



Arden&GEM

Black Country Transforming Care Partnership

Engagement activity to July 2018

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1. Statement of Purpose

This report brings together the service user engagement activities undertaken by the Black Country Transforming Care Partnership between April 2016 and July 2018 during the development of the new clinical model for adult learning disabilities services in the Black Country. It summarises key findings and themes from this engagement and will inform the next phase of formal involvement.

Engagement occurred over the following timeline:

April 2016	Black Country Transforming Care Partnership (TCP) established to transform health and care services for people with learning disabilities and/or autism who may display behaviour that challenges
	Equality Impact Assessment of TCP Programme carried out
	<p>Engagement with carers</p> <ul style="list-style-type: none"> • Commissioned by Sandwell and West Birmingham CCG and conducted by two independent members of the Care and Treatment Review panel • 6 carers took part in half day feedback session • Informal discussions with 10 people with learning disabilities, with or without autism, who had been discharged from hospital following a Care and Treatment Review
4 July 2016 to Monday 22 August 2016	Public consultation in Wolverhampton on moving three Assessment and Treatment Learning Disability in-patient beds at Pond Lane Hospital to existing services in Dudley, Walsall and Sandwell
September 2017	<p>Service User Questionnaire</p> <p>133 questionnaires were completed by service users who were inpatients or at risk of admission, experts with lived experiences, carers, advocates and their support staff</p>
January 2018 to July 2018	‘So what, what next?’ engagement

2. Background

The Black Country Transforming Care Partnership (TCP) was established in April 2016 to transform health and care services for people with learning disabilities and/or autism who may display behaviour that challenges. As part of NHS England's Building the Right Support plan, the programme aims to reduce the number of people with learning disabilities and/or autism residing in hospital so that more people can live in the community, with the right support, close to their home.

The Black Country TCP includes:

- Dudley Clinical Commissioning Group (CCG)
- Sandwell and West Birmingham CCG
- Walsall CCG
- Wolverhampton CCG
- Dudley Metropolitan Borough Council
- Sandwell Metropolitan Borough Council
- Walsall Council
- City of Wolverhampton Council
- Black Country Partnership NHS Foundation Trust
- NHS England

The National Transforming Care Programme mandates that each TCP meets the nationally prescribed trajectory for bed reduction by March 2019. For the Black Country this means a reduction in inpatient provision. The funding released for inpatient beds can be reinvested to strengthen community support to prevent inappropriate hospital admissions and reduce reliance on unnecessary inpatient stays, allowing the right support to be given at the right time, in the right place to maintain people's rights, respect and dignity.

An equality impact assessment into the impact of the TCP programme was carried out by Black Country Partnership NHS Foundation Trust. The level of negative impact was considered to be low, while it was felt the increased community provision would improve the treatment package available to patients and will meet the complex needs and acuity of patients receiving care.

The Black Country TCP is committed to working alongside people who have lived experience of services, their families and carers, as well as key stakeholders to agree and deliver local plans for the programme. Using the nine principles from the National Service Model and guidance from NHS England, the TCP has developed a new clinical model for adult learning disabilities services in the Black Country. This report summarises the engagement work that was undertaken in conjunction with the development of that model.

3. The Engagement Process

Meaningful service user engagement has been continuous throughout the development of the Black Country TCP new clinical model, upholding the statutory and constitutional duties to involve public in commissioning decisions. Engagement activity has been focused on service user empowerment, how health and care services can better support people when leaving assessment and treatment units (A&T), and how providers can strengthen the care and treatment review process when service users are discharged from A&T units. A variety of approaches have been utilised.

Engagement with carers

Commissioned by Sandwell and West Birmingham CCG and conducted by two independent members of the Care and Treatment Review panel, Chris Sholl (independent adviser) and Fran Dancyger (family carer expert by experience) in April 2016. This evaluation sought to gather the views of family carers on the Care and Treatment review process and outcomes for the individual and the family.

Two activities were undertaken: (1) An invitation letter to a half day feedback session was sent to 26 families who had recent experiences of Care and Treatment Reviews (CTRs). Eleven people responded and four were met face to face and two others engaged via telephone. (2) A sample group of 10 people with learning disabilities, with or without autism, who had been discharged from hospital following a Care and Treatment Review, were visited for an informal discussion covering their daily life, aspirations, health, and contact with professionals.

Public consultation about Pond Lane Wolverhampton

A formal consultation was carried out in Wolverhampton (July-August 2016) regarding assessment and treatment inpatient beds at Pond Lane. Following the public consultation, the decision was made to move the three assessment and treatment in-patient beds to other existing facilities in Dudley, Walsall and Sandwell.

Service User Experience Questionnaire

Patient experience questionnaires (Appendix A) were developed in easy read by Dudley Voices for Choice and used in Dudley and Wolverhampton from September 2017.

The questionnaire was based on the nine outcomes and principles in 'Building the Right Support' and were designed to identify perceptions of services; how

supported service users felt; how involved and how much choice they had in their care planning and living arrangements. The questionnaire was targeted at service users who were inpatients or at risk of admission. The questionnaire was additionally completed by others who had attended care and treatment reviews, capturing the views of experts with lived experiences, carers, advocates and their support staff. A total of 133 questionnaires were completed.

‘So what, what next’ Project

The ‘So what, what next’ Project was designed by the national Transforming Care empowerment steering group, a group of people with a learning disability and/or autism, or family carers, with lived experience of long stays in hospital settings. The project was conducted by Community Catalysts and commissioned by the Local Government Association (LGA). The Black Country TCP was selected as the local partner for the work. The project worked with 10 people within the Black Country with a learning disability with or without autism who had recently moved out of hospital, alongside the people who support them in the community. The aim of the project was to support these individuals in creating a plan of action to establish links in their communities, increase independence and enable them to become active citizens, contributing their skills and passions. The project finished in July 2018 and the learning from the project is expected to be shared by the empowerment steering group and the LGA.

Additional Service User Engagement

- A West Midlands Expert Advisory Group with clinical collaboration has been established by NHS England. Dudley Voices for Choice, a local empowerment service for people with learning disabilities and/or autism have attended this group

4. Engagement Responses in Detail

4.1 Engagement with carers

Family feedback session:

Views were sought from families on assessment and treatment services. On the whole families were very pleased with the treatment received, however, they expressed some concerns including:

- An over reliance on pro re nata (PRN) medicines
- Lack of autism knowledge and training among staff - especially in bank workers
- Delay in carrying out mental capacity assessments
- Delay in discharge leading to deterioration in a person's wellbeing
- Families not having access to care plans
- Lack of interest by some staff, especially agency staff
- Boredom - some staff did not actively engage in activities, just "kept watch" on people
- Insufficient numbers of staff to accompany people into the local community on a regular basis.

The families all agreed that increased focus on specialised community support is essential in avoiding admissions to hospital. The families had mixed experiences of community support and not all the families received support from the community health team. However, when it was in place, they reported high levels of satisfaction, particularly with the behaviour support team.

Recommendations from feedback session:

- Families felt that the multi-disciplinary approach to discharge planning, in partnership with families, is essential to ensuring appropriate support arrangements. The CTR process is important in facilitating this approach.
- Increased focus on early intervention is vital to avoid hospital admission.
- Families should be seen as partners, not agitators. At times they felt concerned about raising issues, as they could be labelled as trouble makers. A holistic person-centred approach is essential, but not always in place, and families felt that they were sometimes left out of the planning process.
- The families all want their family member to have full and active lives, with as much independence as possible. Insufficient support is often the trigger to breakdown that leads to hospital admission. Ultimately this is more costly.

- Ongoing monitoring and support is needed to help alleviate crisis situations, rather than different professionals getting involved on a short term basis.

Feedback from Sample Group Home Visits:

Ten service users who had recently been discharged from hospital were interviewed at home. Several themes were explored in the visit:

My Home:

Each of the service users expressed that they were happier in their current home and remembered their time in hospital as being a difficult time. They all reported that they did not like being in hospital and would not want to return there.

“It’s loads better here, I felt trapped in hospital.”

Things I Do

Service users reported participating in a wide range of activities, and compared this favorably to their time in hospital. They reported that life in hospital was boring and often there were not enough staff to take them out. Since leaving hospital there has been greater opportunity to follow particular interests or take up new ones. However, there was variable success in promoting independence skills for example; preparing meals.

Family Contact

All 10 service users had some family contact, although sometimes this was minimal. Some had increased contact with family following transfer from an inpatient facility. Although for some family contact had a very unsettling effect. The staff team would welcome more professional advice and support on how best to manage these situations. They also suggested that the family may benefit from professional support.

People I Live With

Service Users expressed that they felt safe. Although for one there had been two safeguarding concerns, which may indicate some frustration.

My Aspirations:

Many of the service users initially found it difficult to suggest any new things that they would like to try. This may be as a result of them previously leading very restricted lives in hospital. Through discussion, it soon became clear that there are a whole host of aspirations and ambitions.

“I would like to do voluntary work in a cafe.”

“I want to get back into college work.”

My Health

There had generally been an improvement in health since leaving hospital.

Professional contacts

A range of specialist health professional remained in contact with the 10 service users who participated in this evaluation including; community nurses who made regular visits to check on medication; psychiatrists who continued to monitor individual progress; an occupational therapist who is supporting one person to access college; a behaviour support team who advise on behaviour management

Professional support was appreciated by the staff teams; however, they would have welcomed additional psychological support and advice for a number of people who presented particular challenges. None of the cohort had ongoing support from social services, despite their ongoing support needs. One service user expressed that “social services are a waste of space.” It is disappointing that social services are no longer able to provide long-term support to people who have ongoing complex needs, as the crisis intervention model leads to delay and lack of consistency in approach.

Conclusions from Sample Group Home Visits:

None of the service users described admission to hospital as a positive experience, and they would not wish to return in the future. Nearly all have made positive progress since leaving hospital. Care had been taken to identify appropriate accommodation for each person when leaving hospital, and support was provided in an individualised and person-centred way.

Continuing support in the community requires a whole team approach, including timely access to specialist professional support when needed in order to prevent future hospital admissions.

4.2 Service User Experience Questionnaire

One of the main findings was that the services offered were all very different and people had very different experiences because of this. Some stated that their experiences were positive where others felt unsafe in their service. Two quotes which were received from patients were that “there was no choice in where I live” and “nothing to learn when I was in hospital”. Service user priorities were about activities and the lack of opportunities available to people with learning disabilities, whereas parent and carers comments were more focused on the lack of services available for people with learning disabilities. Overall the responses have highlighted the importance of good quality care coordination, effective timely information and interventions.

Other key messages were:

- Service Users were concerned whether they would still see the same team and the same doctor
- A high number of respondents said they did not know who their key workers/contacts were
- There was some doubt that the people who were asked to support others had the right skills and training
- Respondents were not sure about independent advocates and what support they provide but they did know how to contact them.
- Respondents who had not used the assessment and treatment service had little or no knowledge of what services were available if they were to go into crisis or need intensive support
- Varying responses were received to planning care, but evidence that over the course of the 18 months scores in this area improved.
- Many felt that they were choosing who they live with in the future, and where, and people mostly felt safe
- People generally felt they had a good life with opportunities. However, those around them reported those scores very differently, possibly due to differences in expectation.
- Physical health was reported positively.

4.3 'So what, what next' Project

Community Catalysts worked with 10 people within the Black Country with a learning disability, with or without autism, who had recently moved out of hospital, alongside the people who support them in the community. The work was part of the 'So what, what next' Project designed by the Transforming Care empowerment steering group who, along with the LGA, will share the findings nationally to support other regional teams. The report featured eight people's stories along with lessons learned. This report summarises one of the service user's stories and provides the project's key findings and messages for decision makers.

Summary case study adapted from the Community Catalysts "So what, what next' Project, Jack's story:

Jack has a learning difficulty and has self-harmed since he was 13. As a child Jack was placed in a children's home in another part of the country, and as an adult he has spent many years living in secure institutions, often out of his local area. This included six years in prison.

Before Jack moved to his current home he was in hospital. A previous transition plan lasted 18 months after which a decision was made that the proposed placement wasn't the right place for Jack. Jack believes it was due to a lack of

staffing. This was a huge disappointment to him and the setback really knocked his confidence. When the transition to his current home was taking place, Jack says that he 'misbehaved', partly because he felt the same thing would happen again and they would not want him. Jack would hate to go back to hospital or to prison and he worries about this.

Jack currently lives in a residential home with one-to-one support when he goes out. He is building his independence skills, including cooking for himself, and has a long-term goal of moving into supported living accommodation. Jack is enjoying the flexibility and increased choice he has since he left hospital. He has recently helped interview for new staff, something that he would not have done a short time ago.

Jack's family is important to him. He has recently reconnected with his sisters after nearly 30 years and is relishing being able to communicate with them on Facebook, meeting with them whenever possible.

Jack enjoys working outdoors with wood and has recently rediscovered his talents as a photographer. He hopes he might be able to enter local photography competitions. Jack has recently started a programme at a craft centre where he has focused on woodcraft, making a sign for his house and a bird box. His next goal is to make shelves for his bedroom.

Jack and his support team also have plans for the future. Jack's care and support provider has identified a 12-week, three-day-a-week training programme for Jack working with pigs and owls, woodcraft and horticulture. The Community Catalyst team also identified several opportunities including helping the RSPB as a volunteer ranger and finding a local voluntary organisation with large gardens and animals where people can go and help. These opportunities were written up in a plan to make sure they are not lost.

As Jack builds up trust in his new staff team, he is trying to talk more when he is upset and not harm himself. As Jack's confidence increases he sets himself new challenges, with help from his support team.

'So what, what next' Project key findings and messages from service users for decision makers.

- Start early. Don't wait for me to move into my new place. Start while I am in hospital.
- Remember my history. Understand the impact the health and care system has had on my life. Don't forget you are playing a part in how my life looks in the future.
- Work with all the people in my life. You can't do this on your own. Partnership is very important, and everyone must work together. My family and friends

might be the people who know me best. If they are, bend over backwards to learn from their experience.

- Focus on the positives. Start by thinking about my strengths, what I am good at and all the things I care about. Don't focus on the challenges I face.
- Find out about my dreams. Use what I am good at and what I care about to learn about my dreams and aspirations.
- Stretch further than person-centred. Think about the kind of creative and consistent support I will need to reach my dreams. Not just 'what shall we do today'.
- Don't let the risks take over. Think about my ideas before considering the risk. Then explore how to make things happen in a positive way that takes account of the risk and manages it carefully, without allowing it to mask everything else.
- Understand what my community can offer. Find out about local opportunities and resources. Discover who might be able to help me get involved.
- Understand what I might offer my community. Discover what is needed locally. Help me think about ways I might be able to use my skills and strengths.
- Help me meet new people and make new connections. We all need people in our lives and not just people who are paid to spend time with us. Help me to make new connections and develop friendships and relationships. Having new people in my life could open up all sorts of opportunities for me.
- Plan for my good days and bad days. Don't let the possibility of a bad day stop positive, creative planning. Don't let a good day go to waste.
- Recognise and celebrate all achievements. I might have had a difficult life. I might face lots of things I find challenging right now. Success looks very different for different people. Make sure you spot and celebrate all my achievements – even if they look tiny to people who don't know me very well.
- Hold my dreams through good times and bad. My circumstances might change for the worse but I am still good at things and still have my dreams. If I have to go back into hospital don't forget all that. Make sure your systems help me remember all the good stuff and reconnect with it once I am well enough.

5. Key themes

The following common themes have emerged across the different engagement processes:

- Service users had a negative experience of hospital care and were much happier in their community placements where they generally felt safe and experienced improved health
- Service users have a variety of aspirations and ambitions and should be helped to pursue them to promote independence and self-confidence
- Increased focus on early intervention is vital to avoid hospital admissions
- Service users and their families should be seen as partners in planning their care
- Service users require consistent and ongoing support from a multi-specialist team to avoid/alleviate crisis situations and prevent future hospital admissions