Appendix U: Service user focus-group report

1 Perspectives of people with learning disabilities about the Challenging Behaviour and Learning Disabilities NICE guideline: a report for the NICE Guideline Development Group

1.1 Aim of the focus group

The Guideline Development Group for the NICE Guideline on 'Challenging behaviour and learning disabilities' approached the The Elfrida Society and The Advocacy Project to organise and facilitate a focus group event for people with learning disabilities. The aim of the focus group event was to present the guideline to the group and gather their views about included topics with a view to incorporate the information in the guideline and adapt any existing recommendations.

1.2 Background information about the organisations which took part

1.2.1 The Power and Control group (The Elfrida Society)

The Power and Control group is a group of adults with learning disabilities who represent the views of people with learning disabilities in Islington, London. The group are consulted on local services and issues and hold larger forum meetings, which anyone with a learning difficulty in Islington can attend. They are funded by The Elfrida Society, a charity based in London which aims to make it possible for people with learning disabilities to manage as much of their lives as they want and feel able to do.

1.2.2 Camden Speaking Up Rights Group experts (The Advocacy Project)

The Camden Speaking Up Rights group experts (SURGe) are a group of adults with learning disabilities based in Camden who give advice to health and council services on what people with learning disabilities need. They are a service user involvement group which is part of The Advocacy Project, a charity specialising in advocacy and user involvement in London.

1.3 The focus group workshop: who attended on the day

Four members of the Power and Control group attended the focus group. These were: Martin Wallin, Adrian Brown, Celia Lockhart and Paul Davies. They were supported by Vincent Bottomley, consultation manager at the Elfrida Society, who also facilitated the group. Five members of Camden SURGe attended the focus group. These were: Stuart Dunn, Jackie McMorrow, Fatima Begum, Musa Khan and Maureen MacDonald. They were supported by Kath Dawson, the Camden SURGe coordinator who also helped facilitate the group. Professor Steve Pilling and Elena Marcus from the National Collaborating Centre for Mental Health carried out a presentation about the NICE guideline and helped facilitate the group.

1.4 The focus group workshop: methodology on the day

The workshop started at 11am and finished at 2pm. After introductions Steve Pilling took both groups through an Easy Read PowerPoint presentation about what a NICE clinical guideline is and what areas this particular guideline covered. During the presentation, people asked questions and there were some brief discussions.

Once the presentation had finished the group was asked to consider their views and experiences about the following areas covered in the guideline:

- Causes of behaviour that challenges in people with learning disabilities
- Staff training
- Medication for behaviour that challenges in people with learning disabilities
- Other therapies for behaviour that challenges in people with learning disabilities

During this part of the day, the group addressed each question in turn. Both Vince and Kath facilitated the discussion making sure everyone had the opportunity to comment. All expressed thoughts and views were recorded on a flip chart which have been organised according to general themes below.

1.5 What are the causes of behaviour that challenges in people with learning disabilities?

1.5.1 Problems in childhood

A troubled upbringing was seen as a potential cause of behaviour that challenges by some service users, particularly through learnt behaviour:

> *"Some people, when they are a child they see their parents shouting or being violent so they think this is the way to behave"*

1.5.2 Not being understood or able to communicate

The group described personal experiences of having disabilities communicating physical or emotional problems. In addition to disabilities communicating, the general view was that professionals or family member's had often not taken the time to try and understand the persons underlying problem. The inability in being understood was seen as a contributing factor to behaviour that challenges.

> *"I had difficult behaviour as a child because it was hard to say how I was feeling"*

> *"People did not find out early what was upsetting me, they did not do a proper assessment"*

> *"It might be that someone doesn't get on with a person who doesn't understand them"*

1.5.3 Lack of support from people who can be trusted

The group felt very strongly that a lack of support could lead to behaviour that challenges. They stressed the importance of having good quality relationships with staff and other people who supported them.

> *"Some people might not have any support"*

> *"You need someone to talk to who you can trust"*

"Not having good relationships"

"A bad experience of support can make it hard to trust anyone to help you"

"A lot of people with learning disabilities have other needs like mental health, or sensory impairments, but if you have high support needs you have to rely on good staff to get the right tests"

1.5.4 Physical health problems

There was a consensus among the group that underlying physical health problems could often lead to behaviour that challenges if they were not addressed. Some members of the group said that their own physical health problems had often been ignored by healthcare professionals in the past.

"I had a lot of health needs in my life, but my needs were not being met"

"Late diagnosis of health problems"

"You might have an accident which affects your behaviour"

"Health staff might think your health problems are part of your learning disability and not see them or treat them properly"

1.5.5 Mental health problems

Untreated mental health problems were also seen as a possible cause of behaviour that challenges. Being able to communicate mental health issues to others was seen as a difficulty.

"Some people have depression and this causes them to get upset and angry"

"You might have emotional problems and not be able to say how you are feeling"

1.5.6 Not being included in decision making about care

Within the group there was an overall sense that service users were rarely included in decisions about their care as their views were deemed unimportant. They also felt that there were too many healthcare professionals involved in their care. Being undermined in such situations was perceived as a potential contributor to behaviour which may challenge.

"I was angry because I wasn't being listened to"

"What the person themselves wants can get left out. Services are not person centred, not including the person in everything about their lives."

"There are too many people involved in your life – staff, friends, family"

"Often not being included, getting left out of decision making."

1.5.7 Prejudice and discrimination

Most members of the group had experienced discrimination from health professionals, care staff or members of the public. The fact that stigma pervaded most areas of their lives made it all the more difficult. The group felt very passionately about this topic and had many experiences of discriminatory behaviour to share. The group felt that these experiences had negatively impacted their well-being and could lead to behaviour that challenges.

"It is getting even harder to be included. This leads to anger, frustration, hurt"

"We want to be treated equally but it is not happening. For example how hard it is to get a job"

"People in charge didn't respect me, they talked over me, they didn't treat me with dignity"

"Discrimination. You suffer this as a child and all your adult life – not being treated fairly, being rejected all the time, not being included, not feeling good enough"

"How society looks at you. They don't understand disabled people. You get judged. It is painful"

"You get a negative label"

"Snakey government policies"

1.6 What should staff training involve?

1.6.1 Training

The group listed a range of areas they thought were important for staff to be trained in. They felt that training should occur before people started working and that regular monitoring of performance would help maintain an appropriate standard.

"Staff need training to have a calm approach with people, especially if they are angry, give people time"

"Training on how to be person centred, how to work in a person centred way"

"Training on how to build good relationships with people, how to get to know the person and make a person centred plan with them"

"Training on good communication skills – talking, Makaton, signs, pictures, objects of reference"

"Staff should be able to work with the person to make a plan of what helps them when they are angry – like going to a quiet room for a drink."

"Managers and staff need to be able to sort out a problem quickly before it gets to be a bigger problem"

"Staff should get training certificates so we can see what level of skills they have"

1.6.2 Appropriate support for staff

As well as training, the group felt that it was important for staff to receive good support from managers as the job could be very stressful. The group also highlighted that being able to build good relationships with staff members was crucial for the maintenance of a good experience of care. In their experience this had been difficult to achieve as staff were often recruited through agencies which meant that different people were involved in their care.

"*Staff need good back up support and expert advice from their managers and others"*

"Managers need to take responsibility and have experience of the people they are working with or managing a service for".

"Make sure that the support is consistent, not lots of change – over and agency staff."

1.6.3 Staff qualities

The group listed a range of qualities which they felt were important for staff wanting to work with people with learning disabilities these included:

- being good communicators
- being nice and friendly
- being polite, respectful, understanding, a good listener
- a good attitude and to understand the people they work with and what problems they face
- taking time to build relationships, getting to know the person and how they communicate
- treating the person with respect, making sure they get enough one to one support when they are angry

1.6.4 People with learning disabilities need to be part of interview process

There was a strong feeling from the group that people with learning disabilities should be involved in the interview process for recruiting members of staff and in delivering training. This was seen as a good way to empower service users and to make sure potential candidates were suitable for the role.

"Staff should be interviewed by people with learning disabilities"

"At interviews they should interact with the people they are going to be working with so that we can see them in action – we can tell if they have the right attitude"

"Staff should be checked by people with learning disabilities to make sure they are doing good quality work – like the Elfrida Society User Led Monitors"

"They need training from people with learning disabilities before they start, about what their job is about"

1.6.5 Surveillance

In light of the Winterbourne View report, some members of the group felt that there was an extra need to monitor staff and to check they did not have a history of abusive behaviour.

"If people agree there should be CCTV in some places so we can keep an eye on staff"

"Everyone should have a police check so we can make sure they are not lying about their experience"

1.7 What are your views on medication for behaviour that challenges?

1.7.1 When medication should be used

The group felt that healthcare professionals were too quick to prescribe medication when people presented with behaviour that challenges. They felt it was important to understand the cause of the change in behaviour and to use medication only in the short-term or combined with other approaches.

"The doctor needs to meet the person to know what will help. They need to get to know them and see how they are"

"It is important to talk to the person and try to solve the problem at its root cause"

"A balance of both can work – medication can help the person to be calm so problems can be sorted out"

"Medication is not the solution, but it might help for a short time"

1.7.2 Dosage and monitoring

If medication was prescribed the group felt it was important to make sure dosages were checked and monitored by appropriate healthcare professionals. They also felt it was important for people to understand more about the medication being offered and being involved in decisions about the prescription of medication.

"Get the dose right and the type of drug"

"Make sure you check with the person about how they are improving as time goes on, so that they are not stuck on the same dose all the time"

"Monitor the treatment very carefully and regularly. It can be addictive and have bad side effects"

"It is important to have an accessible review and assessment of medication that is as inclusive of the person as possible"

"Help the person to understand about their medication so they can feel in control"

1.8 What are your views on psychological therapies for behaviour that challenges?

The group did not have any experience of psychological therapies for behaviour that challenges so it was not possible to get their views on this topic. Instead the group talked about therapies, other than drug treatment, which may help in preventing or reducing behaviour that challenges in this population. These are listed here:

"Music therapy"

"Art, pottery"

"Movement, dance"

"Massage"

"Hypnotherapy"

"Meditation"

"Anger management – having a punch bag!"

"Someone there to listen would be helpful"

"Giving the person the chance for a break, respite, change of scenery"

"Be creative in finding out what the person is interested in, what might work for them"