



## 2 and 3 DECEMBER 2014 MINUTES



**In the chair:** Craig Hart with supporter Catherine O'Byrne and Karen Flood with supporter Paula Camborne

**Apologies:**



**People at the meeting:**

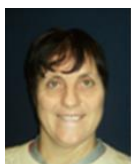
**North West:**

Mark Shackleton with supporter Jeanne Smith



**North East:**

Harry Longmoor with supporter Elliott Dougill



**Yorkshire & Humber:**

Alison Owen with supporter Eden Haytree



**West Midlands:**

Ruby Walker with supporter Sylvia Meyrick



**East:**

Carol Lee MBE with supporter Alex Morris



**London:**

Carrie Anne Beavan with supporter Jessica Manley



**South West:**

Kerry Martin with supporter Hannah Leach



**East Midlands:**

Clare Crawford with supporter Marie O'Sullivan and Ian Davies

## Day 1



- The Chair welcomed everyone to the meeting.
- Everyone introduced themselves.
- Ground rules outlined:
  - Laptops not to be used
  - Mobile phones to be turned off
  - Supporters cannot speak
  - Give members time



- Members were requested to use the traffic light cards
- The actions from the last National Forum meeting were discussed



- Reps met without Voiceability staff to discuss issues

## Regional Updates



### North East – Harry Longmoor

1. The regional forum held a joint meeting in Newcastle on 1 October with the North East Learning Disability Partnership Board.

This was an event to help advocacy groups get their voice heard with local councils, clinical commissioning groups and Health Wellbeing boards.

It looked at helping groups with practical skills to get their message across to the councillors and others who make the big spending decisions on social care and health.

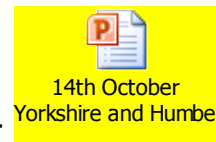
2. The next meeting of the regional forum on 10 December will be all about the 2014 Care and Support Act.

3. The team of self -advocates on the North East and Cumbria Transforming Care Group (new name for the Winterbourne Group) have been working very hard to make the meetings more relevant and user friendly.

**ACTION:** Harry to bring more information on future meetings



## South Yorkshire and Humberside



For **Alison Owen's** presentation –

## North West



**Mark Shackleton** discussed the CQC checks at Secure units.

Mark said he would be attending a conference in Blackpool which will involve different workshops.

## West Midlands



**Ruby Walker** discussed the Homes not Hospital conference.

We held our first Regional Conference in October. It was about moving on from Winterbourne View. We wanted to give all the groups in our Region the

information they need to speak up about the needs of people in hospital units.

And we want to work with their local councils to stop people from being put in hospital units in the first place.

The conference went very well. We had presentations from the Winterbourne Improvement Team. The SpeakEasy NOW Health Checkers team talked about their work reviewing Locked Hospitals for Worcester County Council.

Learning Disability Commissioners came from all over the West Midlands. Also new self advocacy groups who do not usually come to the Forum.

Groups were given a sheet to work on that asked:

- What have we got that is good?
- Who's involved?
- Finding out more

Everyone worked on these questions with a commissioner.

Groups are now more aware of the issues around hospital units. We hope it will help them speak up about it more strongly.

At our next meeting everyone will feed back what they have done in their areas to help people who are in hospital units.

### **Actions from the last National Forum Meeting Joining with the National Valuing Families Forum**

We said that it could work well for one good organisation to run both National Forum and the National Valuing Families Forum.

But we said it would **not** be a good idea for the 2 Forums to join together.

We think that the voice of people with learning disabilities would be lost if the Forums join together.

### **Ministry of Justice**

We know that people with learning disabilities are sometimes treated very badly by the criminal justice system. People can be kept in Assessment and Treatment units for too long.

But we are not clear about what we should be doing to get things made fairer.

We have not had Gavin's notes about how to campaign in our areas.



### **East Region**

For Carol Lee's presentation – [Click here](#)



### **East Midlands**

For **Claire Crawford's** presentation - [click here](#)



### **London**

For **Carrie-Anne Beavan's** presentation - [click here](#)



### **South West**

For **Kerry Martin's** presentation - [click here](#)



Public Health  
England

## Co-Chairs and National Updates

Craig spoke about the new position of Programme Manager, within Public Health England. This had been accepted by Donna Glover. Donna would be gathering information about people with learning disabilities. Donna has asked if she could attend the next National Forum meeting in March. A discussion took place around this.

**ACTION:** More information is requested on the work Donna Glover is doing. Karen and Craig to send out further information on this.

national forum  
of people with  
learning disabilities



## Role and Vision of the Forum

The National Forum works towards total inclusion and human rights for people with learning disabilities living in England.

### What does this mean?

The right to:

Choose where we live and who we live with

Gain employment and have equal pay

Use the same services as everybody else

Have support to be independent and confident

### What else?

The right to:

Make friends and see them when we want to

Have a sexual relationship, get married have children and bring them up

Have support for our feelings and our mental health

## **There's more!**

The right to:

Information we can understand and the support and time we need to make decisions

Independent advocacy to make decisions for ourselves and choose the advocacy we like

Any behaviour labelled as 'challenging' should not take away our human rights

## **There's even more!**

The right to:

Be safe in our local community and to have the right support to access it.

Be respected by our local communities and the police, health workers and housing services

Be safe from hate crime and discrimination

## **Our Action Plan**

We have talked and listened to people with learning disabilities across England and have three priorities that support our vision

- Helping people have a voice
- Welfare reform
- Being safe and staying safe

This is what we are working on.



Karen said that some taxi's charged more for people with learning disabilities.



Karen and Kerry attended the launch of the Learning Disability Alliance. This was seen as a positive day. It was decided that everybody needed to support each other.

Mark talked about employment of people with learning difficulties.



## **Future of the Forum Contract with Department of Health**

Presentation by **Christopher Cox** – [click here](#)

### **Questions**

What happens if there is a tie?  
Everyone has to agree or it won't work



When is it going out to tender?  
A notice has gone out on the website and emails have been sent.

Will there have to be joint meetings and carers voices being heard?  
It will be up to the members. Currently planning to have one joint meeting

Will the money be the same?  
It is a bit less.

Will there be the same number of meetings?  
The National Valuing Families Forum meet 3 times a year.

### **'Living Independently and being Included' Green paper Presentation by Christopher Cox**

For presentation - [click here](#)

**ACTION:** To inform Christopher Cox of any changes the 'green paper' presentation



Christopher asked the National Forum to send in stories of their experiences of how they wanted to be treated, about how they are involved in the local community or about how they felt going into an assessment.



**ACTION:** To complete the form attached, 'tell us your stories' and return.

To assess the form [click here](#).

Christopher Cox to send further information  
Any further questions can be passed to Chris.

## Presentations for Vice Chair took place

Presentations for Vice Chair were made by:

Mark Shackleton, Harry Longmoor, Kerry Martin, Alison Owen and Carrie Ann Beavan.

Voting took place for Vice Chair.

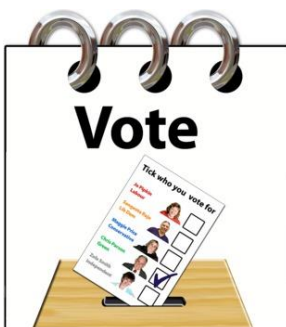
Kerry won the election.

## Day 2

### The Learning Disability Alliance

Presentation by **Tim Kealty**

Tim said we would be powerful if people who have learning disabilities, their friends and family stood together.



## 10 Reasons

1. Peoples basic rights are under attack
2. Self advocacy groups closing down
3. Public services are being cut
4. 1,000's people stuck in institutions
5. Independent living is getting harder
6. Hate crime is on the rise
7. Benefits cut and sanctions are hurting
8. Legal Act is disappearing
9. If we do nothing, nothing will change
10. But if we come together

## We can stop this injustice

The Launch of the Learning Disability Alliance took place in November.



A questionnaire will go out to everyone who signed up to the Learning Disability Alliance. These will be available on line. The questionnaires will help to create a report. The report will be passed to the Houses of Parliament in February.

The layout of the form was discussed. Improvements to be made were:

- Green amber and red
- Smiley faces
- Make the boxes a bit bigger for stories, if using paper copies
- Some people don't have access to a computer  
- Could do work on paper copies in groups – if done in groups there will be a box to say how many people took part in the work.

- Make sure the questions are able to be answered by people with learning disabilities and by family members and friends
- Tick box asking if the person who filled it in has a learning disability

**ACTION: Learning Disability Alliance questionnaire - To get the information out as soon as possible.**

### Next steps

1. Trust Tim to work with local people to do 'what good looks like' for the questions
2. Make sure changes take place
3. Get the questionnaire on line

### What can you do?

- Join the Learning Disability Alliance
- Tell friends and supporters
- Vote in May

### Group exercise

What does good look like?

### Community Care – Carrie-Ann, Ian, Karen



- People would feel safe when out
- Community officers to support/help people – more police
- People with learning disabilities should be treated equally and with respect
- People understand what it means to have a learning disability
- There should be keep safe places for people

to use if they feel unsafe

- People with and without disabilities working together to make a stronger community
- People with learning disabilities would be training with others (schools, police etc)

### **Money, benefits and fairness** - Carole Lee, Ruby



- Getting a job should be easy
- If on benefits – should rise in line with cost of living
- Good – tax rich more – equality
- Fair assessments (ESA) – assessors trained to work with people with learning disabilities – reasonable adjustment
- Benefit forms should be accessible and in paper form. Many forms are on line which doesn't work for everyone.

### **Own home and right support** – Mark, Kerry, Alison



- Good support 'joined up'
- Living near your family/where you chose
- Feeling safe
- Encouragement to be independent
- Choice of an agency – PA
- Being included in selecting staff
- Having access to a Social Worker

### **Access to health services** – Harry and Craig



- Being offered an annual health check and a hospital passport and health action plan and health professionals knowing to look at these.
- See someone that knows you and understands if there have been changes to your health
- Knowing how to complain and having support to do this

- Getting a service that meets your needs. With assessable information and appointment booking. Being able to have an appointment when you have transport and support, having choices.

## Action Plan



**ACTION:** Sue to email Action Plan to members

After last meeting we developed three priorities:

- To help people have a voice
- Understanding Welfare Reform
- Keeping Safe

A workshop took place on delivering our three priorities

## Helping people have a voice

What can we do now and how can we feed back to the forum in March?



- How many Self Advocacy groups closed?

Regional coordinators who have an overview of Self Advocacy to see how many have closed – by end of Feb

- Put on hold contacting Housing and care homes
- Equality impact assessment – Freedom of Information requests by March – to contact

152 local authorities

- Report on self-advocacy and share this with Learning Disability Alliance
- Self-advocacy groups regional annual reports shared by end of January ?- on hold
- Facebook added to website
- Collecting stories from the region by the end of February about where self advocacy has helped people
- Session about - who? Carol Lee
- Report to go to Department of Health

**ACTION:** Regional coordinators who have an overview of Self Advocacy to see how many have closed

**ACTION:** Equality impact assessment - Freedom of Information requests by March – to contact 152 local authorities

## Welfare reform

What can we do now and get more information for March?



- Set guidelines for accessible information
- This will be the base line
- Job Centre plus - can supporter go with you (mystery shopper) and observe what is going on. Ask if there is a learning disability specialist advisor there.

- Award system for Job Centre Plus

**ACTION:** Supporter to attend at Job Centre Plus



**ACTION:** To develop an award system for Job Centre Plus

## Keep Safe

What can we do now and get more info for March?



- Do people feel safer?
- Stay safe card – evidence that they are being used – to look at one area to find out if they are being used
- Lack of support hours increase isolation and anxiety any stories? – to take to Learning Disability Partnership Board
- Could learning disability become part of Local Authority induction training
- How much do we know about mate crime? Highlight issues of Mate Crime and domestic abuse

**ACTION:** Stay safe card – check on one per region if being used.



**Hear My Voice**

**Ciara Lawrence MENCAP**

Ciara talked about the MENCAP Campaign 'Hear my Voice' and members were handed copies of MENCAP leaflet.

Ciara discussed:

- What the campaign was about
- General election
- How to take part
- Website [www.mencap.org.uk/hearmyvoice](http://www.mencap.org.uk/hearmyvoice)

For information about campaigns please contact:  
**Ciara.lawrence@mencap.org.uk**

## Get more from Social Media Workshop



By Karen Orchard (VoiceAbility)

Presentation – [Click here](#)

Karen explained how the National Forum can use Social Media and talked about Facebook and Twitter.

Social Media is a way to share information online. It enables you to have a profile and it is a way to present yourself. A way to share information and photographs.

The National Forum could share information about campaigns.



### Facebook

Karen discussed in detail the privacy settings on Facebook and showed us how to upload photographs and how to write a status.

You can block people from viewing your site. When you post things online, you must check your privacy



settings. Privacy settings can be different on your phone, tablet and laptop, so you must check them regularly.

Karen discussed the possibility of a National Forum Facebook page.



### **Twitter**

On Twitter, you have 140 characters on each tweet to share information with people.

In twitter you can search for organisations and campaigns with the # key.

You can send people messages, either publicly or directly to them.

Like Facebook, you can block people who you do not want to see your site/tweets.

There is a notification section to tell you if anyone has tweeted or forward your tweets.

Karen stressed the importance of keeping strong passwords to access social media sites and checking privacy settings regularly. Everything you post online is there forever – even if you delete it!

Stay safe on line. Never give out any personal information.

**Adverts.** Everything you search for online will be shared with other sites. Adverts will appear on your Facebook account.

Karen said she would be happy to attend the next forum to see what members have achieved.

Members were asked if they would like to work with Karen in mini groups at the next meeting.

### **Question**

How many people handle the sites in VoiceAbility?

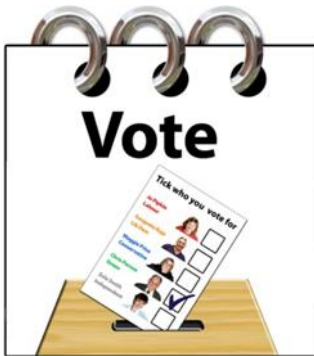


This is solely Karen's job.

## Summary of the day and future plans

On 1 April there will be a new contract. Because of all the changes, Craig and Karen offered to stay in post a little while longer. Members were requested to consider this.

**Question.** Do Craig and Karen remain as Co-chairs for a little while?



At the moment, Karen will leave in June and Craig will leave in November next year.

**Vote** – To keep Craig and Karen in post to support Kerry.

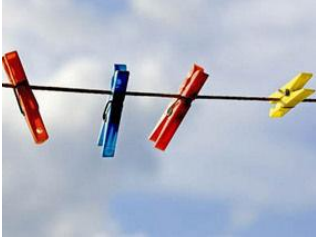
**Question.** How long should Craig and Karen stay in post?

**Vote** – 3 months.

Kerry announced to the Co-chairs that they would stay for a further 3 months.

## Washing line

- More time to discuss things.



- I don't agree with the rules. I would like to use an ipad not pen and paper. Kerry to take this to the planning meeting.
- Why didn't the National Forum answer the Department of Health consultation on accessibility last month?
- Was the National Forum represented at the Learning Disability last month?

**Next National Forum meeting 17 and 18 March 2015 in Telford.**

**Email address to contact VoiceAbility:**

**[nationalforum@voiceability.org](mailto:nationalforum@voiceability.org)**