

Developing community based services for people with learning disabilities and challenging behavior

1. Summary

Only providers can develop the capacity needed to support people with learning disabilities and challenging behaviour

There is currently insufficient capacity to successfully move everyone back home from secure and inpatient care and keep people from going into inpatient care unnecessarily. There are providers already supporting people with learning disabilities and challenging behavior successfully in their communities. The capacity for community based support that does exist is not being used effectively.

We need to find ways for commissioners to be working with providers who can deliver

Current commissioning systems are not effective at making use of this limited capacity and there are frequent blocks created by clinical decision-making and the lack of appropriate infrastructure in local communities. Providers cannot change current commissioning systems but at the very least, commissioners need to know who does provide the right type of support needed to keep people in their communities.

We need a transparent and independent process to identify those providers. We will work with the Challenging Behaviour National Strategy Group¹ to identify the providers that can and do support people with learning disabilities and challenging behavior successfully.

We need to make sure that more good providers have the skills and capacity to support people with learning disabilities and challenging behavior

Even with the providers that successfully support people that challenge, there is not enough capacity to support the large numbers of people needing to leave inpatient care or avoid being unnecessarily admitted. We need to invest in developing capacity and skills in good providers and eliminate any

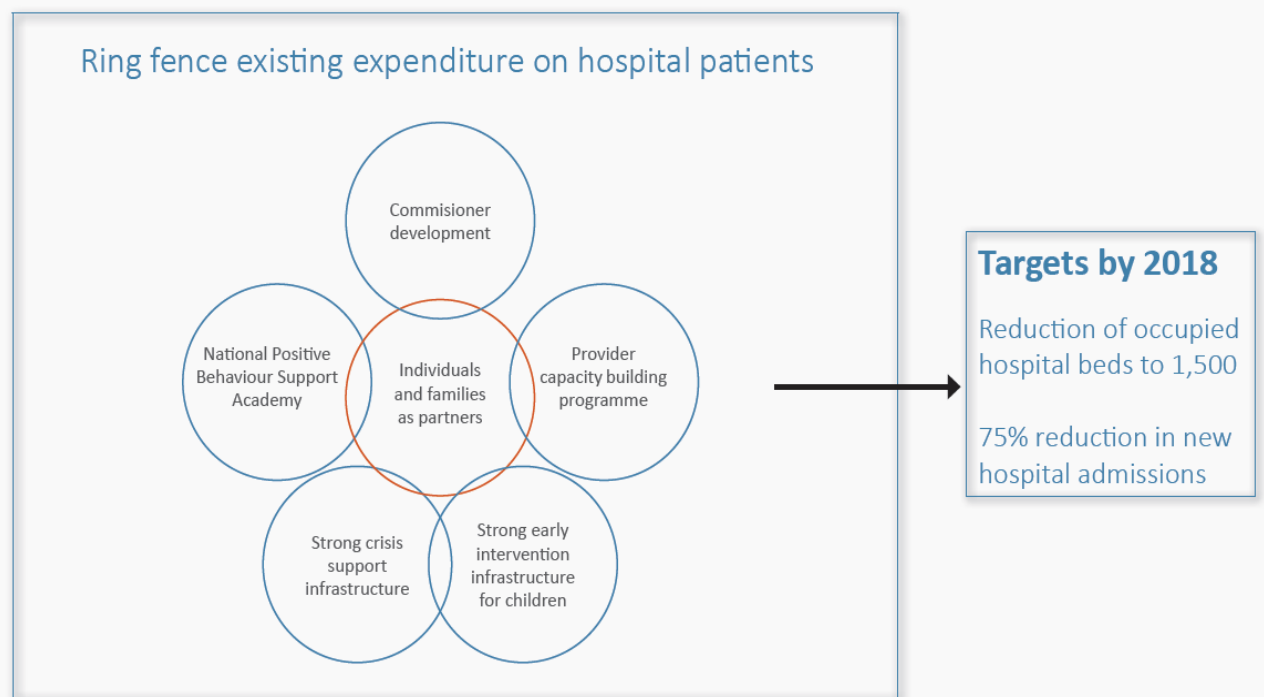
¹ <http://www.challengingbehaviour.org.uk/strategy-group/strategy-group.html>

risk that people are again excluded from their community and unnecessarily institutionalised. We propose that there is a Positive Behaviour Support Academy (PBSA) established in partnership with specialist organisations and individuals in this area, to develop the necessary capacity in the workforce to support people with significant challenges.

We need to take action alongside other organisations to further strengthen our commitment to the Winterbourne View Concordat and support the Winterbourne View JIP & NHS England

There is a lot going on to improve the lives of people with learning disabilities and challenging behavior but it is not making enough of a difference. Good organisations are doing good work but too many organisations are doing things in isolation and we are not working effectively together to tackle the big problems we have in supporting people that challenge. Our approach is to work collaboratively with other people and organisations that are expert in this field through the Challenging Behaviour National Strategy Group and the Driving Up Quality Alliance as part of a Challenging Behaviour Action Plan.

Challenging Behaviour Action Plan



Within this H&SA propose to specifically do the following:

- Work as a sub group of the Challenging Behaviour National Strategy Group (link to list of members) that includes sign up from sector wide groups and organisations with expertise in supporting people with challenging behavior.
- Define the size and scope of the national capacity that currently exists in provider organisations to support people back to their communities and avoid new people entering inpatient services.
- Offer support to NHS England to develop a new commissioning strategy that makes best use of existing capacity and ensures that capacity grows quickly to bring home everyone as quickly as feasible, prevents others entering unnecessarily and addresses crisis support.
- Find ways to connect local and regional commissioners to appropriate service providers as a matter of urgency
- Provide support for the development of a Positive Behaviour Support Academy (PBSA)

2. Introduction

The Housing and Support Alliance share a concern with other groups and individuals in the learning disability sector about the lack of progress in discharging people with learning disabilities from inpatient and secure settings. Around 3,500 people currently live in those settings and we believe the real figure should be nearer 500. Over the past three years, there has been very little progress in implementing the Winterbourne View Joint Improvement Programme despite commitment from the delivery team and concordat signatories. We find this particularly frustrating as an organisation as we have many provider members who have demonstrated the ability to provide high quality individualised services for people who can present significant challenges who would otherwise be living in inpatient care.

We believe we could facilitate the development of housing and support for 200 people in 2014/15. This paper sets out how that programme could work and goes on to describe a four year programme during which housing and support for 2000 people could be developed, significantly reducing the number of people living in inpatient and secure settings and massively improving their quality of life whilst saving money and developing an effective national infrastructure reflecting the ideas recommended by the late Professor Jim Mansell.

3. Background

The Housing and Support Alliance reflects organisations with expertise in housing and support models that give people with learning disabilities control over their lives- these include big and small organisations in the independent and voluntary sector. Our members have provided many inspiring examples of individuals with challenging reputations being supported to live a good quality of life in their community with services that are designed around their needs and which are cost effective. H&SA members have access to capital and property that could house approximately 200 people with learning disabilities. There are also likely to be similar organisations that are not our members.

Initial discussions with a number of Chief Executives of leading learning disability providers indicates there is an appetite for developing new individualised services and a willingness to work together in partnership. Those Chief Executives have experience of providing services based around the principles of positive behaviour support and individual service design and recognize that, to set up services effectively for this group of people, it is not realistic for a provider to take on the development and management of a large number of services in a short space of time. The consensus is that a medium to large provider with a strong infrastructure could realistically develop services for a maximum of twelve out of the 200 people for whom there would be capital available. That would indicate a need for at least 15 – 20 providers, with a mix of smaller and larger ones, being involved in the programme to develop services for 200 people. This process could easily support people who have personal budgets or want individual service funds.

It is proposed that the Housing and Support Alliance works with the Challenging Behaviour National Strategy Group to co-ordinate an initial framework which would be used to select providers to be involved in this first wave programme. ADASS and NHS England could be partners in this programme, but there would need to be a recognition that there is insufficient time to go through a convoluted and elaborate procurement process. In addition, there are not that many provider organisations in England who have the skills to do this work and it would make more sense simply to identify those that have.

4. Principles of Individual Service Design

The principal of individual service design should underpin the whole programme. **ALL** services, including the design of housing, should start with the needs and wishes of the individual or individuals who will be supported. This is a real opportunity to demonstrate the principals of the Mansell Report in action and to show how personalisation can work for the most complex people. People with learning disabilities and/or their families should be offered control over the funding paying for their support, through personal budget or individual service fund, or if that is not feasible, an independent broker should be identified.

We could show, once and for all, that people who can present challenges do not need to be grouped together in congregate services but through person centred approaches to housing and support designed around their specific needs, can live successfully in their communities.

5. How we could do it

To develop housing and support for 2000 of the most complex and challenging people in our society people over a four year period will require a very detailed overarching programme supported by an effective project management arrangement. Key elements of that programme include the following:

- **Central and regional leadership** A national programme board which oversees and draws together all of the key workstreams. That should link into individual project management arrangements in each local authority area where new services are being developed. There will be two aspects of project management required, firstly senior people with sufficient expertise to oversee the development plans for new services in a particular geography, and facilitators with expertise in individual service design who can manage the process of designing new services in a person centred way for the individuals for whom specific accommodation is being developed. We know that there are a number of senior managers in provider organisations that have the expertise to provide project management support and have made direct offers of support already. In addition, more junior staff, for example at first line manager level may well have the expertise, with some additional training, to take on the facilitation of individual service design.
- **Capital for housing** Detailed work will need to be undertaken drawing up a capital programme which is able to deliver housing and support for 2000 people over a four year period. The Housing and Support Alliance has extensive expertise in this area and is

already exploring both charitable and private sources of capital. There is also RCGF funding available which is held by RSLs. In addition, a number of former long stay hospital resettlement schemes are coming towards the end of their life. These were typically funded using Section 64 grant money and were developed on the understanding that those resource was available for future generations of people with learning disabilities as an alternative to long stay hospital. A number of those schemes are being sold with proceeds going to support other parts of the NHS, while other properties are waiting for disposal. These should all be ring fenced and the capital used for this new hospital closure programme.

- **A Positive Behaviour Support Academy to build skills and capacity**

In order to provide the level of specialist services required to support 2000 people coming out of in-patient and secure services, there needs to be considerable capacity building. There are two elements to this:

- Supporting the development of smaller micro providers who are able to support a small number of people in very person centred ways. This should balance out the larger providers in the market to ensure an effective range of choice. This could also include supporting Shared Lives schemes which can play a part in supporting some of the people moving from hospital settings.
- Workforce development to ensure that there are enough trained and skilled staff to support people with complex and challenging behaviour. It is proposed to establish a Positive Behaviour Support Academy whose remit would be to skill up 5,000 staff over a four year period. There are already a cohort of highly skilled and knowledgeable individuals in provider organisations, the NHS, in universities and in national organisations represented in the Challenging Behaviour National Strategy Group. It should be possible to identify trainers who are able to support staff to undertake an advanced diploma in positive behaviour support, whilst also having work place experience and effective supervision. The aim of the Academy would include offering participants the opportunity to work across different provider organisation to broaden their experience. It also means, that over time, a team of people get to know each other who are able to provide crisis support in their local area.
- The work of the academy will sit alongside the Driving Up Quality Code.

- **Build capacity for crisis support in the provider sector** The programme could also develop a crisis support infrastructure to prevent future generations of people admitted into assessment and treatment units. People should only be admitted to hospital in the future if they have a diagnosed mental illness requiring treatment in an in-patient setting. No one with a learning disability should be admitted to hospital just because they are presenting challenging behaviour. A key element of the programme needs to be the development of robust community-based crisis support services which are able to support people when they, their family or their staff team are experiencing a difficult time. Providers have a valuable role to play here as we employ a number of skilled and confident staff who are able to provide hands on support to people in crisis, both in and out of hours, to prevent them needing to be admitted to hospital. It is proposed to pilot the provision of out of hours crisis support staffed by teams of providers, rather than individual provider organisations, which will offer the level of infrastructure required. There will need to be close collaboration with the NHS to ensure seamless support.
- **Ring fencing revenue funding to build capacity** Another strand of the work programme relates to the revenue funding of services. Ideally, all of the funding currently being spent on individuals in hospital settings should be made available, both to support them in the community and to develop the necessary additional infrastructure required. On average, people in hospital settings cost around £4,000 per week to support. That should reduce to around £3,000 per week when they move into community settings, if not less. On a cautious assumption, £1,000 per week should be saved when someone is discharged. That means that a four year programme resulting in the discharge of 2000 people will result in savings of approximately £100m to the NHS. There is a strong case for investing most, if not all of this money in the necessary infrastructure to ensure admission to hospital only happens for the right reason in the future. That £100m could fund a very comprehensive Positive Behaviour Support Academy and robust crisis teams across the country. Clearly, there will be a timing issue as money can only be released as patients are discharged. There would need to be pump priming to fund this programme, but there is scope to explore opportunities for providers to assist with this creatively. For example, providers can be better placed to hold underspends in one financial year and transfer them into another, than the statutory sector. It is also possible, in some cases, for providers to run services free of charge for a few months allowing a commissioner to release the necessary resources. The provider can then be paid a higher fee over the next two/three years to repay the initial free service.

6. Making sure the right people are involved- collaboration, independence and transparency

For a programme like this to be successful, there will need to be support and engagement from a wide range of relevant people and organisations who have expertise in these areas, crucially with people with learning disabilities and families at the heart. We propose that the governance of this programme comes via the Challenging Behaviour National Strategy Group and becomes a sub programme of their work.

There will need to be engagement with NHS England, the Department of Health, CCGs and local authority commissioners as well as members of the Challenging Behaviour National Strategy Group.

We want to support the Winterbourne JIP and ensure it has a legacy post March 2015 by collaborating with others in the sector who share a vision and passion for helping people with learning disabilities and challenging behavior to lead good lives in their communities.

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