



# Department of Health: Winterbourne View Review Engagement

## *A Summary of responses*



## The Engagement

To understand the breadth and depth of opinion about the events that took place at Winterbourne View Hospital, the Department of Health held a number of stakeholder events and workshops held between September 2011 and August 2012.

These involved discussions with people with learning disabilities who use care and support services, families/carers, commissioners, care providers, workforce, and the voluntary sector about the priorities for improving care and support for people with learning disabilities. As part of the review, an independent Expert Panel was appointed in an advisory capacity.

## Who contributed?

In association with key partners:

- we received over 1,000 separate pieces of correspondence, in the form of letters, reports and feedback;
- We held monthly Expert Panel meetings
- We held engagement events with:
  - People with learning disabilities and members of the National Forum of People with Learning Disabilities
  - Members of the National Valuing Families Forum
  - Voluntary sector organisations with an interest in learning disabilities and autism.
  - Commissioners from across the country
  - Professionals<sup>1</sup> from across the country
  - Representatives from National Care Providers

The engagement generated extensive material in a variety of forms, much of which was rich and detailed feedback. We have presented this word for word and in its “raw form” in this document. We would like to thank those who took the time to contribute and work with Government in such a collaborative way. It enabled us to hear the many different perspectives on how better outcomes for people for people with either learning disabilities or autism, together with either mental health problems or challenging behaviour.

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<sup>1</sup> General Practitioners, Psychologists, Nurses, Psychiatrists, Social Care workers, Speech and Language Therapists, Occupational therapists, academics

# **Feedback from People with learning disabilities and members of the National Forum for people with learning disabilities**

**Main Points from a discussion with Sheila Evans  
at the National Forum For People With Learning Difficulties <sup>2</sup>in Telford on 8<sup>th</sup>  
September 2011, about what should happen after Winterbourne View**

- We want to make sure that people are safe and OK where they are living, especially in similar places to Winterbourne View.
- The people who live in these places should have (access to) independent advocacy at all times.
- We want to see more peer advocacy funded, but are worried about the funding cuts for self advocacy groups all across the country.

**The Inspections**

- Staff and Inspectors should be trained by people with learning disabilities.
- Members of Self Advocacy Groups have good experience of being Quality Checkers.
- Staff in these places should be supported better to report abuse by “whistle-blowing”.
- We need to publicise the complaints procedure better.
- We are concerned that the CQC is focussing on “big level abuse”. There’s more to it than that, for example “the smaller level stuff” like when people have no choice about when they get up; to have a bath or shower etc.
- We rely (too much) on the staff that work with people who use non verbal communication, to tell inspectors & others what they are feeling.

It’s important that the Inspection Teams talk to and spend time with the people with learning disabilities who live there, without the staff being present.

- The CQC should be looking at all types of institutions –not just hospitals. For example, day Centres and also small organisations that are using Direct Payments.

People on Direct Payments and Personal Budgets don’t get the right information about people who have been banned (from working with people with learning disabilities).

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<sup>2</sup> Now the National Forum for People With Learning Disabilities

We are worried that someone who has run a home that has been closed, can still go out and start up a new one. This needs looking at.

### **Involve us from the start**

- We want to be involved in all stages of the process.

It is very important that the local voices of people with learning disabilities and family carers are heard (for example, through their Partnership Boards).

We need to continue to support people's natural relationships with their home communities, rather than sending them away to "closed" institutions.

Self Advocacy Groups could develop Friendship Groups that would include people living in Winterbourne View type places – If they are given the funding to do so!

- We should be involved:

In planning new services (with proper Person Centred Care Plans).

In Best Practice Commissioning (to reduce the number of out of area placements and to review these placements regularly).

In looking at how Safeguarding works.

### **Other Issues raised:**

- We would like to look at the best ways of involving us in the Department of Health's review.
- The Co-Chairs can collect Forum members' views and report on them at the Review Group's meetings.
- We could ask people with learning disabilities that have lived in places like Winterbourne View, if they would be willing to talk about their experiences, so that we can make sure these things don't happen again.
- We would like to get regular Updates from the Department of Health about their Review –in Easy Read, and at face to face meetings.
- We understand that in Wales, there are limits to the numbers of beds in such places as well as on how many different units one organisation is allowed to own and manage. Could the Department of Health check about making similar rulings in England?

- We don't understand why private hospitals like those run by Castlebeck were not included in Valuing People Now's plans to close all NHS Campuses and Hospitals.  
Should a provider that has had such a serious quality failing be allowed to continue running services?

## Report from the DH Review meeting on 1st December 2011

### Attendance at both the 1 December 2011 and 29 March 2012 events:

Jane Abraham  
Paddy Burke  
Joanne English  
Gloria Ferris  
Lyn Gregory  
Gavin Harding  
Jason Hill  
David Morley  
Tanya Orchin  
Val Parsons  
Chris Pasmore  
Naomi Richardson  
Tom Simmonds  
Nick Taylor  
Rob Wait  
Steve Watley

plus:

John Hersov  
Geoff Hodgson  
Liz Preter - Centrevents

Sheila Evans - Department of Health  
Morenike Williams

### **Our experiences years ago**

I was sent to the hospital more than 50 years ago when I was 17. I did not know how long I was going to be there.

Most of the clients on this ward went out to work or had jobs to do on the ward. Some of the staff said I should not have been sent there (I got on with some of the staff) and that I did not need the hospital but should have been out at work.

Why did I end up there? Maybe it was the tablets that I took for thyroid problems, but my parents were not confident to get my tablets sorted, so maybe that's why I went to the hospital for assessment.

When you were at the hospital, you used to help on the ward. I helped on the ward at C1 where people needed a lot of looking after (with) feeding, dressing etc. I used to be there all day until 9pm at night. I used to like that.

In the hospitals there was often not enough staff for people to go out. There were some locked wards – I had a pass key when I was working there as a domestic.



They had to keep the doors locked because the people on the wards might have run away, and they needed to have someone with them – but there were not enough staff.

If you were a person who is kind and interested in other people you had a role, a chance to help other people in the place you were living together. You became friends and when you moved out, you stayed in touch. Most of the people I got to know had come originally from where I was from, so when they left they stayed in the area and I could stay in touch.

Looking at Winterbourne View, that wasn't a place like that. No... that was cruel.

At the hospital it was OK in some parts, but some parts were not. On a Monday they used to show us pictures on a screen then we had dances, but sometimes it was on a big ward and you didn't have a lot of privacy what you wanted.

People lived in long wards. It was cold, the rooms, they were very big. I'm living in a house on my own now, but with support workers.

(When I first moved out from the hospital, there were) loads of clients living there. Sometimes, there wasn't enough staff to help you do what you needed to do.

Now I have more freedom it's much nicer, where I am now. I've been wanting that for a long time.

One of the staff that I used to know (the social worker), she said "Ooh this is the best thing you've ever done".  
I said "Yes, I have always wanted to do this".

I think all hospitals need changing.  
I spent half my life moving around the area I'm from.  
They were the big hospitals, and bullying is a big issue (there).

I don't think the old ways have changed.

### **Our experiences more recently (up to the present day)**

It is hard for me to talk about. I was detained under the Mental Health Act in a hospital when I was 17.

I was on section 3 for 6/7 years. They said it would be for 6 months, and every year they would review it.

I was sectioned for 6 years and moved around the country. One hospital wasn't very nice; the staff did things I didn't agree with, and it was only when I got out of hospital that I could tell people about it.

They said you had to go in there for 6 months, every year that got rolled on. I moved to different places – to different parts of the country. You wouldn't have known anyone from round here? – No.

There were some pretty bad things that happened that you couldn't talk about until you were out.

I was too scared at the time to say anything.

I was frightened that people wouldn't believe me.

It was only when I got out that I told my social worker

"This is what happened, this is when it happened", and they looked into it, but the people who treated me badly were not there anymore so they got away with it.

When I first got sectioned, I thought in 6 months I'd be out but then they kept going a year, then another year, then another year and I was forgotten. I felt neglected. I felt very alone; I felt like no one was listening to me.

"Each time you had that meeting every 6 months, did you know or understand why they were saying - you have to stay another year?"

Yeah, but I didn't really agree with it. I gave up after a while; I accepted it because they said I needed to be on the section. No one would listen to me about what I wanted when I wanted it.

Each time I had a tribunal, where 3 or 4 people sit in a line and they decide if you should be sectioned or not.

I had one every year, and each year I thought to myself this is it, this is when I will have freedom but it didn't work.

The doctor was like "You should be doing this, you should be doing that" and I thought "Wait a minute; this is my life you are messing with!"

It was only when my clinical case manager got another organisation involved and we did a person centred plan.

In it, you did lots of work where you worked out what you wanted and where you wanted to be, and it took 18 months.

## **Guardianship**

The Guardianship needs looking at. Once you are on it (and put on Section), it is difficult to get back off it.

They can place you anywhere in the country with Guardianship. They have a right to have control of your money, your rights and they can move you anywhere across the country (from Bristol to Leeds)...places are decided by the psychiatrist who goes through court.

It really needs to be looked at.

How many different places have you lived in? -16

How old are you? - 40.

Don't you feel that your whole life has been taken away from you because of the system?

Yes, once you are in it, it is very hard to get out of it.

### **When do we need assessment and treatment units?**

An assessment and treatment unit should be the last resort, when you are a danger to yourself or others, and the others can't cope.

Why aren't people going through crisis intervention teams? It was a lot better standard service, and you felt you were being treated normally.

There is a fine line for some people between Learning Disability and Mental Health, and it's hard to know which one you fit into. The services may not be set up well to support you.

Someone is crying out for help, but the services are failing.  
On Friday night they are trying to get a bed anywhere.

There are a lot of people with Mental Health and Learning Disability issues in prison, and they need to be supported.

If there was the opportunity to support people in their community, they may not need to be in prison.

### **Assessment centres:**

They provide an opportunity to observe people's behaviours, so we can see how unwell they are mentally.

Are we giving the right tablets; are they doped up;  
are we giving too much/too little?

They are useful to a point, but some people are very ill when they go and they need time to convalesce.

As they get better, there needs to be more done to help them manage day to day things like putting the washing in.

The Assessment and Treatment centre helped him to cut down on the drugs and function normally.

They supported him to do that as part of the person centred plan to prepare him to move into his own flat.

There are other important issues to be dealt with:

When people are under Section, they don't explain exactly what your section order is, and there is no accessible information on sections.

The mental health department has been told that.

The staff were all right, but I'll never forget the manager from the NHS. Because I was from "Bridges", he walked in with a calculator and said to one of the senior nurses "have we got a budget for him from Bridges?" like you were on the end of the conveyor belt.

What needs to happen when people are there?

Hospitals rely too much on medication and not enough on psychology or counselling; it's all medication.

When I used to get really anxious and kick off, they used to just inject me and that would be me for the next few days, asleep. They would just say "Do you want tablets?" And I would say no, and they would pin me down on the floor and inject me.

I spent 5 years on different medication.

The first day I was there, they put me on 16 tablets. My granddad thought I was stoned, but I told him to go and ask in the office as they gave them to me.

There should be something for that person to do, or (the chance of) going out.

If you want to go out to the shops, it's 2 to 1 and you have to wait for 2 weeks to go out; and if you are in a lock up ward, you can't go out.

The staff are bored and they don't know what to do.

There was a majority of people I could relate to with the same sorts of problems, and we could help each other out. We talked together and had group drama sessions each day.

Sit and talk to people, and listen to people to hear what they have to say and find out what their problem is.

It's important to listen and have eye contact.

You need to have a lot of patience. There needs to be someone first of all who can do that, maybe a professional. You could then help refer them.

Also having friends, people like myself who know what I am going through as they may have gone through it themselves.

"Peer Advocacy" - people like me, speaking up for me.

Would you be left in the home, or would any staff give you some support?

There was an advocacy service in the hospitals but I didn't use them because I couldn't speak about it. I felt isolated.

Did you have any independent support at the tribunals?

No.

In all cases, people in tribunals ought to get independent support at these tribunals.

It's important to have people who believe in you and believe that you can do things and be independent.

My sister told me I could be more independent and that made me feel more confident and happy to move into my own place. And I do like it here!

### **Looking to the Future**

It was a private hospital so my local authority was paying that hospital. Looking back now, I wonder if they did it (kept me in hospital) just for the money, or what?

With the organisation that supports me now, I go around England and Wales telling other people about my story.

I feel quite pleased about how far I've come, and its taken years.

I feel there must be so many other people up and down the country that are not getting listened to.

(It's important that) people are listened to, and know what their rights are within the place.

Our group is full of people who can speak up for themselves (really well!), but we are very concerned about the large number of people with complex needs who have been placed in assessment and treatment units, and must not be forgotten.

People with learning disabilities should be doing the training of the nurses and the people working in these centres.

There should be compensation for people with learning disabilities who have had to go through these hospitals.

## Report from the DH Review Meeting - 29<sup>th</sup> March 2012

### The Voice of People and Families

#### On the issue of "Open Access"

- We felt it should be made clear between units being open to visitors (whilst making sure that this meant that the people living there still felt safe) and that "It's still secure" - you can't just come and go if you are a resident there (depending on your status).

#### "Coming in /Going out"

- The location of Assessment & Treatment units is very important. It should be made easier for people from the local community to go in i.e. not hidden away on an industrial estate (like Winterbourne View).
- "Although the places I was at (in 2 different "out of area" counties) had "family rooms", I had very few family visits".  
"I shouldn't have gone there, far away from my family, but there was nowhere else to send me".  
"If you come under "X provider" funding, you should stay in "X provider" as far as possible".
- The access arrangements vary considerably from locality to locality. Sometimes the managers aren't up to it.  
The Mental Health Act needs to be reviewed to give people with learning disabilities, families and professionals the right to check up on places. We should also put pressure on the commissioners who are paying for people to go there (to check that they are being properly provided for).

#### Making Complaints

- "The managers are always in the office doing paperwork. The nurses are on the shop floor".
- "In our organisation, all the managers work two shifts a week (including over weekends). We have an open door policy to the office so people can come in and say "Bill, I need to have a word".
- "They should listen to the people inside more often"  
"Talk to them and listen to what he or she wants.  
Ask them questions to find out what they think and feel (about where they live); if the staff are no good or if they are being bullied there.  
Take them away from the atmosphere (of the place). Go for a walk; have a cup of tea.  
Make sure they get support to write it all down".
- People may not know that they can complain.  
It's like they need to be given permission.  
"Tell them "You've got your rights"  
"They need to know that "that's not OK; that's abuse" and "Do you understand how you can complain?"
- The organisation's policy should be put down on paper (in Easy to Understand words and pictures) and made pretty clear to the people there.
- There also needs to be clear information about who staff can complain to and what will happen then.

It's important to include people who use services in providing the training (to staff and service users) around Safeguarding and Whistle blowing, as well as helping to interview new staff when they are being recruited. Then it's a partnership.

### **The Voice of People and Families**

- We asked which Boards (and at what level e.g. the Health & Wellbeing Board) Commissioners would be reporting to, especially on the large number of out of area placements in a particular area.  
It could be hard for LD Partnership Boards to hold them to account, so this needs to be raised at a high level so it's clear who is checking up on them.
- Changes to how we do things need to "Start Early".  
Children's Social Services need to stop placing young people of 16 -17 in Units on Guardianship, rather than supporting them to live locally (and independently) on foster care placements.  
This makes them more likely to be put on a route through to an adult unit and then become "stuck in the system".
- "They should talk to the person", when deciding what is going to happen to them after the first 6 months in a unit.

### **Advocacy**

- Some local authorities are saying you can't have Advocacy if you don't use a service, so there's the question of eligibility.  
Also, Kent has large numbers out of county people living there.  
The new Advocacy contract says that you can only provide Advocacy to "Kent people".
- We would prefer that the Advocacy organization be "local and independent", but where is the money going to come from? The Commissioner or the Provider? Or from somewhere else?
- For someone living in a unit –how do you get one (an Advocate) in the first place, especially if you have to go through the staff (whom you may want to complain about)?
- Some people are entitled by law (to an IMHA).  
Some people can get an IMCA if they lack capacity.  
If self advocacy groups wanted to get involved, they would need training on the Mental Health Act and knowledge of the law, which is expensive.
- An advocate could help people to move forwards,  
or to change the situation for the individual.  
They should give them a card with a phone number they can ring.
- Who is the advocate working for? The person in the unit, and their family might have different concerns.

### **Commissioning**

- No single body regulates Commissioners.  
The Councils do.

- How can people with learning disabilities and families influence Commissioners' decisions about the kind of service they are buying, so that the person gets the right support at the right time?  
The danger is that they still go for the "quick fix" problem solving approach by "spot purchasing" a place, rather than putting the person at the centre of things and considering what's best for them.
- We had different views about the value of Person Centred Plans (PCPs) and Care Programme Approaches (CPAs) (updated every 6 months by law if you are in the unit under the Mental Health Act). "They should work alongside each other".  
It's important that any plans should be flexible enough to take account of "when I start to feel unwell or show signs of relapse".
- We need to have much better figures about the numbers of people who are in Assessment and Treatment units, where they come from (who is paying for them) and how long they have been there.  
We also need to be able to check how effective they have been for the person.

### **Professionals**

- They need to have training by people with learning disabilities.  
Sit and talk things over with people. Communicate things better and listen to them.  
"It's about HAVING RESPECT for the person with a learning disability and looking at the skills (and abilities) that they have got".
- The main bosses and managers should be trained separately from members of staff.
- The example was given of someone who used to get a regular injection. Once that stopped, the nurse still came round to check in how they were doing, which was appreciated – "Connection not Injection!"
- Learning Disability Nurses need to be trained up on Mental Health issues.
- There should be a greater "emotional literacy" content to training courses, including "compassion".  
The "Put yourself in my shoes" approach has also had a strong impact.

### **Providers**

- Providers should ask the people they serve (people and families, and other agencies they are linked with - for their feedback) and publish the results on their websites or in other forms.
- The Welcome Standards are a good example of how providers, people's friends and families can work together to create a better environment in which people can live together.

### **Regulators**

- We think that CQC must continue to use Experts by Experience on their Inspections.
- There should be regular inspections.



- They should be making at least one unannounced visit to every unit per year, not just scheduling lots of inspections after an Abuse scandal. Find out after a year how it's all working.  
They could arrange to work there, not just inspect.
- LINKs have powers to go into local establishments. Will these be passed to HealthWatch?  
This would be a local check to pass on to the CQC.
- More support is needed for whistleblowers. Encourage people to report their concerns, knowing that they will be better supported.  
The CQC have set up a new system for whistleblowers since Winterbourne View.

## **Other Issues**

### **Guardianship**

- "I hate it!"

The process needs to be more flexible (with regular checks), geared around the individual's needs rather than that of the system (sticking labels on people).

e.g. He is doing very well at the moment, but it was felt that it wouldn't be right to come off (Guardianship) too soon so things will be reviewed in three months, and then if everything is still OK, he will come off it then.

### **Developing good local services**

- Some areas have built up their local teams.  
It should be more cost effective to treat people locally and with early (therapy) intervention when they become unwell, before they deteriorate into depression and get placed in a unit (far away).  
It's good to put workers in "before they get worse".
- Better information for parents who can't cope (and the family's GPs) about the support options available locally, to prevent large scale "far away" moves.

### **How can we reduce the numbers of Assessment and Treatment units?**

- "Market Forces":  
Commissioners need to stop sending people to these places, so that they close their doors.
- It's linked to the shortage of houses available locally.  
If nothing is there, then it's easier to "bung them" into Mental Health units.

## **Key Questions/Other Suggestions**

- There need to be meaningful and therapeutic activities (when people are placed in units) that have value for the residents to experience.

Learning Disability Nurses and Assistant HealthCare workers need better training & support to organize creative activities in short term units.

- Someone who is on a Section should have their reviews more often than once a year.
- It's important to interview residents of units after they leave, as that may be when they feel safe enough to be honest about their experiences – "Evaluation forms on Exit".

# **Feedback from members of the National Valuing Families Forum**

**DH Review: Winterbourne View Stakeholder meeting**  
**National Valuing Families Forum**  
**9<sup>th</sup> January 2012**

**Family carers' experiences of Assessment and Treatment Units**

**Notes from group 1:**

**Staff and Training:**

- Doctors are often inexperienced and don't understand learning disabilities and challenging behaviour
- There can be a negative attitude towards families
- One family carer commented that the A & T Unit manager didn't explain what was going on – they said they would be 'observing' the person with LD
- Staff need to talk to families, not just the person with LD, as families are fully aware of the history of the person
- Some families felt that staff attitudes change once you challenge them
- All felt that staff should be open and understanding
- There should be better training of staff and particularly training around awareness of abuse especially when the person is non verbal
- Staff should have training on what to do in difficult situations
- The role should be well paid and valued – ensuring good quality staff and managers.

**Confidentiality:**

- Up to the age of 19, you would be told what happens to your child, afterwards families are not included.

**Medication:**

- Levels of medication can be very high and can affect behaviour. Use of medication must be appropriate.

**MHA and MCA:**

- There was concern around the appropriate use of sections. One family stated that the section destroyed their family; their son was petrified; he had no mental health need therefore should not have been in a mental health unit and sectioning was the worst thing that could have happened to him.
- Some families thought that sectioning should not be permitted for people with LD
- MHA should be used as a last resort – use MCA first - legislation must be applied correctly.

### **Assessment:**

- Professor Mansell's reports (Raising Our Sights) were very good but hadn't been actioned
- It was felt that there is sometimes a different standard of care for people with LD; there is little understanding of needs
- The situation isn't bad everywhere – some places have good LD nurses
- LD passports are used in some hospitals and were very useful
- CPA meetings can be very frightening – in one case 16 people were in a very small room
- Communication needs of the person need to be addressed
- One family carer commented that if the carer wasn't around to move things on, their son would still be there (now moving to another provider in Devon – family and staff have been working together for last 5 months to secure this move)
- There should be a time limit on how long is someone staying in an A & T unit
- Ask what is the process for moving people on. This should not be the job of the family carer, but the family should be able to be involved in the care pathway
- How can behaviour be assessed in an alien environment? It's about asking the right questions to the person with LD – sometimes just rephrasing the question in a way that the person is used to or understand better can help.
- Knowing that behaviour can be learned in A & T units and sometimes can be used to get a reaction – people with LD in A & T units can learn new behaviours by copying and this can be self-perpetuating and can lead to them staying in the unit for longer
- ASK FAMILY CARERS!

### **Funding and commissioning:**

- Navigating the funding between health/social care is difficult
- Families need to be able to trust the government
- Good practice must be shared - bad practice is often well known
- How services are commissioned needs examining

### **Advocacy and support:**

- Circles of support
- Office of public guardianship needs better publicising - families should get deputyship
- Include advocacy in assessment - advocacy should not be provided at the provider's discretion

- One family carer told of accusations that were made against the person with LD – their son was accused of calling 999, of turning phone on so that family could listen into what was happening at the unit
- CPA meetings can be very frightening – in one case 16 people were in a very small room – need to consider the need of the person with LD and their family when organising meetings.

### **Access to and visiting A & T units:**

- Family carers should be able to visit at any time
- There should be funding for families to visit – families may have had a cut in benefits anyway with the person with LD being admitted and there is no funding (unlike for prison visits) to allow families to visit. Units are often a long way from the family home.

### **Complaints:**

- Need quick, clear procedure

### **Finally:**

- A & T units should be high quality and local, open access part of the community
- Think local, act personal

### **Notes from group 2:**

#### **Do we need Assessment and Treatment Units?**

- Some families felt there was a need for A & T units. A & T units should be a place of safety to go in cases of crisis and should be used as a last resort/in exceptional circumstances.
- A & T unit should offer a therapeutic environment.
- It should be short term.
- There should be a discharge plan in place for people placed in A & T units, which should be monitored by care managers.
- There should be a guideline of justifications for the use of A & T units. This will list situations where it might be appropriate for a person to be placed in an A & T unit.
- There should be a duty that family carers/members are involved in the process from beginning to end.
- There should be proper management and training of staff working at A & T units.
- Sufficient time should be given for the assessment of a person with mental health issues especially where medication is involved.

- Assessments should be done in a tailored/person centred way, at times it is not in the patients interest to be assessed in a clinical setting. In such cases it may be more appropriate to assess/monitor people in a familiar environment.

### **What could have been done to prevent admittance?**

- Early identification, intervention and support of challenging behaviour, should not wait until it gets to a crisis stage.
- Proactive response - early and proactive review of patients in A & T units
- A person centred approach at all times.
- Respite centres which are run by social care, assess individuals over a short period of time in a place where the individual is familiar with.
- Families proactively going out of their way to gather information themselves.
- Containing the situation as a family; families may do this in fear that if they ask for assistance the authority will admit their loved ones.

### **Commissioning:**

- When commissioners place people how do commissioners review whether placement is appropriate and successful? Do commissioners get the families view on how successful they think the placement has been?
- Commissioners should not just rely on the feedback of providers as to the success of a placement but should speak to families who are able to give a better picture.
- Commissioning should use a person centred model of commissioning. Following assessment of a person's needs, the care package should reflect the needs of the individuals. People should not simply be placed on a unit because commissioner has block purchased beds in particular sites.

### **Funding:**

- A lot of time and resources is wasted debating whether a service requirement falls under social care funding or continuing health funding. There should be a pooled health and social care budget.
- There is a need for a ring-fenced budget for people with LD to ensure that resources get to this group of people.
- The need for personal health budgets. This could have the long-term effect of improving the quality of service of providers and encouraging competition, as with a personal budget people can easily decide for themselves whether to remain with a particular provider or leave if dissatisfied with their service delivery.
- There should be funding for preventative services not just when crisis happens.

### **Support and Involvement of family carers:**

- What is a family?

- There needs to be a clear structure that aids effective communication with families and allows for family involvement at every stage.
- There should be a requirement in LA tender documents to consult families.
- There should be an appointee from the family who represents the patients' interest and acts for the patients
- There should also be a family advocate to ensure that the interest of the patient comes first.
- A carers group/ board that meet to discuss cover the issues relevant to families and family carers.
- Travel expenses should be paid through public funds in cases where a person has been detained.
- Families should be informed about the content of the MCA , MHA and DoLS.
- There was a case where a son was sectioned under the MHA, family members were kept in the dark about decisions made about the sons well being and had no say in where he should go. There was a total breakdown in communication and family was not supported with the process.

#### **Staff:**

- People working with people with LD require above level empathy and care skills.
- There is a need for rigorous recruitment and training of staff.
- Care workers pay is poor. Commissioners should ask how much support staff earn and how it relates to total costs.
- Valuing the work of care workers and providing good training and the expectation of minimum standards of quality.
- The importance of good management and effective monitoring of staff.

#### **Other recommendations:**

- There should be good practice guidelines that cover a range of issues i.e. prevention, good model care, safeguarding etc.
- In the diagnosis of people with mental health or learning disabilities, families wanted to avoid labelling
- Families have experienced incidences where symptoms of learning disability condition wrongly diagnosed as a mental health issue.



## National Valuing Families Forum stakeholder meeting 23<sup>rd</sup> February 2012

### General session:

- Commissioners MUST involve families at all stages and EVIDENCE this
- Commissioners must show they have considered other options other than Assessment & Treatment units. If Assessment & Treatment units are used they must be small and local
- People with autistic spectrum condition/challenging behaviour often find change difficult – therefore need a move towards where things are more constant, secure which leads to improved behaviour. Need to have familiar staff (possibility bring staff from home?) and create a familiar environment
- Open access as a matter of course – if not this should be explained. Welcome packs should be provided.
- High risk aversion – need to persuade that risk is low – Local Authorities don't want people in their local community
- Default position should always be to ask WHY placement has failed and WHY problems have happened
- Things go wrong – LA asks for increased funding – this acts as a catalyst top shift to CHC funding

How do we get families listened to?

### Commissioners:

- Listen to families
- See what works well
- Cost/savings
- MUST visit all facilities

Rules are applied because of perceived risk

Families must be given the option to be involved at every stage of commissioning

Care planning and reviews

Power with wrong people

People have no time

Set in their ways

Families should be involved in design, staff recruitment, staff training

Managers must walk the corridors observing staff as well as people with LD

Direct payments – personalised services

Often decisions are divorced from diagnosis

### Ask commissioners:

- WHAT are they commissioning?
- HOW will this work
- How long?
- Care pathway?

There is money in the system but the person with LD isn't getting it

What is the legal requirement for commissioning services? And how they are provided?

NHS/Social services not joined up and working from different models

## EXPERTISE-----LOCAL

Are they mutually exclusive?

Some places, families are encouraged

## FAMILIES

Open access/culture

Links with local community

Provider boards should have paid family members on them

Family members should be giving feedback

Use the internet for family members to talk to each other and give feedback on outcomes

Providers' confidentiality can compromise family involvement

All the money to support someone needs to be in one pot with power and control of this pot given to the person or their family.

Independent advocacy should be written into all contracts

There must be clearly defined outcomes agreed by families

There must be an agreed timescale for treatment

Outcomes must include moving on and what this might look like

Person centred plan should have legal status. Use budget to pay for advocate to support implementation of the plan.

## **The Mental Health Act and the Mental Capacity Act - Group 1**

- The 2 bits of legislation can be confusing
- Councils don't use MCA in deciding payments, they decide who to give direct payments to/don't involve families
- Do we need a hierarchy of best interest decision takers as per REC consent decisions?
- Being a deputy doesn't guarantee control over financial decisions.
- How MHA is used
  - In crisis to move people to A& T
  - Social services need to provide support earlier to avoid crisis

'Family are the continuous thread through our son's life'

## **MHA/MCA-Group 2**

- Need info for families
- Families often explain/give info to professionals
- Services misuse MCA-say person has capacity to make decision and ignore family
- Capacity to understand consequences
- Best interests meeting don't include families

- Assessor needs training in assessing capacity- who checks this?
- How to do MCA assessment for people with autism?
- Misuse of MHA- CB is not a reason to section
- Lack of skill in LAs to come up with creative packages
- Homes with low grade abuse:
  - If respond violently, used as excuse to use MHA
  - Medication to deal with behaviour not the problem
- Use place of safety - home from homes
- Good quality care
  - Run by people with right ethos/past personal experience
  - Provide good training
  - More activity, person-centred
- Do you need to section in a crisis?
  - need person centred plan for individual, including emergency plan
- Who is responsible for following plan
  - need safe places to go in a crisis
  - Need right services locally or use circle of support as personal resource
- Use MHA properly - risk to person or others - for mental illness, not CB.
- Discharge plan from day 1

### **Complaints-Group 1**

- 1) Families informed
  - Handbook
  - Part of contract
  - Transparent procedure
  - Good communication
  - How to handle complaints
- 2) Advocacy
  - Independent and unbiased
  - For family
  - Peer support/other families
- 3) Good practice (Avoids complaints)
  - Good assessment
  - Care planning (copy to families)
  - Care management
  - Review

- Training social workers etc in LD
- Families not penalised
- Support needs of individual
- Good calibre management and staff

## **Complaints- Group 2**

### 1) Culture change

- Providers, commissioners, LAs, councillors
- Open, honest and transparent
- Good management
- Getting real about capabilities of individuals
- Complaining is constructive and can improve services
- Ministers listen and be realistic
- Ministers for LD (and complaints)
- Healthwatch supports family carers

### 2) Good carer support services

- Early information
- Guidance on complaining in accessible format
- Hotline (like child line)
- Clear info on who you go to
- Staff/Managers have real experience

### 3) Protecting individual and families

- Penalising individual
- Taking advocates seriously
- Don't hide behind safeguarding
- Clear accountability structures
- Family advocacy with respect and resourced

# **Feedback from the Winterbourne View Special Learning Disabilities Programme Board**

## **Special Learning Disability Programme Board- Winterbourne View, 28 February 2012**

### **Present**

#### **Chair and Co Chair**

Paul Burstow, Chair, Minister for Care Services (DH)

David Behan, Co Chair, DG Social Care, Local Govt and Care Partnerships (DH)

#### **Forums**

Viv Cooper, (National Valuing Families Forum (NVFF))

Cally Ward (National Valuing Families Forum (NVFF))

Amanda Platts (Supported by Marie O'Sullivan) (Co-Chair Nat Forum)

Gavin Harding (Supported by Lyn Gregory) (Co-Chair National Forum)

Jackie Edwards, Autism Family Carer

John Simpson, Autism Self-Advocate

#### **External Partners**

Mark Goldring Mencap

Scott Watkin, Mencap

Bill Mumford, Providers' Forum

Andrea Pope-Smith, ADASS

#### **Department of Health Officials**

Bruce Calderwood

Ben Dyson

Patience Wilson

Sheila Evans

Pam Nixon

Anita Wadhawan

Morenike Williams

Zawar Patel

Kim Dhadda

#### **Guests and Presenters**

Bernadette Hanney CQC

Geoff Baines, NHS South Strategic Health Authority

Peter Murphy, Director of Adult Services, South Gloucestershire

## Key Points from Group Discussion

### Group 1 - Voice, Advocacy & Commissioning

#### Voice

- There is a lack of clarity about what voice means.
- Should there be a principle of equal voice?
- Messages are not being sent across clearly enough so people know what is happening. People need to get the right information - this should be readily available.
- If a person falls under the Mental Health Act that person and their family/carer have to be given information and ensure they understand what is happening, why they fall under the act, how they can get out of the acts remit etc. This is the law. However, this does not happen in practice. Why doesn't it happen in practice and what can be done to make it happen in practice?
- Rather than providing information and support to family/carers, family/carers are left feeling patronised by best interest speeches. So that although the principal of equal voice/partnership appears widely accepted, its implementation is minimal. How can we encourage equal voice?

#### Advocacy & Commissioning

How to commission and monitor advocacy? What outcomes do we expect from advocacy and how do we implement them?

- Advocacy should be provided by commissioners not providers, this is to avoid a conflict of interest - If advocates are employed by providers, then they will be hindered from carrying out their role as they will seek outcomes that are in the interest of the provider. The contract must be commissioning and not employment.
- What are advocates doing? What are the right skills? Independent advocates should listen to both sides and speak up for that person. Otherwise, it defeats the object of having an advocate.
- What is the framework of accountability? Commissioners should challenge advocates and ask searching questions to satisfy themselves that the advocates are fully aware of what is going on with people that are in contact with services. The framework of accountability would also mean that commissioners receive feedback from advocates rather than just the provider. As advocates, they can see a pattern.
- Power advocacy, who sees the person and how often? There needs to be an improved care management approach.

- How do we organise ourselves to make sure advocacy happens at ground level? (1) Care programme approach- however this is only limited to the mental health perspective. (2) Advocates on health and wellbeing boards. (3) A forum to get all the voices together.

### **Three Key points for Group 1**

- Improving the quality of person centred planning - not just care plan. This means not just planning for when things are going well but also planning for when things may go wrong so as to avoid spot purchasing in times of crisis.
- Advocacy - Advocates need to be commissioned by commissioners and not by providers.
- Strengthening involvement of families on health and wellbeing boards - to make a contribution to improve quality of care and long term results.

### **Group 2 – Commissioning and Planning**

#### **JSNAs**

- We know who the people are who need support as information comes up from schools, there should be no surprises for adult services. Child and adult teams don't talk to each other and don't learn from each other.
- Is it that we didn't know the needs or that we didn't plan for those needs? General view is that it's the latter. So the issue may not be so much about improving JSNAs as improving how commissioners use the information in commissioning services to meet needs.
- Accessibility-language of JSNAs is often not accessible to users and carers.
- Currently look at what service is available not what service are needed- How do we turn that around?
- In assessing individuals' needs, teams don't take a lifecourse approach. We need to look at an individual's history, not just where they are now, and at what could be needed in future.

#### **Commissioning**

- Why do commissioners buy places in big units? Because they are there and it's easy. The big question is how do we change that? To change the current provider model we can either
  - restrict planning for units by using planning laws, or limiting bed numbers or setting standards (i.e. attack provider) *or*
  - change commissioners' behaviour. How do we do that?
- What skills do commissioners need? What training do they get? And are those the skills and training which the commissioners ought to have?
- Discharge plan - needs to be focused on what the individual needs, and not simply returning them back to where they came from. It shouldn't just be about putting people back into the bad situations which triggered problems.



### Three Key points for Group 2

- Transition: not just about knowing the needs but acting on them. Children and adult teams do not talk to each other.
- History: Looking at what was as well as what is and will be in planning.
- Move away from short term thinking and focusing on this year's budget.

Not about needing new information but sharing and acting on information to plan and commission for change/across and individuals life.

How to drive change? Where does the power lie?

- Really involve individuals and families

How to incentivise local leadership?

- Look at good practice, not about describing a good service but identifying what we need to do to change lives and outcomes for individuals. One option could be to develop pathways.
- Incentivising multi-agency teams to drill down and identify needs. Needs not labels.

### Group 3 - Providers and regulators

- **Training** - Professionals and care workers are not the same thing. Care workers don't need minimum qualifications or training. Need to set out the minimum training requirements/ qualification levels for care workers.
- CQC should inspect training, for example on use of restraint & positive behaviour support training (Studio 3)
- **Recruitment** - The response to the pin-down report in 1990s (Lord Warner) set out importance of values based interviewing as part of recruitment. Recruitment processes could be improved through:
  - Peer monitoring of the interview process
  - Involvement of people and families in interviews
  - Profiling is rarely used in social care – could be used to weed out unsuitable candidates (NB. link to the findings of the Dignity Commission today)
- **Culture** - Role of the registered manager is really important in setting the culture. Managers need peer mentoring.
- Providers can be reluctant to report all incidents of restraint
- An organisation with a good open culture will be one where:
  - There is a continually changing process - using reflection and review
  - Healthy environment
  - Open to learning – not fear of failure/cover up
  - Open scrutiny
- Culture needs to be demystified and measurable:

- Providers to set out a position statement – what you will see when you visit
  - Providers need to demonstrate that they govern themselves well
  - Openness to families is essential
  - Commissioners need to look at quality of provider – for example, track the record on moving people out (not look at policies).
- **Regulators** - CQC have to register new providers if they meet the minimum standards set out in regulations – regardless of whether or not the new service has been commissioned locally
  - There are no minimum/maximum numbers for size of A&T units in the regulations – is it for govt /regulators to manage this?

### **Top 3 points**

- Needs to be greater openness about reporting on use of restraint
- Providers to set out statement of purpose – what you will see when you visit - will help with transparency
- Give commissioners top 10 tips on what a good provider looks like