# Transforming care –
## the challenges and solutions

VODG

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# Introduction

NHS England has a policy ambition to move people with learning disability, autism or both out of long-stay inpatient facilities.

Under its national plan – entitled *Building the right support* – NHS England explains that transforming care "is all about improving health and care services so that more people can live in the community, with the right support, and close to home".

"Transforming care will mean that fewer people will need to go into hospital for their care. This means that we can close hundreds of hospital beds across England. To do this we are making sure that services in the community are much better."*

This is an area that some VODG (Voluntary Organisations Disability Group see box, 'Voluntary Organisations Disability Group') members have been actively involved in through the Provider Taskforce.

This report, produced by VODG, identifies the learning from the Provider Taskforce's project, the London Demonstrator (see section 2, 'The VODG Provider Taskforce's London Demonstrator Project'). The project was commissioned by NHS England (NHSE) and undertaken by London-based members of the Taskforce. The primary aim of the pilot was to develop support assessment and proposals for 27 people originally from London who have been in inpatient settings for longer than five years.

This report sets out the work carried out, the learning and recommendations for next steps both in London and nationally.

The purpose of this report is to share learning. It is not a formal evaluation, nor a proposition for the provision of services, but offers insight into the challenges and solutions in delivering the "transforming care" agenda. VODG acknowledges that there are improvements that need to be made across the system, including for community-based providers.

**VODG (Voluntary Organisations Disability Group)**

VODG is a national, pan-disability, infrastructure body for voluntary sector disability and care organisations. Member organisations provide social care and related services to over one million disabled people, delivering in excess of £2.8bn of publicly funded services, the majority of which are registered with the Care Quality Commission and/or Ofsted.

*NHS England, Home not hospitals. Accessed: www.england.nhs.uk/learning-disabilities/care

# The VODG Provider Taskforce's **London Demonstrator** project

The VODG Provider Taskforce was originally established in 2015 to collectively respond to the transforming care agenda. The Taskforce is a sub-group of the broader VODG membership.

The Taskforce consists of organisations that provide care and support for people with learning disability, autism or both. Each member of the Taskforce has been independently quality assured by the Tizard Centre, University of Kent, in terms of their experience in supporting people who are identified as meeting transforming care criteria (such as having been an inpatient for at least five years).

Through VODG, the Taskforce offers statutory organisations, government departments and sector agencies a single point of contact to engage and work with voluntary sector organisations in delivering the transforming care agenda. Under the VODG umbrella, the providers involved have offered support to local authority and NHS commissioners to develop their approaches and have worked together to facilitate and coordinate support assessments and proposals.

The Taskforce began working with NHS England London to develop a plan to undertake support assessments and proposals for a priority group of 27 people. The people in this group are all originally from London and have been in inpatient settings for longer than five years, and therefore meet the transforming care criteria.

There have been two elements to the project, known as the **London Demonstrator:**

- to develop appropriate support options for 27 people to enable their discharge from inpatient settings

- to identify learning in relation to challenges and barriers to successful community support as well as actions to enable positive change.

Thirty people were referred and representatives of the Taskforce met with four of the six London transforming care partnerships (TCPs) made up of clinical commissioning groups, NHS England's specialised commissioners and local authorities. Panel meetings for each TCP area were used to discussed the support needs of each individual. Shared action and outcomes were agreed with the clinical and social work leads and care and support providers were identified for each person. Referrals were then made by the Taskforce representatives to appropriate providers and contact established between the provider, and commissioner and funding agencies to take forward the assessment and support planning process.

# Provider capability and workforce skill set

A key element of the London demonstrator was identifying the housing and support needs of the people we worked with. The provision of bespoke options to meet individual needs is a crucial factor in the development of a person's discharge plan.

Whilst the sample size means that we do not know how representative our experience was, three indicative patterns of housing and support needs began to emerge. Providers may find the information useful for future business and workforce planning.

## 1 Bespoke accommodation and support for people to live alone

The provision of bespoke accommodation, where people can live alone and receive high, intensive levels of support, is needed for some people, particularly in the initial period once discharged from hospital. For five people in the London Demonstrator the need for sufficient space and appropriate adaptations was significant. Identifying and sourcing detached properties, for example, is an important part of the planning process and can take considerable time. The earlier this starts the better.

Where people have been receiving high levels of support in a hospital setting, this often needs to be replicated in the initial stages of moving into their own home.

It is critical that providers plan for a sufficient, highly skilled support team. The skill set and experience of the team includes a sound understanding of supporting people who have autism and who can experience prolonged periods of distress. Providers need to give consideration in their planning to the ongoing resilience and emotional wellbeing of the support team and how this is achieved through reflective practice, patterns of working and ongoing supervision and support.

# Provider capability and workforce skill set

## 2 Bespoke accommodation and support within a core and cluster model

For other people in the London Demonstrator, the need to live alone, with the opportunity to share communal space, was identified as important both to and for them. A core and cluster model based on independent self-contained flats (ideally 6 or less) where people are able to share communal spaces when they want to. This model enables providers to be flexible and able to respond with immediate support in response to how someone is feeling.

This requires a skilled workforce that have the flexibility to work with people who have experienced high levels of institutionalisation. Specific skill sets may be needed, for example, to support people who have experienced exploitation, are vulnerable or have experienced trauma and abuse. Workers may also need to be trained in supporting people who have been through the community justice system.

## 3 Shared housing and support

Shared housing and support may be an appropriate option for people with similar support needs and who want to live communally.

The workforce will need to be skilled in supporting people with a range of needs who live together and be able to do so in a way that enables personalised support rather than shared ways of doing things. Understanding how to balance person centred support with communal living will be important to ensure that individual needs continue to be met.

Specific skills sets may be needed. These include, working with people with a mild learning disability who are affected more significantly by autism and/or ADHD along with skills to support people with mental health support needs such as paranoid schizophrenia and personality disorder. Workers will also need to be able to support people with experiences of abuse, typically sexual and physical abuse and ongoing sexual exploitation. Understanding of issues relating to substance misuse and vulnerability to exploitation may also be needed.

Providers working collaboratively within a geographic location to enable a responsive and effective housing and support pathway that works with the person not against them as their needs and wants change is critical in sustaining good community support.

# Challenges and solutions

This section focuses on the challenges involved in discharging people from inpatient care and the barriers to developing appropriate support plans in the community.

For each challenge identified, we present an anonymised example to illustrate the problem and a solution to tackle it, based on what worked for providers involved in the London Demonstrator project.

## 3.1 Discharge plan delays

### The challenge

It is important to stress that every single person supported who was part of the London Demonstrator could be enabled to live in the community with a fit for purpose housing and support package. However, progress was hampered by whole system issues involving commissioners, funders and providers, which all play their part in delaying discharge and developing support plans.

### Case study

For one person, VODG identified an appropriate support provider to carry out an assessment and support proposal. The person has a long history of being let down by inappropriate or insufficient support leading to an understandable degree of anxiety about who is the right provider – from both their family and the professionals involved. The identified support provider was asked by the local authority to hold off on assessment as a number of assessments had previously been carried out. This was not picked up again until five months later when it emerged that these assessments would not work. When we spoke with the care manager about the person's support needs, there was a genuine lack of knowledge about community support and how this could be provided safely and successfully. We therefore guided the care manager throughout the assessment process in evidencing available support options.

## 3.1 Discharge plan delays

### The solution - Provider capacity

The time frame for supporting people to move from hospital into their own home can be up to 12 months from the point of agreeing the support provider. Agreeing a discharge date before a provider has been identified and a support proposal designed, costed and agreed will create delays.

Providers do not have support options that people can be immediately discharged to. The majority of people require bespoke support, even if shared. Identifying the providers at the earliest possible stage and committing to working with them, in the longer term, to design the best possible housing and support option is critical to future timely success.

Having an overview of the capacity and availability of a number of providers at any one time will enable TCPs to minimise discharge times. It will also support providers to recruit and retain the right workforce.

There was evidence that providers have a threshold for the number of people who need intensive bespoke support that they can support appropriately at any one time, in order to achieve sustainable alternatives to hospital provision. Building a greater overview of the provider market across London, in terms of capacity throughout assessment to delivery, will help to deliver the transforming care ambitions.

## 3.2 Lack of clarity about expectations and accountability

### The challenge

Delivery of the service assessments has been hindered by unclear expectations and accountability. We found that the professionals involved in a person's discharge are not necessarily the people accountable for making funding decisions. This led to delays and confusion as to who needed to be involved.

Delays have been encountered through the commissioning process because funding bodies vary in their approaches to commissioning services outside existing frameworks. However, when one person from the commissioning or clinical team takes the lead for an individual, positive steps can quickly be made towards planning for an appropriate discharge. The process is also made easier when there is a joint funding arrangement between health and social care.

In addition, a number of people have had a history of repeatedly being let down by inadequate care and support arrangements. People and their families can feel a lack of trust and confidence that community support can work. Commissioners and professionals can also feel the same. Some local commissioners and care managers have limited knowledge of providers who can support this group of people and may therefore approach those they commission with directly. This will not support capacity building across providers.

### Case study

One person has been in hospital for over five years, and was ready to move out with a community support provider identified. However, no progress had been made as the ongoing funding for their support is in legal dispute between four different funding authorities. Over 20 providers had been approached to carry out assessments and all had declined. Some of the providers who had been approached included VODG members. There was a lack of clarity about who had been contacted within the provider organisations or the reasons for them declining to assess. Through the VODG work, we identified the most appropriate provider(s) from our perspective and brokered the initial conversation about the person and their support requirements and the input needed. In each case, the provider agreed to assess and carry out a support proposal.

## 3.2 Lack of clarity about expectations and accountability

### The solution - A one provider approach

When providers are identified early and take proactive action, greater progress is also made in managing the priorities of the various stakeholders. At the outset of phase one of the project the plan was for VODG to identify up to three providers to undertake detailed service assessments. However, the complexity of individual needs raised issues of provider capacity and ability to respond to multiple service assessment requests.

The expected timescale for discharge has often been unrealistic, particularly in terms of the availability of housing. This has led some providers to invest resources in the assessment process for limited, if any, return.

An approach focussed on a 'best fit' with one provider can help progress things more readily. Through this approach the provider can work closely with the person, the clinicians, commissioners and family over a period of time to develop an appropriate housing and support package.

This approach is not a quick fix and requires intensive input with a clear understanding of the expected outcomes and costs for each individual. An early conversation, pre-assessment, on likely costs ranges is important to ensure that all parties are clear at the outset on the true costs of high quality community provision.

In addition, exploring the history of failed support needs in face-to-face meetings can help identify the most appropriate provider based on expertise, location and capacity. VODG was able to identify providers that commissioners and care managers may not be aware of. These providers were able to respond to the specific needs of the individual. The development of a pan London provider infrastructure that is able to respond to support delivery at scale will also help, and we refer to this concept in more detail later in this report (see Section 4, Conclusions and recommendations).

## 3.3 Negative attitudes and aspirations

### The challenge

Initial information and descriptors of people can be negative with insufficient information. People are often described as “the most complex person known to services”. With prompting, more detailed conversations can quickly lead to a wealth of knowledge and aspiration about how people can be supported well and safely within the community. The initial TCP planning meetings were helpful in facilitating and building this shared knowledge and setting out what a good life looks like for each person.

### Case study

One person involved in the London Demonstrator was initially described to VODG by their patient identity number, the hospital they were currently at and the length of time they had been there. At a round table discussion, facilitated by VODG, this information was added to in terms of their support needs and information on why a number of previous community placements have failed. One of the professionals knew the person and was able to describe in a positive, respectful way what was great about them – the things that matter to them and what good support looks like. This approach completely reframed the discussion and established a shared incentive to identify community support options that enabled the person to live in a way that matters to them.

At a separate meeting, in contrast, the starting point for the discussion about one person was again their patient identity number. The professional at the meeting had never met the person and had only been handed the case as staff turnover meant there was no one else available and a tribunal hearing was imminent. This proved much harder to build a sense of who the person was and what was important in terms of community support.

## 3.3 Negative attitudes and aspirations

### The solution - Understanding people's needs

In the London Demonstrator we have been able to identify individuals' needs, wants and aspirations and how these may align with what others are seeking. The work has started to identify how these might map out across London in terms of where people want to live and the support (shared or otherwise) they require.

However, our sample is small and focussed on people who have been in hospital for over five years. A more detailed demand analysis will aid the planning and prioritisation of future work and enable early identification of providers.

The demand analysis should go further to understand the required infrastructure to enable people who need to live on their own but who at times, and without notice, may need additional support. For example, someone may generally need one to one support but when anxious or distressed they may require additional staff support.

The demand analysis should usefully contribute to identifying appropriate commissioning arrangements. Similarly, support packages are being designed for people who do not fall within the same TCP and yet may benefit from sharing support or property. This has the potential for enabling speedier discharge which can be more financially sustainable. Developing a strategic overview of the numbers and needs of people requiring specific support will help build provider capacity in the market.

As well as this, face to face meetings with clinicians, care managers, commissioners and funding bodies could offer opportunities to discuss each individual in detail. The meetings are also useful to explain the type of community support available. By reframing information about people and their support needs, it is possible to identify appropriate provider(s) to undertake assessment and support planning. This also helps implement a proactive approach to case management with providers to ensure the assessment and support planning process remains on track.

Where possible, this relies on stakeholders across a TCP area coming together to collectively plan and deliver good support to people rather than focusing on one local authority area at a time.

## 3.4 Confusion about costs

### The challenge

There is a lack of understanding and a gap in knowledge about the costs of community support for people who have a history of being failed through insufficient support and/or a history of being institutionalised.

Initial costs for discharging someone from hospital may be similar to the costs of hospital support due to replication of levels of staffing in the first few weeks or months. Generic brokerage teams are used to negotiate the cost and specifically the hourly rates without the knowledge or experience of the specific support needs of this group of people, instead the cost of packages is compared to standard domiciliary care rates.

Related to the lack of understanding about costs is a similar absence of knowledge about the need for ongoing therapeutic support to be provided alongside community support. A large number of people involved in the London Demonstrator sample have a history of abuse and/or trauma which requires specialist long term therapeutic support and cannot typically be met through local community teams for people with learning disabilities, either due to capacity or skill set.

### Case study

One person had been in hospital for the majority of their adult life. They need intensive and ongoing therapeutic levels of support to manage a move from hospital. A community support provider and property had been identified, but progress was slow due to the perceived high level of cost of the support package.

For another person, a support provider was already involved in assessing when VODG became involved. It transpired that subsequently it was viewed that they had developed a “perfect” support proposal that clearly met the person’s needs. The cost of this support, however, was seen as too high and other providers were being identified to re-assess and develop support proposals. VODG was asked to assist with this. We illustrated the average cost of support packages, to enable a shared understanding of the costs of provision for the work involved.

## 3.4 Confusion about costs

### The solution – Early conversations

Earlier dialogue is needed about the level of support to enable people to move and about the likely costs. These conversations should include both NHS England and local commissioners. In addition, it is worth having input from specialist services into the assessment and support planning process as well as the ongoing support post discharge. It is also possible to start the assessment process even when there are ongoing disputes on funding responsibilities.

Building shared knowledge and expectations of the support costs of people with specific needs is advisable, as is considering the best approaches to procurement for this specialist group, especially in ways that do not further delay discharge. Greater understanding and take up of personal budgets and individual service funds will also increase individual choice and control whilst simultaneously reducing time delays.

## 3.5 Lack of support to families

### The challenge

Support to family members who themselves have also often been through significant trauma and/or abuse is often not considered, factored into proposals or costed. Yet the support needed by families is intensive and critical to the ongoing sustainability of the support to the individual. Without responsive ongoing support to families, there is likely to be a knock on impact on the quality of community-based support to the individual.

### Case study

Involving and investing in families from the beginning is critical to sustaining community support once someone moves from hospital. One provider started working with the family at the point of assessment, involving them in the development of the support proposal and identifying a dedicated family support worker once the proposal was agreed. Weekly meetings took place with the family during the transition stage, using the time to learn more about the person and their wider family while also providing practical and emotional support.

The family were actively involved in recruiting and training the support team and developing the support plan that will be used post discharge. The emphasis has been on building a team around the person which means the family, support staff and professionals are working collaboratively. Whilst this approach can mean a shift in practice for providers, it is required alongside time, commitment and resources to ensure people and their families are well supported.

## 3.5 Lack of support to families

**The solution - Involve and invest**

There is a growing awareness of the need to include support to families as part of the community support offer. Providers can help to build approaches to working with families to better understand and deliver support to families as part of their overall offer.

# Conclusions and recommendations

## 4.1 Conclusions

Based on the VODG Provider Taskforce's London Demonstrator project, it is clear that every single one of the people we have been involved with would be able to live well within a local community, with the right housing and support.

However, for each individual, progress has been hampered by multiple, often system-wide issues that are blocking their successful move from hospital. VODG acknowledges that there are issues for providers to address, and are committed to supporting this improvement from assessment through to sustainable support delivery.

Based on our experience through this project we have identified several issues that could help reduce delays in discharge times and support successful housing and support options in the community.

**A pan-London approach to meeting individual needs**

The housing and support needed for people within the London Demonstrator (see Section 1 Introduction) are from different London boroughs. To date it appears that they been viewed in isolation by their individual funding authorities, making it harder to identify people in borough that they can live with, when living by themselves is either inappropriate and/or financially unsustainable in terms of the cost of the service model.

This project has been able to share support information with other boroughs and funding authorities. Whilst this small project has begun to map people across transforming care partnerships who have similar needs and who may be able to live together further work may be required to enable local authorities or clinical commissioning groups to achieve this mapping at scale.

**Stronger accountability**

Our experience is that whilst a care manager may be initially liaising with the support provider in relation to the assessment and service proposal, they are unable to agree the proposal without referring to others within the local authority and/or the CCG.

This includes referring up through their own line management structure and will also involve procurement who may have additional requirements. Timescales can also differ. Care managers may be guided by panel dates (which can be monthly) to present support proposals. Submissions which fall outside of these dates by providers can delay progress for up to a further four weeks.

# Conclusions and recommendations

## 4.1 Conclusions

**Clearer communication between professionals**

The drivers for an individual's discharge may not always be shared between the stakeholders involved in the case. There is a question over the financial drivers and their prominence in the decision-making process. This dynamic can create tensions amongst professionals involved.

We have experienced local authority and CCG staff overly focussed on discharge dates and progress reporting to deadlines. Conversely, a sense of inertia from local authority or CCG staff in achieving progress has been reported by others.

Shared meetings at the beginning of the process with all relevant professionals to discuss and agree the way forward for a group of people has been helpful in agreeing a shared understanding. This includes what has not worked to date and what the important issues are for different stakeholders. These meetings have also been helpful in refocusing on the person rather than as cases to manage and process.

**Improved knowledge and information about the cost of high quality care**

Critical to the success of this programme is being realistic about the financial costs of supporting people in the community. For individual support packages when moving from hospital on a minimum of 1:1 or 2:1 support, best practice is to replicate support levels (at least in the initial phase of moving from hospital).

Provider costs have been challenged by brokerage teams in the funding authorities. This may be attributed to brokers usually negotiating support packages for people under generic domiciliary care frameworks. These are not transferable to the levels of support required for people who meet transforming care criteria. Establishing a wider, shared, understanding of the financial costs of community support packages for people is required.

# Conclusions and recommendations

## 4.1 Conclusions

**Earlier identification and sourcing of housing options**

Housing has been described in our work as one of the biggest challenges in enabling people to move out of hospital. In London this is a particular challenge because of the cost of housing.

It is possible for housing to be identified, designed and sourced for people through a range of options. An important consideration is understanding the time this can take and planning and working accordingly.

At the point of VODG starting this project housing had been sourced for only one person from the group of people who need to live on their own. For most people in this group their housing needs can be specific to their own requirements. To therefore find property meeting these requirements in inner London can be difficult in the current funding climate.

Identifying and sourcing property is resource intensive and has the potential to significantly extend the discharge planning period. The majority of community support providers are able to identify and source appropriate housing. However, they will only start doing so once their support proposal has been formally agreed by the relevant funding authority. The active search for housing therefore may start some months after the initial assessment.

A lot of support providers intentionally keep housing separate to the support they provide to enable people to have greater choice and control over who and how they are supported in line with best practice. At the point of referral, for the group of people involved, it has been expected that the support provider will manage the housing requirements which is and can be done. The earlier the provider has been identified in the discharge process, the quicker the housing solution can be agreed and sourced.

# Conclusions and recommendations

## 4.1 Conclusions

**Better links with clinical and therapeutic support**

Many of the people involved in the London Demonstrator have ongoing and significant challenges. This may include issues relating to abuse, trauma, exploitation, substance use, sexualised behaviour and mental health needs.

Clinical teams and care and support providers often need to work in partnership with ongoing specialist therapeutic services to deliver successful support. Recognising and agreeing the need for additional support through specialist organisations in providing ongoing support is important to achieving successful, sustainable, community support.

## 4.2 Recommendations

Learning from the VODG Provider Taskforce's London Demonstrator project, we can suggest a number of next steps to help move people on from long-stay inpatient care:

- development of a strategic regional pathway to move people out of hospital and/or prevent readmission. This should include demand and supply mapping with a detailed analysis of costs and funding arrangements
- development of a sustainable care, support and housing market to support the current and future needs of people with learning disability, autism or both
- creation of a provider network which dynamically maps organisations' capacity, skill set and infrastructures to identify an appropriate provider for each person. This could include regular TCP panel meetings with providers to strengthen shared working and to maintain momentum in terms of progress
- regional work with providers to develop shared and standardised approaches as appropriate, to develop joint approaches to shared challenges such as housing, recruitment
- creation of an enhanced brokerage programme to facilitate discharge of people in hospital settings to living with the right support in their chosen community
- the piloting of a therapeutic support programme in order to understand the demand and impact of this type of support.

## 4.3 Future strategies

The learning from this project should lead to the development of tools, templates and resources as well as providing a forum for good practice to be shared across the system. This includes an agreed process and structure for engagement and communication to be developed.

Rather than there being a need for increased competition amongst providers for supporting people, there is actually an issue of balancing demand against a finite supply. This does not mean there are not enough community support providers, but it does mean that a more strategic approach to identifying the appropriate provider for each person is needed. This should not be based on rigid procurement processes but focused on the best outcomes for the individuals concerned.

Understandably, different providers have different approaches to managing referrals, carrying out assessments and developing support proposals. Through our work, we have established the need to standardise a number of approaches amongst providers to respond to demand in a way that builds trust and generates capacity and resilience through joint working. Resources are required within local teams to ensure that emergency plans are in place and have been agreed with all partners.

Closer working between providers working together in the VODG London Demonstrator project has led to a shared understanding of local capacity and capability, which can help to build resilience amongst local groups of providers.

The learning from this will be an important factor in any future work. More systematic information about provider capacity and capability is needed to enable this approach to be developed in the future.

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