



# **The Patient Journey**

Capturing the experiences of people  
with learning disabilities using  
mental health services  
in the Black Country

Wolverhampton  
Sandwell  
Dudley  
Walsall

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## Section 1 Introduction

- 1.1. Following the abuses revealed in the Panorama programme on Winterbourne, (BBC, Panorama 2011) there has been a great deal of debate about how mental health services should support people with learning disabilities. At Changing Our Lives we believe that the commissioning and development of services should be done in co-production with people with learning disabilities. With this in mind we worked with people with learning disabilities to find out their experiences and opinions of mental health services, so these views could be used to shape future commissioning and service provision.
- 1.2. We have presented the findings of this work to the Black Country Programme Board which is made up of commissioners of mental health services for people with learning disabilities from across the Black Country and the Black Country Partnership Foundation Trust. We have also presented the findings to the Learning Disability Partnership Boards in Wolverhampton, Sandwell, Dudley and Walsall and to provider forums.

## Section 2 Methodology

2.1. In order to explore people's journeys, we decided to collect stories of people's experiences from across the Black Country. We spoke to people who had used both in-patient and out-patient mental health services. In total we followed the journeys of 30 people, 27 of whom were from the Black Country and 3 people from outside of the Black Country. All 30 people had experience of using specialist learning disability mental health services, and 5 people had accessed mainstream adult mental health services. The journeys covered people who had accessed specialist assessment and treatment, secure services, behaviour support teams, psychiatry, psychology, occupational therapy, dementia services and health facilitation. Of the journeys followed, ten people had been sectioned under the Mental Health Act and six people had been admitted as informal patients.

2.2. We were aware that this process would not be as straightforward as just speaking to people about their experiences. Some people we spoke to, due to the nature of their illness, were unaware of their journey and how they came to be in an assessment and treatment unit, some people were unsure about what professionals were involved in their care and treatment and some people found it difficult to talk about the circumstances that had led to them experiencing mental health difficulties. In these circumstances we gained permission for other people close to them to talk to us on their behalf.

2.3. In addition to speaking to people with learning disabilities and their families, we also spoke to some of the professionals involved in their treatment such as Behaviour Support Teams and psychologists.

2.4. We gathered information about patient journeys through conducting interviews. We asked everyone a series of questions about how long they had been in assessment and treatment, where they had lived before, what support they had received in the community, what had really helped them and what needed to be improved.

2.5. From speaking to a wide group of people and gathering their experiences and views, we were able to identify the following themes:

- Family Contact
- Lack of early intervention
- Being supported to be aware of and manage my own mental health
- On-going support to remain in the community
- Length of stay in assessment and treatment
- Gaps in services (Dementia, older people, autism)



## Section 3 Family Contact

3.1. Throughout our discussions with people, the importance of maintaining contact with family and friends was a frequently noted theme, especially for those patients who had experience of being admitted to hospital. Many people were able to describe how frightening the idea of being admitted to an assessment and treatment service was, particularly in the case of a first admission and the fact that relationships with the people's family could be maintained was considered a positive factor.

People were able to describe the value of continued family contact whilst staying within in-patient services. One person told us that it was very important to him to spend time with his family whilst he was admitted and how he was visited by them most days and often went out for lunch with them. He felt that this helped him to cope with a difficult situation and improved his recovery. Another person recalled being unable to have family visits

during the first part of his admission, he described feeling isolated and alone and "that he had been forgotten by his mom". He suggested that this anxiety would have been reduced if the staff team supporting him had honestly discussed this with him and reassured him it was not his fault.

3.2. Work with staff from in-patient services showed they promoted family contact; family members and friends of patients were welcomed and considered an integral part of the patient's recovery. It was recognised that family members are often the best source of information about the changes in a person's mental health, and whilst a person is unwell and possibly unable to state their preferences, family members can provide a wealth of information about the person's needs which mean the person's support can be individually tailored to provide the best chance of improvement in their mental health.

3.3. Something that most people commented on with regard to being admitted to an in-patient service was the amount of meetings that are held about them by professionals. People were keen to highlight the importance of having someone there from their family to support them. People also were reassured that their family members were being kept up to date with how their treatment was progressing. Most of the services we spoke with ensured that family members were invited to attend all meetings. In addition to inviting family members to important meetings, patients were allocated a named nurse from the first point of admission. This worker can also play a crucial role in providing a link between the patient, the service, professionals and the family.

3.4. Evidence from interviews showed that prior to most admissions, family carers had experienced a stressful and traumatic time in coping with the person's change in mental health. This can sometimes result in a lack of confidence to continue with the caring role. Therefore, we can assume by involving the family as equal partners and supporting them to resume their caring role where appropriate, services are promoting a better recovery for the person and contributing to a potentially safer discharge. Other professionals that we spoke with also reminded us of the need for continued family support by services following a person's discharge from an in-patient unit as this can help to keep the person in their own home.

3.5. Given that having family contact and members of the person's family involved in their support whilst in hospital is so important, services need to be local and easily accessible for families. Where people are placed out of area this contact can easily be lost and this can have an adverse effect on the person's mental health.

## Section 4

# Lack of early intervention

4.1. With the move towards more community based services there will be a greater reliance on care providers and families supporting people in their own homes. In order for people to stay in their own homes, early intervention is needed and this relies on families and providers being able to recognise when someone's mental health is deteriorating and getting the support services involved early to prevent the need for an admission. Throughout this study of the patient journey, it became apparent that currently this is not always happening:

***"The main concern and issue is that often changes in mental health are missed or overlooked by staff working in support services, they seem to be even more overlooked when affecting people with moderate to severe learning disabilities."***

4.2. We found that some Behaviour Support Teams provide training for care providers to enable them to better support people with their mental health but provision across the Black Country was patchy. Where staff supporting people in residential homes or people's own tenancy are not skilled in identifying mental health needs, people generally reach the point where the only option is an admission to an assessment and treatment unit, for the person's own safety. Due to the high turnover of staff within support services information about individuals, such as their history and what is usual behaviour for them can get lost. Also there seems to be little awareness and understanding of how people's behaviour changes when they are distressed and how this behaviour is a means of communication.

4.3. We found that a lot of the people in assessment and treatment were there because their situation at home had broken down. This was happening to people who had come from residential homes, supported living and the family home. We met several people who had been

'removed' from their residential setting by the care provider because they were seen to be a risk to themselves, other residents and staff. One lady we met had lived in several residential homes outside of the Black Country but all of the placements had broken down as it was alleged she had attacked members of staff. She was eventually taken into an assessment and treatment unit in the Black Country 'for her own safety' as there were allegations that staff members had abused her. At the time of writing this report, this lady is now due to be discharged to a local provider with a package of 24-hour support and skilled staff to ensure this placement does not breakdown again.

Another lady we met had been 'removed' from a residential home because it was alleged she had attacked a member of staff due to being mentally unwell. The provider did not want the lady to return back to them so the Community Learning Disability Team (CLDT) was looking for a new home. Meanwhile this lady is in an assessment and treatment unit until somewhere can be found.

4.4. We also met people who had been "removed" from the family home on the request of family carers who could no longer "cope with" the person's behaviour. One family had seen their daughter sectioned following a breakdown in her mental health, which resulted in her attacking a sibling. The family were given the option of having their daughter back at home with community support, which they wanted, but later this was not deemed possible due to a safeguarding concern around the sibling she had previously attacked. At the time of writing this report, this lady was still in assessment and treatment as we were told there is nowhere else for her to go.

One man who was in an assessment and treatment unit receiving support for dementia had been living with his family at home for years. His family had not wanted any service to go into the home, however by the time the family allowed services in it was felt the man needed an admission to an assessment and treatment unit due to his advanced dementia. If the family had services in earlier, the admission could have been avoided. The man was recently discharged to a residential home but he absconded after 4 weeks and threatened to self-harm if he was sent back there. At the time of writing this report, this man is currently back in the assessment and treatment unit receiving treatment.

## Section 5 **Being supported to understand and ‘manage’ my own mental health**

5.1. People with learning disabilities told us they should be fully included in decision making at every stage of their patient journey. We came across some excellent examples of this. In one service patients were supported to produce their own ‘relapse prevention plan’, using their own words and pictures that they best understand. This document was accessible to the person and empowered them to understand their own mental health.

5.2. The people we worked with told us that having access to a full range of therapies helped them to both recover and gain control of their own recovery. The majority of people we spoke with had regular contact with a psychiatrist and in some cases, also had the services of a psychologist. People liked this combination; people were clear that being given time to talk was helpful to them and that the use of medication alone was not sufficient for them.

5.3. People also told us that having appointments when they needed them and having services respond quickly, aided their recovery.



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## Section 6

# On-going support to remain in the community

6.1. As very few changes in a person's mental health require an admission to an in-patient unit, having local community services that are timely in their response and person centred in their approach is an integral part of mental health provision. Through the course of this work although we identified a number of ways that people with learning disabilities were being supported to remain in the community, the support people were receiving was coming from specialist mental health provision and very few people were being supported by a mainstream provider. However, regardless of where their support was coming from it did mean people were continuing to live in their own home and maintaining their usual lifestyles, including continuing to work, volunteer and attend day placements.

6.2. One example of community support was the "Feeling Good About Yourself" course which has been designed and is delivered by a multi-disciplinary team (psychology, speech and language therapy and occupational therapy) within a specialist mental health provider. People either self-referred or more frequently were referred by a health or social care

professional. We had the opportunity to meet with a focus group of eight people who had previously completed this course. They told us that this group had provided them with a forum for discussing their mental health. One person wanted this statement to be included within our report:

***"this group was a lifesaver for me, I can't imagine how I would have gone on without it".***

For many people this was the first time they had met with other people with a learning disability who also experienced mental health issues. One person stated that she began to realize she was not the only person to feel depressed and that she felt "free" to talk about the effect her low mood had upon her daily life. She said that before she had the support of the group, she often felt ignored and misunderstood by her staff team.

The focus group told us a great deal about the work they had undertaken through the group, which included recognizing

their symptoms and developing coping strategies. This is particularly significant, as it is widely acknowledged within mainstream mental health services that self-awareness is a key factor in early intervention in a mental health crisis. Therefore, it seems relevant and important to ensure people with a learning disability also have a fair opportunity to develop this particular skill.

- 6.3. Another example of community support was the Behaviour Support Service. We visited two of these services. Each Behavioural Service was based in the community, working with people who either live with family carers or people who are supported by residential or supported living services. These services worked in a variety of ways, working directly with the person or supporting the person's carers to identify the part of the person's behaviour that may "challenge" and finding ways that the person can stay safe and continue to be part of their community.
- 6.4. We worked with 5 people that had used mainstream services for support to stay in the community. All of these people

said it was difficult to access mainstream community services. One person related her difficulty accessing mainstream mental health services when she visited her GP, during her first expression of what she now knows was depression. She said:

***"He couldn't have cared less, couldn't get me out quick enough. That was terrible wasn't it?"***

We asked her why she thought this was and she said she felt it was due to her learning disability. This view was also expressed by several people who felt that many GPs were unsure how to best support their mental health.



## Section 7

# Length of Stay in assessment and treatment

7.1. Throughout this project, we met people who had been in assessment and treatment units ranging from 2 months to 2 years. Out of the people we worked with the main reason for lengthy stays was not because people were unwell or needed treatment, it was because suitable homes for people could not be found or the social workers were awaiting funding.

One man told us that he had been to see his new flat and met the person he was going to be sharing with but could not move out yet:

***“because they are waiting for money to be sorted out.”***

Another man told us that he had spent a year and a half in assessment and treatment after being sectioned following an incident with a family member. Due to the incident the man was unable to return home so it was felt a suitable residential placement needed to be found. It took a long time for the funding to be agreed and the first offer of a

placement was withdrawn delaying the process even further. The man told us:

***“I became more and more anxious about moving because nobody could give me a definite answer of when it was going to happen”***

7.2. Delayed discharge has a negative impact on a person's mental health and this can then further delay them moving on. We came across people who were experiencing delayed discharge which led to extra anxiety resulting in these individuals becoming distressed and displaying this distress through their behaviour. This then resulted in PRN being administered and new medication being looked at. We spoke to people who had their offer of a residential placement removed due to the fact that they displayed such behaviours. This resulted in the person getting stuck in a vicious cycle as the process has to start all over again. People we spoke to felt that if they were discharged as soon as they were ready it would mean their

mental health would remain stable. Where people's mental health had declined due to a delayed discharge there was a feeling of failure, they had worked so hard to get well and now they were back where they started. Some of the staff in assessment and treatment that we spoke to said it was 'demoralising' when someone regressed due to not being discharged when they should have been.

- 7.3. Some of the people and families we spoke to told us that they felt the process of discharge was all about 'budgets and money' and not enough about the person and what they needed.
- 7.4. In general, people in assessment and treatment said they had very little contact with their care manager or community nurse and did not feel fully involved in the decisions about where they were going to move to.

7.5. One worrying trend we came across during this work was the apparent growth in independent providers that have established themselves around the needs of people who have been in assessment and treatment units or forensic settings. We found that people who come through NHS in-patient mental health services or low secure settings are often placed with these providers. People who are supported by such providers told us they did not like living with so many other people who had mental health issues; some told us they were bullied and others told us living in such environments made them 'really angry and sometimes very sad'. With the anticipated closure of assessment and treatment units following on from the Winterbourne abuse scandal, the danger is that independent providers will recreate "assessment and treatment" style provision and rebrand it as supported living.

## Section 8

# Gaps (Dementia, older people and people on the autistic spectrum)

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- 8.1. Throughout the work we spoke to people who had used the services, family carers and professionals about where they felt the ‘gaps’ were in mental health services for people with learning disabilities across the Black Country. We spoke to people from all four boroughs and there was a consensus that services needed to develop for people with dementia, older people and people on the autistic spectrum.
- 8.2. Dementia - Although people with mild learning disabilities can access mainstream dementia services, diagnosis and treatment for dementia is different in people with a more complex learning disability. The dementia assessment that is used in mainstream services is very complicated and not valid, as the person has to be measured against a baseline of what is ‘normal’. Where someone with a learning disability is being assessed a baseline has to be developed around what is ‘normal’ for them, based on what that individual is normally like. To create the baseline you have to involve lots of people who support the person; this is time consuming and mainstream services do not always have the skills for this.
- 8.3. Assessing dementia in people with Profound and Multiple Learning Disabilities (PMLD) is even more difficult. Screening for dementia is not really happening. National guidance states that people with learning disabilities should be screened from the age of 30 onwards, specifically people with Downs Syndrome but in reality this is not happening. *Ref: The British Psychological Society (2009), Dementia and People with Learning Disabilities Guidance on the assessment, diagnosis, treatment and support of people with learning disabilities who develop dementia*
- What often happens is that people are misdiagnosed or often not diagnosed at all and this leads to them not getting the right support they need at home. We met people who were in assessment and treatment units because they had not received the right support that would have enabled them to stay at home.
- Diagnosis of dementia is only the beginning as people need on going support and treatment. What can happen is people are diagnosed and then go away again and
- only go back to services when they are in crisis and then generally people are referred for “challenging behaviour” intervention rather than support with their dementia.
- 8.4. Older people - We also met older people who were in assessment and treatment units, with people far younger than themselves who were communicating via “challenging behaviour”, leaving the older person very vulnerable. If you compare this situation to provision within mainstream mental health services, where there are adult services and older people’s services, this mix of age groups would not happen.
- 8.5. Autism - There appears to be a lack of suitable services for people on the autistic spectrum. We followed one young man’s journey, which had seen him originally admitted to a mainstream mental health hospital where he had not coped well with the environment and the staff had not been skilled enough to support him, leaving him vulnerable to other patients. As the man did not have a learning disability he could not be admitted to the specialist assessment and treatment unit and therefore was admitted to the adult high dependency unit where again staff were not as skilled in supporting people with autism.
- 8.6. We also followed another young man on the autistic spectrum. Throughout his childhood this young man had received support from children’s services, nursing and psychology for his ‘challenging behaviour’. The man was excluded from the special school he attended and shortly afterwards assaulted family members resulting in him being admitted to an assessment and treatment unit, due to a forensic unit being deemed inappropriate for him given his age. The young man was later diagnosed with bipolar. It is the family’s belief that if they had received better support when the man was a child, the admission could have been avoided. The young man spent a year in the assessment and treatment unit.



## Section 9

# These are the main things people with learning disabilities told us were needed:

- People with learning disabilities experiencing mental health issues should be supported to remain in their own homes like any other member of the community. On the rare occasion when people need to be admitted to an assessment and treatment unit, this should only be for mental health reasons. Admission should not be as a result of a placement breakdown due to behaviours which “challenge” or to review someone’s medication. Discharge should be planned from admission so people do not spend any length of time in an assessment and treatment unit.
- Whatever services are developed, they should be local so the person can be supported to maintain relationships with family and friends.
- Early intervention services are needed to raise awareness of mental health issues and enable people to remain in their family home, residential home or own tenancy.
- A range of community services should be available to continue to support the individual to maintain good mental health throughout their life.
- People should be supported to understand and manage their own mental health.
- Dementia services need to be developed so they can provide diagnosis and on-going support for people with learning disabilities.
- Appropriate services need to be developed to support people with autism experiencing poor mental health.
- People with learning disabilities should have access to the full range of therapies including the talking therapies.

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