

# **An evaluation of the Lancashire Welcome Values Project**



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## A. Introduction

### 1. Background

“People with a learning disability and their families have not always been served well by the health and care systems. This cannot be right at any level, and all too often has had disastrous and tragic consequences for individuals with a learning disability and their families. This has particularly been the case where people have been admitted into mental health and learning disability hospital environments. What should have been short-term assessment and intervention programmes, have become long-stay institutional care with sons, daughters, brothers, sisters and other relatives stranded many miles from their homes and families for disproportionately long periods of time. This approach signifies the breakdown in personalised care where individuals and families are central to the care planning processes we have in place.” (CQC & Challenging Behaviour Foundation, 2014)

In 2011 the BBC Panorama Programme on the Winterbourne View care and treatment facility illustrated the danger of people in institutions becoming disconnected from the community (DH, 2012). The undercover footage showed staff repeatedly assaulting and harshly restraining patients under chairs. Staff gave patients cold punishment showers, left one outside in near zero temperatures, and poured mouthwash into another's eyes. They pulled patients' hair and forced medication into patients' mouths. Victims were shown screaming and shaking, and one patient was seen trying to jump out of a second floor window to escape the torment, and was then mocked by staff members. One patient was repeatedly poked in the eyes. A clinical psychologist who reviewed the footage described the abuse as "torture".

Since then there have been a number of initiatives to increase the quality of care services for people with learning disabilities. The Care Quality Commission (CQC) ran a targeted programme of 150 unannounced inspections of hospitals and care homes that care for people with learning disabilities. The programme looked at whether people experience safe and appropriate care, treatment and support and whether they are protected from abuse. CQC inspectors were joined by 'experts by experience' – people who either had first-hand experience of care or were a family carer. The subsequent report revealed that half of the learning disability services inspected did not meet government standards (CQC, 2012). The Out of Sight report (Mencap, 2012) called for the CQC to “conduct rigorous inspections, involving people with a learning disability and their families”.

The Government's Mandate to the NHS Commissioning Board says:

“The NHS Commissioning Board's objective is to ensure that CCGs work with local authorities to ensure that vulnerable people, particularly those with learning disabilities and autism, receive safe, appropriate, high quality care. The

presumption should always be that services are local and that people remain in their communities; we expect to see a substantial reduction in reliance on inpatient care for these groups of people.” (para 4.5)

‘Transforming care: A National response to Winterbourne View Hospital’ (DH, 2012) stipulated that:

- all current placements will be reviewed by 1 June 2013, and everyone inappropriately in hospital will move to community-based support as quickly as possible, and no later than 1 June 2014;
- by April 2014 each area will have a locally agreed joint plan to ensure high quality care and support services for all children, young people and adults with learning disabilities or autism and mental health conditions or behaviour described as challenging, in line with the model of good care set out at Annex A;
- as a consequence, there will be a dramatic reduction in hospital placements for this group of people and the closure of large hospitals.

In response to Action 19 of Transforming Care, ‘Ensuring Quality Services’ was published by Winterbourne View JIP which restates a model of care which is known to represent best practice (LGA, 2014). In addition, the Driving Up Quality code ([www.drivingupquality.org.uk](http://www.drivingupquality.org.uk)) for learning disability services aims “to avoid what happened at Winterbourne View ever happening again.”

The deadlines for reviewing people placed in Assessment and Treatment Units were not met. However the subsequent report Winterbourne View – Time for Change (DH, 2014) recommends the commissioning of more community-based support services accompanied by a closure programme of inappropriate institutional inpatient facilities.

Therefore current Government policy encourages people with learning disabilities and family carers to be involved as experts by experience in reviews of learning disability services, as well as building link with the local community for people who use services. The Welcome Values initiative aims to make these two goals a reality.

## **2. Aims and objectives of the project**

Against this backdrop, the ‘Welcome Values’ project was developed by Pathways Associates CIC, based in the north-west of England. The project recruits, trains and supports learning disabled people, family carers and staff from care providers to visit other learning disabled people who use a particular service and assess the quality of the care and support they receive. The assessments focus on:

“...evidence from provider organisations that they and their staff actively seek to welcome people’s friends and extended families into their environment, and where people have no friends and family, that effort is made to support people develop such relationships. We will be looking for the kind of evidence that we value as humans – how it felt, how it smelt, whether people looked happy and contented, whether people were bored and not well supported etc. These are the kind of standards that all of us would want for ourselves and the people we love – do staff think about supporting someone to get changed if their top is dirty or they have food round their mouth etc.? This kind of gentle support makes the most difference and, if it is in place, people are at less risk of being dehumanised to the point where abuse becomes more likely to happen.”  
(Pathways Associates, 2012)

The results are then fed back to the providers who have the opportunity to respond and make positive changes to provision.

The process has been run a number of times across the UK with different providers. Learning disability providers include Castlebeck (now known as The Danshell Group) across England and Scotland, PossAbilities CIC (Heywood/Rochdale), Shared Approach (Lancashire), Integrate (Lancashire), Castle Support Living Ltd (Lancashire) and SLC Paragon (Lancashire). Older people’s services include Hill Croft Nursing Home (Lancashire), Care Watch (Morecombe) and Lancashire County Council Provider Services including Dementia Services.

However this evaluation will focus on the project that was run with learning disability services in Lancashire between November 2012 and February 2014. This project was funded by Lancashire County Council. Although some Welcome Values projects have used two facilitators – one non-disabled and one learning disabled – this particular project just used one non-disabled facilitator. In addition some Welcome Values projects have engaged family carers as participants; however this did not happen on this occasion.

The aim of the Lancashire project was to effect positive changes to the quality of local care services for learning disabled people.

The objectives of the project were:

1. To develop a set of standards for services around dignity, respect and community participation in collaboration with learning disabled people, family carers and service providers.
2. To train a group of learning disabled people, family carers and service providers to carry out reviews.
3. To review local services for learning disabled people against these standards through volunteer self-advocates and family carers visiting services.

4. To develop friendships, relationships and community participation for people who use services.

### 3. Process for the project

During a Welcome Values review, a team of stakeholders are supported by one or more facilitators to carry out visits to a sample of people who use a particular service over a 12 month period. A stakeholder can be a learning disabled person, family member or member of staff from a provider.

At the first workshop the group come together to learn how to conduct a review and collectively come up with a set of values by which the services will be evaluated. Each member of the team then spends time visiting one person who uses a particular service, ideally carrying out four visits including one in the evening visit and one at the weekend.

At the next workshop they discuss what they have found and whether the standards are being met. Support is available at the workshop and in between workshops via phone and email from the facilitator(s).

At the third workshop they write action plans for both themselves and the provider to help them work towards achieving the values for that particular service.

The final half-day workshop is a celebration event where participants assess progress and revisit the action plans. They also make a return visit at the end of the review to discuss their findings with the person and the provider and end the formal process. In order to achieve on-going progress the process may be repeated over and over again.

The review process is planned and organised by the facilitator(s) with a commissioner / provider manager and/or project team. Mentoring of key personnel during the process ensures sustainability after the first review has been completed. The cyclical nature of the process is outlined in diagram below:



The key activities involved in delivering a Welcome Values review are:

1. Recruit learning disabled people and family members to be volunteer reviewers.
2. Recruit service providers to participate in the project.
3. Co-produce the Welcome Values with learning disabled people, family carers and providers.
4. Run training courses to prepare participants to carry out reviews.
5. Put policies in place to ensure the safety of participants and, if they witness abuse, to support them to report it appropriately.
6. Support participants to visit services on a number of occasions at different times of the day and on different days. This will include an introductory visit to explain the purpose of the project, a number of visits to observe how the service is delivered and a final visit to review these observations with users.
7. Feedback the results of the review to the provider and give them the opportunity to respond.
8. Hold regular supervision sessions to support participants to undertake reviews and further develop their skills.

#### 4. Workshops held in Lancashire

Four workshops were held covering the following aims for the group:

- 29<sup>th</sup> November 2012
  - Why we are doing the Welcome Values review?
  - How it fits in with other things our organisation is doing including delivering dignity?
  - What outcomes people should be getting from services?
  - How we are going to implement the Welcome Values Review?
- 13<sup>th</sup> March 2013
  - Learn what we found out about the lives of the people we visited
  - Decide whether the dignity standards are happening for the people visited
  - Celebrate what is going well and agree priorities for what needs to change
  - Write news headlines to tell other people what we have found out
- 18<sup>th</sup> October 2013
  - Remind ourselves what we found out and the priorities for change
  - Discuss any feedback from the people we visited and others and agree action if needed
  - Create a vision for what life can be like for people in the future
  - Agree an organisation action plan to help services work towards the vision
  - Agree personal action plans for what we can do ourselves
- 12<sup>th</sup> February 2014
  - Celebrate the progress we have made
  - Assess progress towards our objectives
  - Ask what evidence we have to identify what has actually changed in the lives so far for people who use services
  - Assess how well the action plans have been working and make changes to our plans if needed
  - Decide where and when to carry out our next review
  - Focus group evaluation

The workshops were attended by self-advocates and providers but not family members. The Evaluator attended the final two workshops.

## **B. The Evaluation**

### **1. Aims and objectives of the evaluation**

This evaluation will focus on identifying outcomes and positive changes as a result of the project for:

- providers
- the local authority
- learning disabled people who carry out reviews
- learning disabled people who use the services.

In addition, it will identify potential improvements to the Welcome Values process.

### **2. Method for the evaluation**

This is a summative evaluation taking place after the project has been completed. Information was gathered using the following qualitative methods:

- Examination of the notes from workshops and other relevant meetings
- A one-to-one interview with the project facilitator to learn about the Welcome Values process
- A written questionnaire emailed to local authority commissioners.
- A focus group with 6 representatives from service providers, 4 self-advocates, 1 self-advocacy worker and 1 commissioner, all of whom participated in the project.

## C. Findings

### 1. Outcomes of the Project

#### a) The set of values

Below are the Welcome Values that the group came up with, taken from the notes from the first workshop. The notes say that these are "things we would want to find out about the person we visit so we know if the important outcomes are happening. We have also included some ideas about the way we might find about what is happening in the person's life."

#### 1. CHOICE

We might look at:

- Who/how are staff selected that support you?
- Do you like who supports you?
- What makes someone supporting you good?
- Can you choose who supports you?
- Do you know who is supporting you and when?
- How do staff find out what you want?
- Where you live / who you live with
- Do you like the people you live with?
- Do you like where you live?
- Can you choose how you decorate your home?
- How did you decide how to live here?
- Do you have photos of what you like doing?
- Who chooses what you do?

#### 2. FEELING SAFE

We might look at:

- Physical security of home (ID checked at front door)
- If people look relaxed/fearful withdrawn etc.
- Risk assessments - review accident book
- Recruitment checks
- Are you happy/do you feel safe? What would you do if you weren't?
- Who would you go to?
- Do family/friends visit you?
- Where do they live/nearby?
- How do people/staff interact?
- Do you go out much? Who with? Where to?
- General atmosphere / how do you feel?
- Do individuals answer questions easily without referring to staff?
- If you want to complain, how do you go about it? Who to?
- Visiting at different times of the day (evening and weekend)
- How do you get help if you need it?

### 3. BEING LOVED

We might look at:

- What contact do you have with family and friends and how often? Is that enough?
- Are you able to have a boyfriend or girlfriend?
- Who's important to you?
- Do you need help to contact your family and friends? Do you get it?
- Would you like photos of family and friends to be on show if you have any?
- Do you get a chance to meet new people?
- How are people spoken to?
- Are there cooking or baking smells? Or bad smells?

### 4. BEING HEALTHY

We might look at:

- How do you stay healthy?
- Do you have an informed choice in what you eat?
- Do you feel anxious or unhappy?
- Do you feel lonely?
- Do you have a doctor / dentist?
- How often do you see them?
- Do you have a Health Action Plan/Health Passport?
- Do you have a menu plan?
- Do you do your own shopping or have a choice in your shopping?
- What activities have you done over the last week?
- Do you feel too hot or cold?

### 5. HAVING FRIENDS

We might look at:

- What contact do you have with family and friends?
- Who is important to you?
- Who are your friends?
- Do you need support to meet your friends?
- Are there photos of you doing activities or hobby equipment?
- How easy do you find making new friends?
- Where do you make new friends?
- How often do you see your friends?
- How do you keep in touch with your friends?
- How long have you known each other?

## b) Outcomes for providers

Provider staff who participated as reviewers were appreciative of the opportunity the project afforded them to get feedback and reflect on their own services:

“As a provider, it’s been very interesting getting to hear the views and opinions of the self-advocates involved as we don’t normally get feedback.” – Provider

“When you’re working for a provider you’re constantly doing [tasks] and you don’t often get time to sit down and reflect with people which is what this process has given us.” – Provider

The opportunity to work alongside self-advocates was also valued by provider staff. This partnership led to the creation of a set of values which differed from the usual criteria by which care services are assessed and led to new ways of working:

“It was nice to move away from the kind of things that people normally come and check up on, such as person centred plans, and look at things that really matter to people.” – Provider

“Some [providers] have previously not worked in partnership with self-advocates on this type of project. For providers the experience prompted self-reflection as they asked questions about their own services based on what they had learned visiting others... [They] had the opportunity to see other services and see things from a self-advocate point of view [and be exposed to] different priorities. Working in partnership with self-advocates meant that providers had to adapt the approach they might normally have taken to checking what someone's support was like and the process encouraged them to think about building more collaborative approaches to evaluation.” - Commissioner

Staff participated in reviews but largely visited people who were supported by other providers. There was evidence that providers had made positive changes to service delivery as a result of participating in the project:

“There have definitely been changes to our services as a result of the project. We’ve put a lot more emphasis on skills matching staff to service users. This has alleviated a lot of the pressures in the house for all parties. Also people’s self-esteem and respect has been raised.” – Provider

“The two people we visited had very different needs and it was always a compromise around staffing. So we’ve now changed the rotas so that people do one to one hours with people that they like and have chosen. It’s not cost any money and it’s not particularly radical but it has made a difference.” – Provider

Therefore an outcome was that more attention was paid to appropriately matching staff members with service users, thus providing more choice for the service user, maximising resources and alleviating pressure without any additional expenditure. Staff commented that in the future they would like to use the process again, perhaps as a way to provide independent advocacy to people with complex needs who use non-verbal communication.

### **c) Outcomes for local authorities**

Commissioners valued the qualitative data produced by the project. Information about the quality of services, alongside the quantitative data usually gathered, can give a more rounded picture of the effectiveness of the service they are commissioning:

“Welcome Values has reinforced to us the need to have good qualitative information that can be set against quantitative data. The in-depth information produced by a mixed group of visitors brings out aspects of what is not working and what is working for an individual. Although the visits are only to a small number of individuals, the results can inform questions we want to put to providers in general and highlight issues that we need to give more attention to.” – Commissioner

The process also highlighted issues for commissioners around planning for the effective use of available resources:

“An individual had his own car and relied on support workers to drive it for him. The visits showed that while it was a major benefit to him and gave him access to opportunities he valued, yet the vehicle sits on the drive for half the week as not all his staff can drive. This raises the question of how many other people have a resource that they can't fully utilise and prompts thinking about what strategies we can develop to ensure people are able to get the full benefit of the resources they have.” – Commissioner

Therefore the process was valued by commissioners as it gave them valuable insights into the services they pay for through qualitative data about the views of service users and self-advocates. It also highlighted areas where resources could be used more efficiently.

### **d) Outcomes for self-advocates who carry out reviews**

There was evidence of a number of positive changes for the self-advocates who carried out the reviews. One self-advocate commented on what they had learnt around staying safe in their own home:

“Through the project I’ve learnt to always ask for ID cards when people come to my house.” – Self-Advocate

For another self-advocate, the project was an opportunity to renew an old friendship. They related how they used to live with the person they were visiting, but about 18 years ago they went their separate ways and had not had much contact since. But through visiting this person as part of the project, they realised they quite like each other and have now arranged to meet up again. For another self-advocate the visits made them reflect on their own living arrangements:

“One self-advocate commented on how quiet the place was compared to where he lives and said he would like to live there. This indicates that self-advocates who participate have the opportunity to see and think about support other people get and use that to compare and contrast with their own support which may lead to positive change for them.” - Commissioner

The self-advocates who carried out reviews also learnt new skills around advocating on behalf of somebody else:

“Having self-advocates who can advocate on behalf of other people can be hard to get. They can advocate for themselves but it’s difficult to find someone who is a powerful voice for people who need quite a lot of support. I think M has developed a lot over the course of the project and we now want him to be an advocate for someone who uses non-verbal communication.” – Provider

People also said they had learnt new skills around working as a team with people they didn't already know, self-confidence and assertiveness:

“At the beginning they were quiet and at the end they were very vocal.” - Commissioner

It was also said that all of the reviewers developed listening and observation skills over the course of the pilot:

“They developed awareness that there is a skill to ‘being there’ in a way that lets people's stories emerge.” - Commissioner

Finally one of the commissioners thought that the project gave participants an insight into their work:

“All participants gained new insight into the challenge of monitoring service quality and being able to get information that is meaningful in helping to determine if services are supporting people to have a good life... People now know what makes good support from everyone's perspective” - Commissioner

So positive outcomes for self-advocates were learning new skills around working as a team, self-confidence and assertiveness, advocacy, listening and observing. In addition, some developed friendships as a result of participating.

### **e) Outcomes for people who use services**

A commissioner commented that people who use services welcomed new people into their homes, who then listened to what is important to them. A number of tangible outcomes can be identified for the people who use services who were visited as part of the project:

“When I first started visiting a person that I used to live with, the member of staff was saying that they had been bullying people. But after a couple of visits they opened up and it turned out this wasn’t the case. So we started meeting in a café instead and talking to other members of staff and now that [initial] member of staff has left.” – Self-advocate

“With the person we’ve been visiting, at the start they said they needed to build up their confidence. From when we first started doing this till now that person has measurably grown in confidence. They now have a little job which I don’t think they would have been able to get before. This means they are getting out more and getting new experiences. It was their birthday last week and they invited around 15 people round which was a big thing because I don’t think that would have happened before.” – Provider

“One gentleman that we support had 2 brothers, one who lives locally and visits twice a month and another who lives in the north east who he had not seen for years due to a family rift. But through the project we were able to support him to contact this brother. They now have regular phone conversations and we are looking at supporting him to go and visit.” - Provider

“One of the two ladies we visited had had a difficult year and one of her housemates ended up moving out which was stressful because she had been a friend in the past. But when we visited her this week she was much more relaxed and all that stress had gone.” – Provider

Therefore outcomes for people who use services include developing new relationships, more choice about which staff support them, greater confidence in going out and accessing the community and support to contact family members.

## 2. The Process

In terms of what worked well, participants liked the fact that they came up with the values themselves as part of the process:

“I quite like the fact that at the beginning we came up with the standards ourselves and no one was telling us what to look for. It was really inclusive.” – Provider

“The development of our standards involved everyone and there was one or two that surprised us, such as being loved.” – Provider

Participants were asked how the Welcome Values process could be improved. People said that it would have been useful to have a clearer explanation at the start of what the project was and what was involved in terms of time commitment. Also some thought that the workshops should have been closer together with all of dates publicised at the beginning. In addition, frustration was expressed that a couple of providers did not attend all of the workshops.

One member of staff from a provider commented on the issue of which providers should be visited:

“There was some confusion at the start as to whether we would be visiting other organisations or our own organisation but the solution seemed to grow out of the process and in the end we did a bit of both” – Provider

One of the self-advocates commented on the amount of jargon used in the workshops:

“The first couple of workshops were quite difficult to understand because of the jargon but once I got used to it I was fine.” – Self-advocate

The commissioners suggested the following improvements:

- The group should think about what question the results suggest we should put to providers generally, and what issues we might want to investigate on a larger scale.
- Each team of visitors should provide formal feedback sessions to the management of the services they visited, highlighting what they found worked well in the service they visited and what didn't work so well. (This is meant to be part of the overall process but did not happen during this project).
- Participants should be check back with the people visited at a later date to see if things had improved and if the provider had implemented their ation plan.

## D. Conclusions

- There is evidence that participation in the project led to outcomes for providers, in that they made changes to rotas and engaged in skills matching as a result of the process. Therefore they were able to make positive changes to improve the effectiveness of the care and support they provide for no additional expenditure. In addition, the experience of working in partnership with self-advocates led to a degree of self-reflection amongst the staff from providers.
- For commissioners, a positive outcome was a valuable insight into the services they commission through qualitative data about the views of service users and self-advocates which gave a much more rounded picture of the effectiveness of a service than the quantitative data which they usually use to monitor services. It also highlighted from them areas where existing resources could be used more efficiently.
- For self-advocates who carry out reviews, positive outcomes were learning new skills around working as a team, self-confidence and assertiveness, advocacy, listening and observing. In addition, some of the self-advocates developed new (or rekindled old) friendships as a result of participating.
- For people who use services a number of different positive outcomes were identified. These included building new relationships, positive changes in staff and staff rotas, greater confidence in going out and accessing the community and support to contact family members.

## E. Recommendations

The following recommendations are made based on the findings of this report:

- There is considerable evidence that the Welcome Values process yields significant positive outcomes for providers, local authorities, learning disabled people who carry out reviews and learning disabled people who use the services for no additional expenditure. Therefore Pathways Associates should actively look for more opportunities to deliver Welcome Values projects.
- Welcome Values should be tried as a way of providing independent advocacy to service users with complex needs who use non-verbal forms of communication.
- Clear, accessible information in easy read needs to be developed outlining the process and the time commitment for participants, so that people know exactly what they are signing up to.

- Workshops should be planned closer together so that the group do not lose momentum in between meetings. The group should be given the dates of all the meetings at the start of the process.
- Pathways Associates should develop ways in which teams of reviewers can present formal feedback to the management of the provider they visited, highlighting their findings.
- Pathways Associates should consider facilitating follow-up visits 6-12 months after the reviews have finished to see if improvements have been made and things have got better for the person using the service. However there are resource implications to providing additional visits.

## **F. References**

CQC (2012) Learning disability services inspection programme: National overview, accessed at <http://tiny.cc/imt2qx>

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