

Beyond the high fence From the unheard voices of people with a learning disability,

autism or both

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Version number: 1

First published: 28 February 2019

Prepared by: Improving Health & Quality Team, Learning Disability Programme

Classification: OFFICIAL

NHS England publications approval reference 08725

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Equality and Health Inequalities statement

Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have:

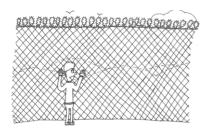
- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.
- Given regard to the safeguarding concerns and issues highlighted in the report. Any safeguarding issues raised during the interview process were discussed and assurance was provided that these had been addressed.

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Foreword Gavin Harding MBE NHS England Learning Disability Adviser





This report is for NHS England, specialist commissioners, clinical commissioning groups (CCGs), local authorities and anyone working in the criminal justice system.

It was co-produced with people with a learning disability and autistic people with the help of Pathways Associates and NHS England. We called it **Beyond the high fence** because it is about seeing what is possible for people who have been in prison, hospital or both.



As an ex-patient who has been in a secure hospital unit, I've fought for people with a learning disability, autism or both held under Ministry of Justice restrictions to be included in Transforming Care since Winterbourne View happened. The breakthrough came when I was asked to co-chair the Transforming Care board in 2013.



Being able to work full-time with NHS England has enabled me to better inform this work and make a real difference to people's lives. In 2015 I started doing focus groups in Mersey Care Whalley and then set up focus groups in the community, supported by Pathways Associates.



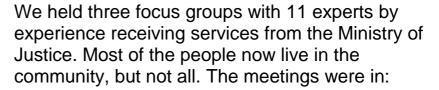
Working with the Working for Justice group, supported by KeyRing, inspired me to take this further. As well as setting up the focus group in the north west which co-produced this document with us, I am now involved in running focus groups in a number of hospitals. This helped to inform the NHS Long Term Plan.

Thank you

Many thanks to all the focus group members, Mersey Care and the providers Open Focus and Future Directions who helped with this work.

1. Summary





- Leeds on 21 September 2017
- Preston on 27 November 2017
- Preston on 20 March 2018



We talked about the reasons why we ended up in prison and/or in hospital, and what it was like. We also talked about what commissioners need to know so it does not happen to other people.

This document contains people's stories told in their own words. Some people talked about historical things that were possible safeguarding issues - we made sure these had been dealt with.

The main things we identified for people with a learning disability and autistic people were:



1. Problems starting as a child/teenager

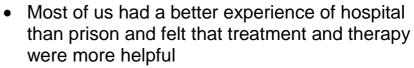
- It was quite common to have been in care
- To have mixed with the 'wrong' people
- To have been in and out of trouble with police
- There was a lack of assessment or diagnosis at school, in the community and in prison
- And a lack of understanding from teachers, staff, police and others
- We needed more support, not punishment

2. Problems in prison

- There was a lack of learning disability nurses and nurses with autism expertise
- Prison staff often did not understand learning disability or autism
- The rules were too strict
- · People were restrained a lot by staff
- And bullied by other prisoners because we were more vulnerable than them
- Prison damaged our mental health
- We didn't have a voice or a choice
- There wasn't enough therapy
- Or emotional support



3. Problems in hospital



- But some problems in prison also happened in hospital
- There was poor handover from prison to hospital and people arriving with nothing
- Some of us were over medicated with psychotropic drugs and restrained in other ways
- Changes in staffing cause setbacks
- It was/is frustrating being locked up years longer than we would have been in prison
- No end in sight
- · We lose touch with family and friends
- We become institutionalised and lose confidence about being independent
- Discharge planning causes delays e.g. funding community packages
- There are delays and too long between parole boards and mental health tribunals
- Sometimes it feels like no-one is really pushing on our behalf

4. Life in the community

- When there is a lack of support or the wrong sort of housing, there's a risk of going back into prison or hospital
- Those of us who are now living in the community are keeping well and living well at last
- We believe this is all down to having good support and a good place to live
- We want to do something positive such as training or being an expert by experience – so that the system learns and other people are treated better than we were

5. Better lives now

 People talked about difficult things that had happened in the past. People said life was better now than it was before.











2. Seven steps to success



Christine Hutchinson, consultant nurse and approved clinician at Mersey Care NHS Foundation Trust, has supported the work we are doing, as some of us are or were in her care. These are her top tips for commissioners:



1. Believe in what is possible

Sometimes you might be guided by things that have gone wrong in the past without information about what is possible now. Both are needed for progression through hospital services and particularly for discharge planning. Be realistic and positive about risks (with evidence of recent positive risk testing where needed) to get the best picture of how people can live a good quality life and be safe.



2. Be prepared to put funding into what matters most – at every level

Review what the community has to offer. What things are available that matter the most to people, such as support for making new friends and relationships, having purposeful and social activities and the necessary support to stay 'out of trouble'. Ensure good partnerships between health and social care commissioning and be creative about filling any gaps, including the use of personal health budgets.



3. Think about the person's funded support for bridging, transition and after discharge

For restricted patients, in particular people on prison transfer sections, finances are often a major barrier to progression. There may need to be additional items included in transition costs such as finance to cover rent and utilities (to secure the right accommodation) and funding for nearby rehabilitation support. Make sure there is a flexible service around the person that can respond well in a crisis. Set up the essential formal and informal support networks that will provide a 'scaffold of support' around the person.



4. Ensure all understand the legal processes and discharge requirements

There can be great complexity for people around Mental Health Review Tribunals, the Ministry of Justice, Court of Protection and Parole Board.

It helps to have someone who understands all of the various legal processes, who can advise and inform everyone about what needs to be done for each system and to ensure one doesn't delay the other. Due to this complexity it is important to start some matters early in the pathway, in particular capacity assessments for people who may be affected by case law decisions.



5. Discharge planning is a skill that requires a sharing of knowledge and partnership working

Good communication and working with the person, their family or friends, inpatient multi-disciplinary teams (MDTs), community MDTs, and commissioners is essential. Regular checks on the progression of the discharge helps everyone 'stay on track'. Often when a barrier is met other people in the circle of support around the person know a solution or someone who can help.

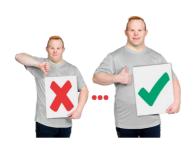


6. Don't underestimate the long term benefit of community support

It is always hard to show what has been prevented, but people can end up back in hospital because their support in the community was not right.

Once discharged, sometimes people's support can be reduced when things are going well, but remember it might be the support that is making it go well. This is particularly important for people conditionally discharged or on licence, who may be recalled at an earlier stage if things deteriorate.

Support should be flexible enough to change with the person as they grow in confidence and skills, with the focus on enabling people. The amount and type of support needed should be regularly reviewed, with full involvement of the person, so it does not block the person's progress or put them at risk of going back into hospital.



7. Get the balance right when commissioning

There is a need for a clear balance between supporting people's rights and the need for boundaries and rules which provide security to the person. Sometimes support services are either too negative about risks or not careful enough.

Either way, this can fail the person and will lead either to discharge not happening or people going back into hospital.

Staff in the hospital and the new provider need time to work together and with the person and their family, to build relationships, trust and to get the balance right.

3. Paul's story - a long time waiting

I am ten years over my tariff. I am finally due to leave hospital soon.



I left home at 14 as I was put in care.

I was in and out of care. I kept getting into trouble with the police.



My children's home didn't give me the right support.

I made friends with the wrong people.
I didn't have the right education. I felt low.



I used to get restrained. I felt unhappy about being restrained. I haven't been restrained since 2013.



In special school I wasn't really diagnosed with a learning disability.

I was only diagnosed in prison. I should have been diagnosed earlier.



I hung around with the wrong crowd. I got done for street robbery, drunk and disorderly behavior.

No one told me about what could happen because of my actions. The courts should have done more to help me understand this.



When I was with the police I had a solicitor and on one occasion an appropriate adult.



I should have had a learning disability assessment but they didn't do one.

What I really needed was help a lot earlier from people trained in learning disability and mental health.



I've been in court a number of times where I was convicted.



At a youth unit I was made to paint my room without the right equipment or staff support.

I fell over and dislocated my wrist.



I did four years in prison and seven years in hospital - 11 years in total.

I'm 10 years over my tariff. The last time I had a parole hearing was 2009.



In prison I was restrained. I've had black eyes.



People were getting bullied, self-harming and getting into debt from borrowing tobacco.



I was alright in prison in some ways. I had mates in from my area.



Because I had a Parole Board I was assessed by a hospital and got sectioned. I kept asking prison officers what it was like in hospital.

My personal officer said he'd transferred someone to hospital and it's a really good service, which helped me feel better about the move.



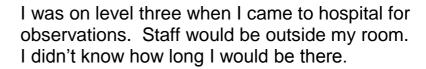
I think they should have a learning disability and autism 'in-reach' team in prison, like they have for mental health.



I was driven to the hospital in a taxi with two prison officers.

The ward manager and two staff greeted me. The staff said "You can take the handcuffs off now."







In hospital I had my own bedroom with en-suite bathroom. I was given a support worker.

When people arrive they should have a welcome pack with a change of clothes and toiletries.

They should be loaned a TV once they have been risk assessed. This is because like me, people can arrive with nothing.



Initially I was surprised that people had ground, community and home leave.

I had a tribunal and moved to a low secure unit after complying with treatment.



When I was in prison I had lots of medication for depression. Trazodone made me very sleepy all the time. They didn't explain what it does.



The hospital took me off Trazodone. I was put on Mirtazapine which made me feel chilled. I'm now off a lot of medication. The hospital took me off it bit by bit. Doctors reviewed my medication every week during ward rounds. The case manager explained the side effects to me.



I've been in medium, low and now step down secure services. I still think in the back of my mind that I will not get out but if the parole board thinks it is OK for me to leave then it will happen.



In hospital I've done loads of therapy like cognitive behavioural therapy, which is a talking therapy that can help you manage your problems by changing the way you think and behave. I've also done sex education and anxiety management therapy.



I've always made sure people have a voice. Some staff said I was colluding because I spoke up for people and myself. I was getting into trouble for it but some staff thought it was good that I was advocating for people.

It was good being the advocate on the management group in hospital. You need skills as an advocate like being patient, polite and not scared to hold people to account. When I challenged management sometimes I was listened to and sometimes I wasn't.



Changes in your service, like staff changes, a ward or hospital closure, have a big effect on how you feel. I am going through this at the moment. Commissioners need to know how much it upsets service users like me, as well as the staff. You don't know what is happening.

It can set you back a long way and people don't always understand how it can have a big effect on your behaviour.



The staff who support you are really important. Agency staff aren't always good at their job.

We want staff we know. Agency staff should only be used as a last resort.



We try to say how we feel when there are big changes, but sometimes people don't listen to us. Change can be good sometimes, but it has to be handled right.

It is wrong when you are not given choices in hospital. Staff can smoke when they leave work, but I can't. I think I should have the same right to choose as other people.



I'm glad people with a learning disability are moving into the community, but we still need good forensic services in prisons, hospitals and the community.



I'm going to be supported in the community by a good provider who I have chosen. The reason I like this provider is they have said they will help me maintain my relationships. I think they will always be there for me to have a chat so I don't fall back into my old ways.



117 meetings help us plan for when we leave hospital. At the meeting we discuss a plan with the social worker, commissioner, care coordinator, doctor, occupational therapist and probation.

The local authority commissioner isn't always there but they get feedback. The CCG commissioner is there. I chair the meetings and people go away with actions.

It is right that the person is in control of their meeting.



At every meeting I kept being told we were getting there. It took nearly two years to get the funding sorted out.

The commissioner was really supportive when senior bosses said there were problems with funding. This made me feel frustrated and angry. I went out on a community trip on my own and didn't return.

This could have got in the way of my future as I could have gone back to the medium secure unit but the Ministry of Justice and my Doctor accepted it was a blip and I'm still in the step down service.



I'm going to be busy when I leave. I like doing expert by experience work. I also want to educate magistrates about people with a learning disability.

4. Joe's story – early support can change your life

If I had got the right understanding and treatment for my disabilities when I was young, I don't think I would have gone to prison at all.



I have bipolar disorder. I was ill but no one picked it up at school. No one picked it up till about ten years ago.

I went to a special school and lived at home.



In the evening I'd hang around with friends. I got into trouble when I was in my teens for stealing. My friends didn't put me up to it, I just did it.

The police arrested me, put me in a van and were rough with me.



I went to court then to prison with no treatment. I have dyslexia, I didn't understand everything.

I went to a learning disability hospital in the North of England in the 80s. I did not receive therapy.



I was released with hardly any money and no support. They just let me go. I had nowhere to live.



I ended up in prison again and was very unwell. I've spent about 16 years in prison in total.

I tried to kill myself. I was going crazy.

I was kept in a cell on my own.



I was on the hospital wing for a while. I saw a psychiatrist the second time I was in. Staff used control and restraint on me.

Sometimes in prison riot officers used shields on me. It had a bad effect on me.



I had lots of medication and sometimes got the wrong medication. I avoided taking it as I thought it was too much and it made me feel drowsy.

I felt better when I hid the tablets and didn't take them. I told staff what I was doing and how it made me feel better, but they made me take them again.



There was some communication between prison and the hospital but I didn't really know why I was moved.

At hospital I repeated the same courses I'd done in prison. The way I was treated in the hospital the second time was more helpful though.



I went from place to place in the hospital with less and less levels of security and more freedom until eventually I went to the open house and made more and more progress.

Then I was discharged into the community. I had a social worker and initially I had 24 hour support in the community which made a difference. But I didn't feel free.



Now I have my own place, I go on holiday, I have a girlfriend. I only need ten hours of support for two days a week. My license from probation has reduced.



I have structure in my day. I don't drink much alcohol through choice and I have staff to talk to when I need them, so I don't bottle things up like I used to.



If I'd been diagnosed, had the right treatment and then got the right support the first time I got into trouble, then I wouldn't have gone to prison.

I should have had an earlier diagnosis in prison and gone to hospital quicker.

5. John's story - good support keeps me out

I want to have a life, not just a service in the community



Since two years old I've been in care. I've been abused but this has been looked into and dealt with.

At 12 years old I got into trouble with the police for making prank calls to them.

From 12 to 16 years I was in a children's home.



At 16 years I was charged with arson. I lit some fires. I was easily led by friends who encouraged me to do it.

I went to The Crown Court. I didn't know what was going on. Then I went to the Appeal Court with three judges. My case was quashed.



I went to a prison where there was no therapy available. I was very unwell. Prison is violent, as sometimes there would be four or five people restraining me on the ground.

I don't think restraint needs to be used as you can talk to people to calm them down or just have a person holding them on each side on a sofa.



At 25 I was in a high secure mental health hospital. I wasn't diagnosed with mild learning disability and psychosis until then. I did some therapy there which was helpful.



The first time I was discharged into the community from hospital there was no support and no proper housing. I was given very little money. I was sleeping on the floor!



When I got arrested again I was put on a section 37/41. I didn't know what it was. The barrister and social worker didn't tell me what it was but a learning disability hospital in the north explained it to me.

At the hospital I had cognitive behavioral therapy for three years and it was helpful.



I'm on licence from probation now. I don't want to drink.

If they had given me the forensic support years ago I wouldn't be here now. The fires were a cry for help.



Now I'm with a provider and I get good support. I get 24-hour support but I get two hours a day on my own if I want. I go to work and in my spare time I like fishing and cycling. I have had two holidays.



I took my second move back into the community slowly. I had housing, the care was person centered and now I get a bit of freedom.

It's important I have a life and not just a service. The support I get is emotional support. Somebody needs to be there just in case so I can't be left on my own. I need support or I will lose everything I have worked for.

6. Nigel's story - a good place to live is key



Having a good landlord to get the jobs done is very important. One time I had a gas leak and it was not dealt with properly by the landlord. This was very dangerous and worried me.

Having good support is also important. Good support will help you find good housing.

I need someone I can speak to when I need them. It's also important having flexible support.



Now I'm out of hospital and living in the community I feel proud of myself.

7. Gareth's story – putting the past behind me



It was terrible in one hospital. The staff used to watch me in the shower. They would sing 'please release me let me go' to me and laugh.



I wasn't listened to and had no friends. I spent all my time in my room. I was really angry. We had rats where we lived.

Now I'm out I work with the police talking about hate and mate crime. I go on holiday and I've learnt coping skills.

Positive behaviour support plans really work.

8. Commissioning good providers – example



The providers we worked with said that funders need to get the funding in place on time.

Slow paying can disrupt providers and therefore affect the care and support people get. They also said it was vital that community forensic services get the investment they need to support people well.



Future Directions used to be the community arm of Calderstones NHS Trust and supported people in the community for over 20 years. Future Directions changed into a not-for-profit social enterprise to develop its services further, and now operates in the North West and Yorkshire. This is what they said about challenges for community support providers:

Overcoming barriers

We overcame some barriers to supporting people in the community. We had to make sure there were enough staff with the right level of experience and skills to support people. We had to find builders and social landlords who were able to work in new ways.

We talk to commissioners about planning new services that will meet people's needs.



We work with the community to overcome any worries about people moving from hospital back to their local community.

We make good links with community-based specialists.

We make detailed care plans with people. They say what will happen in a crisis and how we will involve everyone who needs to be involved.

Staff culture



It is vital that providers have the right staff with the right values. Changing staff culture is never easy. Sometimes, when staff transfer from another organisation they can have very different values and ways of working.

It takes a lot of time and effort to get people on board with new ways of working and supporting people well. There can be no room for staff who do not share these values.

Keeping people safe



As well as having a trained and experienced staff team, as a provider we have to make sure housing is suitable, including assistive technology. We have a safeguarding policy and other policies. We support positive risk-taking to support people to access the local community.

All areas of risk are assessed and actions put in place to deal with them. The risks are owned by the multidisciplinary team jointly with the person and their family.

Working with the Ministry of Justice



As a provider we have a role in meeting Ministry of Justice targets. We support people with appointments to meet their conditions which are set by the Ministry of Justice.

Any conditions of discharge are included in people's care plans so staff can work with people to make sure the conditions are met. If someone is at risk of breaking them, then as a team we all work together to support the person to keep within their conditions.



Being part of discharge planning

We are part of the Transforming Care taskforce and take part in national and local planning. We look at the current discharge rates and targets.

Having providers involved in planning community services in this way helps to ensure that the right sort of services are developed to meet people's needs when they move into the community.

9. What we need commissioners to do



When people transfer from prison to hospital



 Much better assessment, diagnosis and treatment in prison before the transfer



 Less restraint in prison and hospital and other, better ways of supporting us. Positive behaviour support is just one example.



Make sure our notes come with us



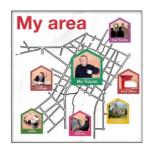
Care and treatment review (CTR) training to support people held under the Ministry of Justice

- Experts by experience need to know what certain terms or words mean
- What the different types of section mean
- What is good practice
- Experts by experience need to have actual experience of hospitals



What would make hospital better?

- More time spent outside
- The opportunity to do courses



- Support to do well in the community
- Better access to the community
- A service more local to where people are from
- Support to ensure health needs are met



- More freedom
- A step-down structure in hospital



What the local authority needs to put in place



- A good support network
- Good support to find a provider
- Better information to support early discharge
- More visits to people in hospital. Ask us questions about our experiences and what we want to see happen



What specialist commissioning needs to do differently



 Make sure personal budgets are being offered to people.



 Work with the person and their family and network around them to make sure care, treatment and support is person-centred.



What activities need to be put in place?



Paid work, voluntary work and leisure activities



- Being part of community groups
- People who have left hospital supporting others to get ready for discharge and join the community



Better access to friends and family



- Training and education on things like hate crime knowing how to recognise it and what to do
- Better networking
- Providers need to support people to get to activities







- Support from family and staff when moving on
- Support around employment and job opportunities
- A staff rota that suits us



- Structured support
- Put a liaison and diversion team in place



What community nurses and support workers need to know or do



- Find out where we come from, our history and what makes us tick
- Get a good understanding of people who have been in hospital
- Make sure our support is person-centred



• Give courses at police stations and involve us





 Help police know not to just put you in a cell but get the right support for you







• Give us person-centred care and listen to us



 Give help with benefits – start applying for my benefits when I get a leaving date so I don't have to borrow money from my provider



- Help us access education, employment and volunteering
- Carry out real co-production with us



 Support us to maintain contact with partners, family and friends



- Provide good support with activities
- Provide skilled workers with good training
- Make sure good managers feel valued or they might go somewhere else.



What we like about our providers in the community

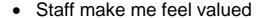


• Staff are on time and are always here for me



• They give support with looking after my money







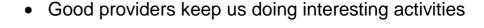
I get support to go on holiday



• I get help to develop relationships



• I get chances to do paid and unpaid work

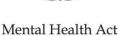




They help us get things off our chest when we need to



 They help us understand what is going on legally with the Mental Health Act



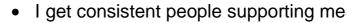
• Give us structure in our care packages



Good providers are positive about risk taking



Staff help to find courses and improve my skills





We get flexible staff who are experienced but not institutional



- Staff are paid good money so they feel valued
- We get someone at the end of a phone when we need them



What support should I have had years ago to stop me from committing my offence?



- Early recognition, diagnosis and intervention to get the support I needed then
- Social worker/professional help
- An assessment of my support needs



• Being helped to get a personal budget



Help to understand consequences



• Not being placed in a special school



Pre-admission care and treatment reviews



Better support for our families



More understanding from police and courts

Thank you to everyone who has been involved with this booklet

About NHS England

NHS England works to help children, young people and adults with a learning disability, autism or both to live longer, healthier lives. We are working with people and their families, health, education, social care and the voluntary sector to make a real and lasting difference.

From annual health checks, to care (education) and treatment reviews, quality checking, Transforming Care, improving people's experience of health services, supporting people to give feedback, raise a concern or complain, and changing the culture of health care.

For more information about our work, visit www.england.nhs.uk/learningdisabilities

About Pathways Associates

Our vision is that disabled people live the lives they choose as equals in society and their local communities. We facilitate the full inclusion of disabled people in community life, through partnerships with disabled people, families and organisations.

We work with disabled people and health and social care services to improve the lives of people and their families.

For more information about our work, visit www.pathwaysassociates.co.uk