeting:**
  - **Yorkshire and Humberside:** Why are we involved in CQC inspections, but never receive accessible feedback?
  - **North-West:** We need to get Iain Duncan-Smith to a meeting. He is responsible for work and pensions in the government.
  - **East:** The Eastern Region has questions for the DWP.
  - **Access to Work:**
    - Why can’t people with learning disabilities (PWLD) get good paid jobs? How many PWLD do organisations employ?
    - We can ask Amanda Platt in the South East about this.
    - We can ask Job Centres how many people with learning disabilities have a job.
    - Advocacy groups in the North West have been sent a letter about how many PWLD they employ. They have been slow to send in this information. It was suggested a letter could be sent by the National Forum.
    - In the North East 9-10 Remploy factories have closed down. There are no jobs for PWLD to go to.
    - Partnership Boards are supposed to report how many PWLD have jobs.
    - One rep has been told by an advisor that she can get a part-time job and earn up to £97 for 16 hrs, with working tax credit and a £200 grant to get into work. She wanted to do a computer course but it is hard to access courses. There are very few jobs to choose from if you have mobility problems.
Washing line:

1. **I would like the National Forum to take a lead on Winterbourne:** A group has now been set up, led by the South West. They will respond to the Winterbourne report and organise a press release.

2. **There should be a National Forum housing rep:** Karen McC volunteered for the role. Lyn Griffiths asked what the rep would do. It was explained that there used to be a housing rep on the National Forum. This was when Valuing People focused on health, employment and housing. Vicki said the Winterbourne report will talk about housing, so it will be good to have a housing rep. Karen brings valuable experience and skills to the role. This plan has been put on hold until it is clear the National Forum needs a housing rep.

3. **Not having too many outside speakers:** Reps liked this. In March there will be DWP, PIP & Norman Lamb. Lyn suggested making the March meeting about work and skills.

Any other business: Karen F reminded reps that this is their meeting, and they will be a lot more involved in the National Forum from now on. Craig said: “You need to make it happen.”

Actions from Day 2 of the meeting:


2. Setting up of group to respond to Winterbourne report on 10 Dec and prepare press release.

3. Lyn Griffiths to contact all regional coordinators to ask for:
   ✓ A list of all self-advocacy groups in their region and how they are invited to be represented on the regional forum.
   ✓ Whether they have a partnership board.
   ✓ If so, how are PWLD & carers are represented on the board.
   ✓ Ideas for how to involve more people from Black & Minority Ethnic communities.
   ✓ Questions and comments for Norman Lamb.

Finishing Up

It was agreed that the next National Forum meeting will happen on 12 & 13 March 2013 in Telford.