Thought
Leadership

Together we can…
… deliver more effective commissioning and de-commissioning for people with learning disabilities and autism

Voluntary
Organisations
Disability Group
V O D G

Contents

Introduction

The Voluntary Organisations Disability Group (VODG) exists to support the delivery of progressive, high quality and sustainable services. A critical issue for the sector is ensuring people with learning disabilities and autism receive the right care, in the right place at the right time. To address this VODG[1] convened a workshop to explore the barriers preventing good commissioning and de-commissioning, and the enablers that allow services to deliver excellent outcomes for individuals – and often cost savings too.

This report addresses five key issues identified by workshop participants as critical to making progress with this agenda. For each issue identified, a number of *practical suggestions* are proposed to support the reinforcement and generalisation of the positive developments seen in some places, and to tackle the barriers which still get in the way.

The workshop represented a wide range of interests and perspectives, including representatives of people with learning disabilities and their families, local authority and NHS commissioners, NHS England, health and social care providers, clinicians and the regulator. Also included in this report are the views of a number of senior commissioners and providers, who were interviewed as part of the research process.

> People with learning disabilities are clear they want to live in homes, not hospitals.

Simon Stevens, NHS England

---

[1] This work was produced through the Department of Health, NHS England and Public Health England voluntary sector strategic partnership. VODG delivers this work alongside the National Care Forum and Sue Ryder.

Gloucestershire's strategy for these services, for example, makes several crucial points:

- Assessment and treatment units are not fit for the 21st century under their present use and model.
- Commissioners should stop using services which are too large to provide individualised support.
- People should not be in placements where they are far away from home and unable to maintain and build sustainable relationships and support systems in their communities.
- A preventative and strategic approach needs to be taken across health and social care which spans children and adult services to support people with challenging behaviour. The focus needs to be to manage down behaviour and avoid the need for hospital admissions or use of specialist services.

We set out to seek ways to deliver progress with both the commissioning of community-based services and the de-commissioning of outdated or inappropriate ones, often based in hospitals. In doing so, the focus was not just on the 2,500 individuals affected by NHS England's transforming care programme[2]; equally important was a focus on:

- 24,000 people with learning disabilities and autism whose behaviour can challenge services and who are at risk of hospital admission and the many more people (of whom 38,500 are currently in residential care) who require community-based care and support.
- Worrying signs that gross expenditure by councils on services for younger adults with learning disabilities fell between 2013/14 and 2014/15 by some 6%, with in year cuts also planned[3].
- Unprecedented levels of trust deficits (whether foundation trusts or not) announced by Monitor and the Trust Development Authority – totalling some £1.6bn for the first half of 2015/16 which could compromise integrated approaches to learning disability provision[4]. Such deficits are likely to absorb a large chunk of NHS funding.

---

[2] See, for example, the NHS England commitment to 'homes not hospitals' for people with learning disabilities.
Accessed: https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf

[3] Association of Directors of Adult Social Services budget survey.
Accessed: http://www.adass.org.uk/uploadedFiles/adass_content/policy_networks/resources/Key_documents/ADASS%20Budget%20Survey%202015%20Report%20FINAL.pdf

[4] The challenging environment for NHS providers is set out by the Trust Development Authority.
Accessed: http://www.ntda.nhs.uk/blog/2015/11/20/challenging-environment-for-nhs-providers/

These rising financial pressures are clearly resulting in delays and slow progress with both the post-Winterbourne View transforming care programme and the move to more community-based support for people with learning disabilities and autism generally. This was frustrating individuals and their families and supporters, as well as providers willing and able to provide new solutions tailored to individuals' needs, such as independent living. Despite these challenges the aim of this paper is to:

- Avoid recriminations and instead seek constructive ways of building and sustaining good relationships between commissioners and providers.
- Explore the barriers preventing good commissioning and de-commissioning and the enablers which mean that in some places innovative services are delivering excellent outcomes for individuals – and often cost savings for commissioners too.
- Come up with some practical suggestions, approaches and tactics for making progress.

Jo's story

Jo is 24. She has challenging behaviour and can harm herself and others. From school, she was placed in a secure setting a long way from home, as there were then no local services confident enough to support her. She had a history of attempting to jump off bridges and being violent to staff and others.

Following a review, a placement was found on the border of her home county. The transition planning took six months. The family was initially very concerned. They felt that even though the current placement was struggling to meet her needs and incidents were increasing, they did not want to place her somewhere that might fail and be worse. She had previous failed placements.

The family, current provider, new provider, commissioner and social worker met regularly to plan the placement. Person-centred plans, behaviour plans and risk assessments were shared and staff worked jointly to ensure a good handover.

Jo moved four months ago to her new placement. She has a self-contained flat so is not targeting others; she has purposeful day activities outdoors on a farm doing rural work (not available at the previous placement). Jo has not self- harmed and has had minimal incidents. She still has 2:1 support and waking night staff support. Her family is closer and is able to see her more regularly, as can social services.

Jo was costing £5500 per week and is now costing £3100. She has an activity programme and appears much happier. The public purse is saving too – by nearly £125K a year.

> "It really does work. It's not all been roses, but it has been about having the provisions, the health teams, the providers, the families, working together and continuing to support for the long run."
>
> **Provider**

Issue one: communication and co-production

What are the issues?

People needing support and their families, clinicians, regulators, commissioners and providers all have important perspectives and insights to offer. All of these views need to be engaged in the transformation process and all should be given equal respect – it is not a hierarchy, handing down solutions from on high, but a network. A network with good communications between the parties is vital. Co-production of solutions involving this wide range of interests is also a vital ingredient for sustainable success.

What did people say?

Providers

> It's about having the right information and all the people involved.

> Where we've found things work really well is where we've had family involvement.

> The focus should be on how do we get the providers' and the individuals' relationships right, rather than between commissioners and providers.

Family carer

> Listening to feedback from providers on the support they need particularly when individuals have behaviour that can challenge. We are closing one of our assessment and treatment units and reinvesting the resources into a community team so that it can provide intensive support in the community to prevent placement breakdown.

> Families are involved in placements and designing new services.

> We have – in partnership with families and providers – set up a positive behaviour support network. And an autism and learning disability partnership board that has open conversations about challenges.

> We have established a strategic provider network, who receive all our referrals – including those from health colleagues so that they can understand what the demand is and what is needed to develop the market. We hold regular provider forums and have relationship managers that meet regularly with providers.

Council commissioners

Practical suggestions for progress

- Promote greater understanding of each other’s roles by organising and publicising representative samples of “a day in the life” – from the viewpoint of a commissioner/ provider/ family member and individuals using support services. This would illustrate each party’s thinking and experiences.

- Develop person-centred outcome measures indicating quality of life. Build a ‘life experience’ checklist.

- Use the transforming care partnerships to build new models of partnership with wider, genuine, community involvement.

Issue two: commissioning and procurement

What are the issues?

Long-term, strategic, commissioning based on clear assessments of need (both individual and local) has been largely replaced by mechanistic procurement, often run by centralised council departments with little specialist expertise. In addition, the costs of procurement and tender exercises are very high for providers – to obtain places on framework agreements and then bid for specific contracts where price considerations dominate those about quality. There is decreasing scope for innovation and provider influence on service design/specification before the formal bidding process starts.

For their part, commissioners worry that there can be too few or too many providers to deal with and that some providers overstate their ability to handle complex cases in the community. In addition, families of people with learning disabilities are understandably cautious about new service models, as are some clinicians, especially if they have experienced the breakdown of community placements.

What did people say?

> Use a variety of commissioning models to get the best results.

Provider

A

Specialist framework: a high-level tender process for ongoing work with selected providers.

> This is what is going to change things for people. It works well because there is less competition.

B

Geographical commissioning: ongoing planned work with councils, the NHS and housing developers to deliver local solutions.

> The benefit is there is that on-going support.

> You build those relationships so you can have those conversations.

> In the last year we've supported eight people using this model, and we know we have a further 17 over the coming year.

C

Individual commissioning: using individual personalised commissioning, with housing and support identified separately.

> Some lessons from the evaluation were the need for flexibility of the transitional budget, good communication, advocacy for the person.

> It was much more led by the person and their family.

Practical suggestions for progress

- Devise a "myth busting guide to procurement" to prevent people hiding behind supposedly prescribed rules and processes.
- Put together a range of available data to clearly understand current and future population needs and the likely demand for these types of services. Ensure that autism, often a relatively forgotten condition, is properly included.
- Develop a range of service models to build on specialist, geographical and individual commissioning approaches.
- Develop the integrated personal commissioning offer to ensure that, where they wish, individuals and their families and supporters can do their own commissioning.

What did people say?

> Although we work closely with health we currently don't have a lead responsible commissioner for learning disabilities or aligned/pooled budgets. This situation is further complicated by the fact that in our county we have six clinical commissioning groups, a county council and eleven districts and boroughs.

Council commissioner

> People perceive procurement as a yearly thing. You need to take a five to ten year view on it. It's very inefficient. You could save a fortune with a longer look.

Provider

Issue three: training and the workforce

What are the issues?

Moving away from hospital settings into community-based services such as supported living poses challenges for staff, particularly if they transfer from the NHS to social care services. Staff familiar with the culture and attitudes of in-patient care may struggle to provide people with learning disabilities with a framework for independent living. Developing the appropriate culture takes time, training and constant reinforcement. There also needs to be a recognition that some community placements will break down, permanently or temporarily, for various reasons. What is important is having support systems in place, such as community nurses and specialist community teams, to manage episodes effectively and minimise the risk of renewed, repeated or lengthy in-patient admissions.

What did people say?

> Training for staff tailored around the individual and developed with behaviour teams – the initial layout and training is really important. Strong manager practice focused on maintaining and supporting the team has been really successful for people. The manager in post makes a big difference.

Provider

> The workforce is vital to service transformation. We will need a blend of skills for the future workforce – how do we build that capability?

Provider

> We need to address clashing perspectives and clash of ideologies and cultures in the sector. The workforce needs the right balance between the medical and social model. We shouldn't assume medical model is all bad and social model all good – or vice versa. Both have a part to play.

Clinician

Practical suggestions for progress

- Groups of providers might collaborate in certain areas to share staff and expertise to support providers to deliver the service; for example, by developing a rapid response team.
- An agreed service model has been lacking, so the transforming care service model can help to change commissioning for all people with learning disabilities. For example, we should change the idea that if somebody has to go back into a different setting, the provider does not stay with them. We should use the service model to emphasise and delineate each player's role, so tackling any clash between health and social models of care and support.
- At a strategic level all parts of the system should work together to develop and commission new workforce roles fit for the future. This requires providers and commissioners working with delivery organisations, including Skills for Care, Skills for Health and Health Education England, to enable these bodies to commission and develop new workforce roles across both the NHS and social care.

Issue four: resources and reinvestment

What are the issues?

Community-based service models can both be significantly cheaper for commissioners – who have to support some people with learning disabilities and autism for most or all of their lives – and also provide a better quality of life for individuals. But, as NHS England’s recent report “Building the right support” helpfully acknowledges, transitional funding is necessary to provide alternative community support before closing in-patient beds and assessment and treatment units. Even then, it can be particularly difficult to realise savings from hospital facilities as many fixed costs remain unless whole wards or buildings can be closed. A key question is whether the £60 million of matched NHS England/CCG funding plus £15 million of capital will be adequate for the transforming care group of people and how to find funds for investment in new services for the much larger number of people not in that cohort. A further key challenge is the cost of affordable development land and housing in affluent parts of the country.

What did people say?

> You have to get people to look at decades not financial years. There might be a role for social finance and Bubb’s social investment fund in that.

> If you look back 15 years to the de-commissioning of long stay hospitals, many contained people with complex needs. The closures happened because it was driven by commissioners. There was capital funding for housing. There was money for double-running. There was a recognition of a need to pay for both.

> We are remarkably inward looking. DH [Department of Health] should be encouraged to pick up some of the investment recommendations in Sir Stephen Bubb’s Time for Change publication.

Providers

> Why not change the system so that money is given directly to individuals and families, therefore shifting the role of the commissioner. However, we have to acknowledge the concerns expressed about the lack of providers in the first place, and about separating health and social care.

Consultant

Practical suggestions for progress

- Bring together groups of people using integrated personal commissioning (health and care budgets) to aggregate purchasing power and meet their needs together.
- Work to raise the profile and understanding of the critical importance of housing to this agenda.
- Following the Bubb recommendations, identify clear next steps in social finance and social investment bonds to help finance this work over the longer term.

Issue five: honesty and trust

What are the issues?

It is clear that great outcomes for people can result from situations where relationships are open, honest and trusting between individuals, families, providers, commissioners and clinicians. In too many cases, however, there are mutual suspicions, serious differences of perspective and method, and rigid approaches. There is often a need for "confidence-building measures" to build greater mutual trust between all the agencies and parties involved.

What did people say?

> Commissioners and providers need to work collaboratively and there needs to be trust. Providers must trust commissioners not to drop them in it, at the first signs of any difficulties. Equally, providers must not walk away in the first year when a contract becomes difficult to manage.

Providers

> I've seen more trust in supported living environments… people who a few years ago we would have thought, 'they can't live in the community'.

> It isn't rocket science. It's about multi agency working and partnership agreement. A project management approach has worked really well.

> Third sector have the skills that can help design the services. It has to be a different conversation and build on the assets of our communities.

> We systematically fail to talk about the asymmetries of power in the system between health and local authorities and the providers.

Regulator

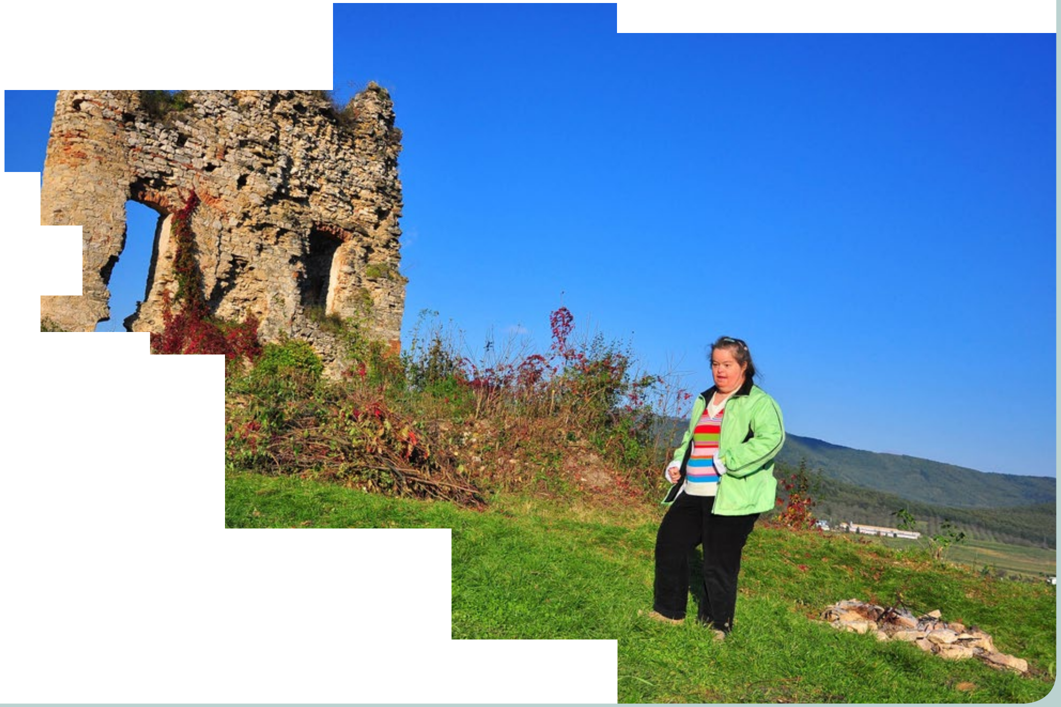
Practical suggestions for progress

- Need for a renewed and clear national mandate to set out a clear vision for care and support for people with learning disabilities and autism. This is happening in respect of the transforming care group but not across the entire learning disability and autism population. A national mandate would help galvanise commissioners, providers, regulators and others – and give individuals and their families leverage to argue for their needs and preferences to be addressed.

- Seek ways of sharing ideas and perspectives between commissioners and providers, for example by establishing secondments in both directions. These could be trailled by – and in – the transforming care partnerships.

- Learn from the experience of insurance companies and others who work with people over very long periods, ensuring the focus is on maximising quality of life rather than financial and/or service inputs.

- Engage with a wide range of local stakeholders around this agenda, including local MPs and councillors who may require robust local data and information to raise their awareness of the issues.



Conclusion

Set against a tough backdrop of on-going austerity, resources and assets (whether buildings, staff, capability or other facilities) were often poorly located and distributed. This works against those seeking to decommission outdated services and to commission much more appropriate services which are known to improve the quality of life of people with learning disabilities and autism. However, as this paper demonstrates, there are practical measures - with genuine support - that can help to move things forward. Taken together there is a real sense that 'together, we can'.

Published 2016
Voluntary Organisations Disability Group
New Bridge Street House
30-34 New Bridge Street
London EC4V 6BJ

info@vodg.org.uk
@VODGmembership
www.vodg.org.uk

This work was produced through the Department of Health, NHS England and Public Health England voluntary sector strategic partnership. VODG delivers this work alongside the National Care Forum and Sue Ryder.