



## Final Report Self-Advocacy Project

### What we set out to do



Inclusion North has been working on a project concerned with exploring and developing self-advocacy within assessment and treatment units. This work began in the North East of England.

This project was instigated and born out of the abuse at Winterbourne View. The basic premise of the work was to explore how to best support self-advocacy in settings which might not have traditionally lent themselves to encouraging this. This includes self-advocacy in both its guises.

We feel these are:

- The choices people make in their day to day lives in this context particularly around their interaction with services and treatment
- Exploring the possibility of developing a collective voice based on a civil rights approach for those described as patients

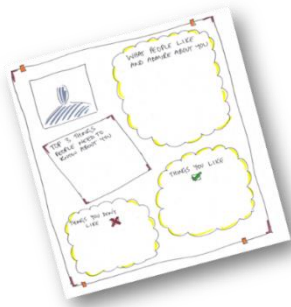
We worked with an NHS provider in the North East to develop and deliver this project. They offered us the space and staff support to deliver this project.

We wanted to give other groups across the country the opportunity to explore this locally.

### We worked on 6 key areas:



- Understanding Self Advocacy
- Making decisions
- Looking out for each other
- Good support
- Having a say in care and treatment
- Interventions



## How we did this piece work

We had an application process whereby we invited local groups to tell us their ideas for delivering this work. We had applications from 6 self-advocacy groups and all 6 delivered a part of this work.

They were:

- Leicester Mencap worked on understanding self advocacy
- Skills for People worked on interventions
- Opening Doors worked on making decisions
- Speak Up Doncaster worked on having a say in your care and treatment
- Cornwall People First worked on good support
- Advocacy in Greenwich worked on looking out for each other



## Understanding Self Advocacy

Leicester Mencap delivered 5 sessions into their local assessment and treatment unit.

They designed lots of interactive ways of supporting people to think about and understand advocacy including - advocacy quiz, advocacy snakes and ladders – all of the resources are available here:

<http://bit.ly/UnderstandingSelfAdvocacy>

The posters that people made about advocacy are all on display for everyone to see.

The staff at the Agnes Unit hope to develop and run their own patient feedback meetings for people to have a say.

### Big messages from the work:

- It's important that you give people a choice of activities to choose from because different people like to do different things and they enjoyed taking control of the workshops
- It's important to be able to be flexible and adapt the workshops to the meet the interest of the people
- Having access to these workshops has enabled
  - ✓ 1 person referred herself for Advocacy
  - ✓ 2 People asked how to join Advocacy Groups,
  - ✓ 1 person was supported to find out about the Advocacy Group in her area and has made contact with them

*'I liked talking, listening, thinking. I think it's important to have my voice heard. Workshops everyday would be good. It's hard to be listened too.'*



## Recommendations

- All Assessment and Treatment Unit should make links with their Local Advocacy Groups / Projects
- These group should have the right funding and support to deliver sessions into ATUs
- Independent Advocacy Groups should be delivered at Assessment and Treatment Units. Failing this, the Assessment and Treatment Units should set up a patient forum where people can go on a regular basis to have their say and to be heard – this should be done away from the main unit and run by a separate staff team.
- It's important that people and staff know how to get an Advocate and have the right information about finding and joining an Advocacy group.



## Looking out for each other

Advocacy in Greenwich worked into their local ATU and over the course of 5 sessions they developed a 'top tips' book written by patients for patients.

This is about things that would be helpful and would help them have the right information to look out for other people- like local information on getting around and charges with cash machines.

You can see the top tips book here:  
<http://bit.ly/LookingOutForEachOther>

*"The work was good and the group members worked well together and very hard"*

## The big messages from this piece of work were:

- All self-advocacy group should be supported to go into Assessment and Treatment Units and help people think about important issues
- Helping people think about looking out for each other, give people the opportunity to actually do it
- Everyone should have the chance to think about what they can offer others
- Self-advocacy groups could help people review this and check people are being supported to use it.

## Recommendations

- Groups from the 'outside' need to be going into these places
- We need to bring self-advocacy to people so they can support people to gain confidence and speak up for themselves when they need to





## Having a say in your care and treatment

Speak Up designed a conference for people who had been in Assessment and Treatment Units in the past and for those who have intensive support from the community team and are therefore at risk of using assessment and treatment services.

The conference was delivered by self-advocates.

It gave some background information about Winterbourne View and the “speaking up and staying strong” project.

After this we did workshops with people to think about the issues in more detail and also got people thinking about their dream of how the services they need could be better. They used resources like - one page profiles, communication profiles and crisis plans – all of these you can find here:

<http://bit.ly/HavingASayINYourCare>

*“It helped the group get along, just because we were talking about ‘looking out for each other”*

### **The big messages from our workshops are that**

- Communication profiles helped people plan how they will speak up.
- People know who is best at supporting them and who understands them best – these people need to be fully involved in peoples care and treatment planning.
- The words care and treatment mean lots of things to different people, people understand it differently and we need to remember that when talking to people about it.
- People said that sometimes when you go in to an assessment and treatment unit some

of the things that are really important to you are taken away – for example not being able to keep your own money. The group thought it was important that people should be able to have as much independence as possible whilst staying in hospital or they feel worse and lose skills.

- Some people knew nothing of advocacy or self-advocacy and as a result of this work are now going along to Speak Up and joining in different things and meeting new people.



### **Recommendations**

- Self-advocacy groups should work closer with assessment and treatment units
- Self-advocacy groups can help people to speak up. Some people said it was stressful speaking up because you are not always listened to and they made people feel unworthy
- Self-advocacy groups have loads of resources and can share these with the assessment and treatment units if they are involved
- People in assessment and treatment units need more easy read information and the care and treatment plan **MUST** be produced in a way people understand.

## Making decisions



Opening Doors advocacy group worked into a hospital they were already going work in. They built on the work they had already been doing and started to attend every patient meeting to support everyone to have an equal say.

They delivered training to 100 staff over 2 weeks, this was very positively received and they found staff could share with them issues they had with moving things forward – the team are meeting with the CEO to feedback all of this work and what it needed to take it forward.

<http://bit.ly/INMakingDecisions>

## Big message from this work

- The team supported patients to make the ‘banned list of items’ easy read so everyone understood what they could and could not have – all services need to be clear about this
- The team arranged for 6 people to go to a local husting event – it is really important that people are able to get information on joining in local events
- The patients are supported to chair their own meeting and have designed the group name and logo – this was essential in giving people ownership
- We have supported patients to start to get their voice heard high up in the Trust by attending HFPT forums and telling the story of their experience of using the service – people need to be heard
- Patients need to have more control over things that affect their lives there - so they decided when we should go so we don’t clash with meal times and cigarette breaks.

*Some patients told us they have been there for 5 years and still do not have unescorted leave.*





### **Recommendations:**

- Groups need funding and commitment to take this work forward as it is essential to people's wellbeing
- If we do not support local people to be present in these services, some people there will never get the chance to speak out
- This work needs to be taken seriously otherwise there will be no self-advocacy groups left to support people to build confidence and take charge.



## Interventions

Skills for People learning disability reference group worked for 2 months on developing a DVD. This built on the work they have delivered on values reigning within staff teams and the work they have been doing with the positive behaviour support team. You can see the DVD on the link below

<http://bit.ly/INInterventions>

## Big messages from this work:

- This project has been running for over 2 years. In that time with the work defined in the DVD - there has been a 50% reduction in control and restraint.
- The Trust are aiming to have a zero use of this in the very near future



## Recommendations

- Independent advocacy / user groups need to be supported to do work around enabling people to communicate their experience to all levels of staff, and for this to be used to make decisions about how the services work.
- This could be done by either paying self-advocacy groups to work into In Patient services, or by service agreements such as the one we have with a Trust/service.
- There needs to be long term commitment – it took the Reference Group time to build up relationships with key staff and leaders in the Service, and time to develop

knowledge and experience about how things work.

- Another essential element needs to be the freedom to define the work, which issues which are taken up, and the way they're taken up.
- There needs to be leadership buy-in as a first stage of staff buy-in.
- Staff and self-advocates need to explicitly explore together how involvement will work (at all levels), and build this into standard processes underpinned by agreed protocols.



## Good and bad staff

Cornwall People First worked on 'good support'. They did this by working into 2 services in their area, one privately run, one NHS.



As part of this work they were keen to involve families, and encouraged families to take part in the sessions they had planned.

You can see all of the resources on the link below

<http://bit.ly/GoodandBadSupport>

*Don't just listen to everyone else and read what is written, talk to me*

## Big messages –

- People had lived in hospital from 6 weeks to 15 years
- Nobody involved in this work had an advocate
- Having choices was important and made them feel better about being in hospital. Nobody we spoke to had a choice in who supported them on a daily basis although one of the hospitals gave people choice around key workers.
- Most people we spoke to went to meetings that were about them when they felt able to.
- Most people we spoke to knew how important it is to be involved in these meetings but also felt that it was important to be given a choice
- None of the hospitals had any self-advocacy group at the moment and none of



the people we spoke to accessed self-advocacy in the community.

- One of the hospitals collects people's thoughts and feelings and any feedback weekly instead of a 'speak out' group as nobody want to attend a group.

*'They have often said we can complain but I don't think there is any point as they don't listen.'*

### **Recommendations:**

- It is really important that people know about safeguarding procedures and their right not to be hurt so that they can look after themselves and each other.
- Support people to be involved in their own risk assessments. One person said that this had helped them understand some of the restrictions put on them and how these are helping to make them better.
- Make sure everyone in service knows how to complain and that they will be listened to.