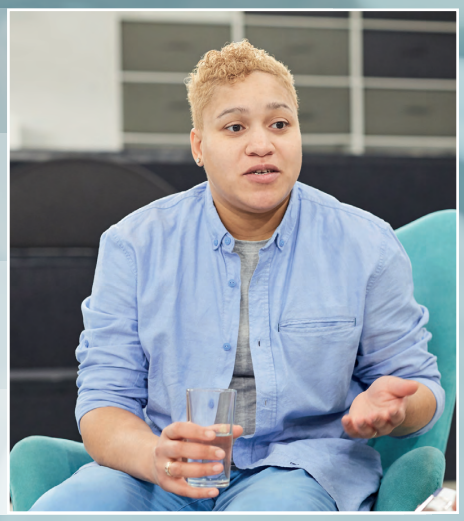


A time for action: ending the reliance on long-stay inpatient units

VODG

CONTENTS

Two lives, one lesson 3

Time to address a national scandal 4

Making change a reality 6

England's detained citizens 13

How did we end up here? 16

A matter of perspective 18

More action less words 22

In the end 23

VODG is a membership body representing organisations within the voluntary sector who work alongside disabled people.
Our members' work is focused on enabling disabled people of all ages to live the lives they choose. VODG believes that an ambitious, trusted and vibrant voluntary sector that works together plays a unique role in achieving this aim.
Our **vision** is for an ambitious, trusted and vibrant voluntary sector that works together to enable disabled people to live the lives they choose.
In pursuit of this vision, our **mission** is to support our members to achieve excellence and to influence those who can improve the environment in which they operate.

Two lives, one lesson

Rob

"Rob[1] is a young man who had behaviours that challenges and during his time in a long-stay hospital he presented a risk to himself and those around him. It meant that the cost of his hospital package continually increased. This was coupled with high property repair costs because of the damage he caused to the building.

Rob moved to a community support provider. The provider co-designed a person-centred and cost-effective service with Rob, his family, commissioners and others. The provider used staff trained in person-centred active support to ensure that Rob was engaged in the activities around him and did as much for himself as he could. This resulted in opportunities to learn new skills and access his local community, including visiting the bank and pubs where he meets his family."

Adam

"Adam[2] was admitted to his current hospital when he was 10. Since admission, Adam has been confined to a seclusion room with dimmed lighting. … The walls of the seclusion room are padded because Adam often throws himself at the walls and bangs his head on them. …

Adam soils himself, sometimes smearing faeces. Staff have abandoned attempts to help Adam to learn to use the toilet after early attempts had not been successful. …

[M]ost of the staff who care for Adam have only received basic online training in autism. There is no plan to remove Adam from long-term segregation or support him to leave hospital."

1 Rob's story (not his real name) comes from a VODG member with a track record in supporting people to leave hospital and live their own independent lives in the community.

2 Adam's story is shared as a case example at the start of a Care Quality Commission (2019) report, *Segregation in mental health wards for children and young people and in wards for people with a learning disability or autism.* Accessed: www.cqc.org.uk/sites/default/files/20190626_rssinterimreport_full.pdf

Time to address a national scandal

In June 2019, BBC Panorama programme exposed another abuse scandal at Whorlton Hall hospital, which is owned by Universal Health Services Inc[3]. This was not the first exposure and until there is concerted policy aimed at galvanising meaningful change, it will not be the last. National scandals involving the abuse of disabled people living in long-stay units must be stopped.

The Voluntary Organisations Disability Group (VODG) remains outraged that the commitments made following the Winterbourne View abuse scandal in 2011 are not a priority for government. Consequently, the needs of the 2,250 people currently living in long term NHS accommodation and NHS-funded accommodation are slipping down the government's agenda. Despite our earlier work pointing to very practical solutions that community services offer[4], VODG continues to see the capability of social care and community sector services overlooked in addressing these issues. We continue to see a dominant focus on NHS provided in-patient services and NHS and local authority commissioning of private sector long-stay hospitals.

VODG welcomes the recent focus of the Joint Committee on Human Rights[5] which called for individuals' rights to be strengthened and for the important role of families and carers to be recognised as upholders to those rights when people are detained. Indeed, Harriet Harman MP QC, chair of the committee, said: "This inquiry has shown with stark clarity the urgent change that is needed...what we saw does not fit our society's image of itself as one which cares for the vulnerable and respects everyone's human rights."

Scrutiny is being increased with the Children's Commissioner for England chairing an independent oversight board that can provide scrutiny and propose improvements to existing arrangements[6]. While Baroness Sheila Hollins will, over twelve months, lead case reviews of individuals in long-stay units[7].

Furthermore, new care models and provider collaborative approaches[8] are being introduced to address fragmentation in mental health services, and are expected to also be used to deliver some learning disability and autism services in the future. This policy development offers an important opportunity to reflect on the learning to date, drawing on the perspectives of community providers, to help ensure that the next wave of policy implementation and reform is as effective as it can be.

---

3 Cygnet Care that brought the Danshell Group is ultimately owned by Universal Health Services Inc with its head office in Pennsylvania, USA.

4 VODG (2019) *Transforming care: the challenges and solutions.* Accessed: www.vodg.org.uk/wp-content/uploads/2018-VODG-Transforming-care-the-challenges-and-the-solutions.pdf

5 Joint Committee on Human Rights (2019) *The detention of young people with learning disabilities and/or autism.* Accessed: https://publications.parliament.uk/pa/jt201920/jtselect/jtrights/121/121.pdf

6 NHS England (2019) *NHS taskforce to drive improvements in young people's hospital mental health, learning disability and autism care.* Accessed: www.england.nhs.uk/2019/10/nhs-taskforce-to-drive-improvements-in-young-peoples-hospital-mental-health-learning-disability-and-autism-care/

7 Department of Health and Social Care (2019) *All inpatients with learning disability or autism to be given case reviews.* Accessed: www.gov.uk/government/news/all-inpatients-with-learning-disability-or-autism-to-be-given-case-reviews

8 NHS England (2019) *NHS led Provider Collaboratives: specialised mental health, learning disability and austim services.* Accessed: www. england.nhs.uk/mental-health/nhs-led-provider-collaboratives/

VODG welcomes the attention being given to the lives of people living in long-stay institutions. Policy making must be informed by professional expertise and the views of disabled people and those they wish to involve. There is much to learn from organisations that support disabled people, and this report shares learning from community services in supporting people out of long-stay institutions.

VODG commissioned independent consultants Cordis Bright to undertake analysis of the published 'transforming care' data and the associated policy ambitions. Their work included a wide range of interviews with providers across the spectrum including VODG members and private (for-profit) operators. Messages were also tested with key individuals within the NHS and local government involved in delivering the programme.

The aim of the interviews was to establish clearly what was working well but also identify any persistent barriers preventing the programme from progressing. This activity was supported by a workshop with providers to consider the interpretation of the key findings and messages contained in this report. This report distils those findings and does not seek to name individuals, organisations or particular NHS regions.

Whilst the focus of VODG is with providers of community services that support disabled people we recognise the importance of individual and family perspectives including groups such as Learning Disability England and the work of Rightfullives campaigning in this area.

Ultimately, VODG believes that it is critical the 2,250 citizens currently detained in NHS accommodation, some for many years, should be clearly seen first and foremost as the responsibility of the UK government.

The coalition government decided that indeterminate prison sentences for convicted criminals, where no end date is fixed, were 'indefensible'. There are at least 355 people who have been detained in hospital for more than ten years where there is no serious prospect of them ever being discharged. Yet, the government refuses to legislate to protect them or force their release back into the community with the necessary support and care.

It would be hard to imagine any other circumstances in which a British citizen could be detained indefinitely by the state, without a trial, where government has explicitly acknowledged that the conditions of their detention are for the majority inappropriate and should be ended and yet continue to detain them in precisely the same, and in some instances worse, circumstances nearly a decade later.

9 Rightfullives. Accessed: https://rightfullives.net/

Making change a reality

VODG members and other providers have a mixed experiences of the transforming care programme (TCP). At its best, it is about professionals working openly and collaboratively, putting the individual at the centre of the process and working consistently towards a positive discharge from NHS-funded care into a new life in the community. Voluntary sector providers are clear that this can and does happen, as other independent sector providers agree. There are positive reports of the process in operation. What is clear, however, is that the pace and approach adopted by commissioners is a localised phenomenon with no consistency across the country.

The data relating to TCPs tells its own story. Some TCPs successfully manage year on year reductions in the number of people in NHS care. Others make no impact on the numbers of people in NHS care whatsoever. There is even a small group where the number of people has actually increased over time. Clearly, there may be some issues with the quality of the data (people may have been accidently excluded from the cohort until a later date, giving the impression of increasing numbers for example) and given that it is such a small number of people overall, it is a concern in itself that data quality remains an issue seven years on.

Set out below is a summary of these findings, illustrating the variation in experience encountered by VODG members and other independent sector providers. At its best, the TCP is highly effective but all too often a pattern of barriers emerged.

VODG is also conscious that there is little new to report in that nearly all other research into this programme has identified the same issues as being problematic. We are, therefore, seeking to establish a positive view, from the perspective of community providers, as to how new arrangements can be implemented successfully and for re-provision efforts to be scaled at pace.

Local support	
Working	**Not working**
Providers praised the level of foresight and planning included in some TCPs. In some instances, there has been a genuine attempt to develop a comprehensive longer-term plan of discharge, which enabled providers to develop and respond with detailed plans of their own.	The TCP has struggled to gain focus and momentum in some areas, at least in part because the resources and capability of the relevant local authority have been eroded through years of austerity. It has often proved difficult to get clarity around a person being discharged in terms of their ongoing access in the community to multidisciplinary local support (community health teams and forensic teams in particular). Many providers had the sense that "they're your issue now" and "it's up to your organisation to secure the necessary clinical and psychological support needed".

Funding	
Working	**Not working**
Many providers reported a positive experience around funding with commissioners resourcing support packages always appropriately, recognising that additional complexity of need required additional investment. A sense that commissioners were getting better at recognising that higher hourly rates are necessary for specialist staff input. Most providers understood and accepted that participation in the programme required upfront investment in staff teams, training, systems etc. Commissioners are recognising the financial costs associated with providers working with individuals, sometimes for many months, prior to discharge from hospital.	Notwithstanding the cost of supporting people in institutional settings some commissioners would not accept that supporting people in the community, at least initially would be expensive when compared with other care groups. This meant commissioners offer unrealistic funding for the staffing ratios and did not recognise the higher salaries needed for more experienced or specialist staff. Commissioners expected providers to invest at risk in the preparation and planning stage of discharge and were often reluctant to underwrite these costs. This means that the pool of providers is limited to those that have sufficient resources and risk appetite to invest upfront.

Staffing	
Working	**Not working**
Although experiences of staff recruitment were not all negative, it was one area where there was very little positive experience reported.	Providers faced three main challenges, which were common to other areas of their work but were often seen as being even more challenging in relation to re-provision from long-stay hospitals: • recruiting the necessary staff, especially highly skilled • recruiting within the communities where individuals are placed through transforming care, and • retaining staff.

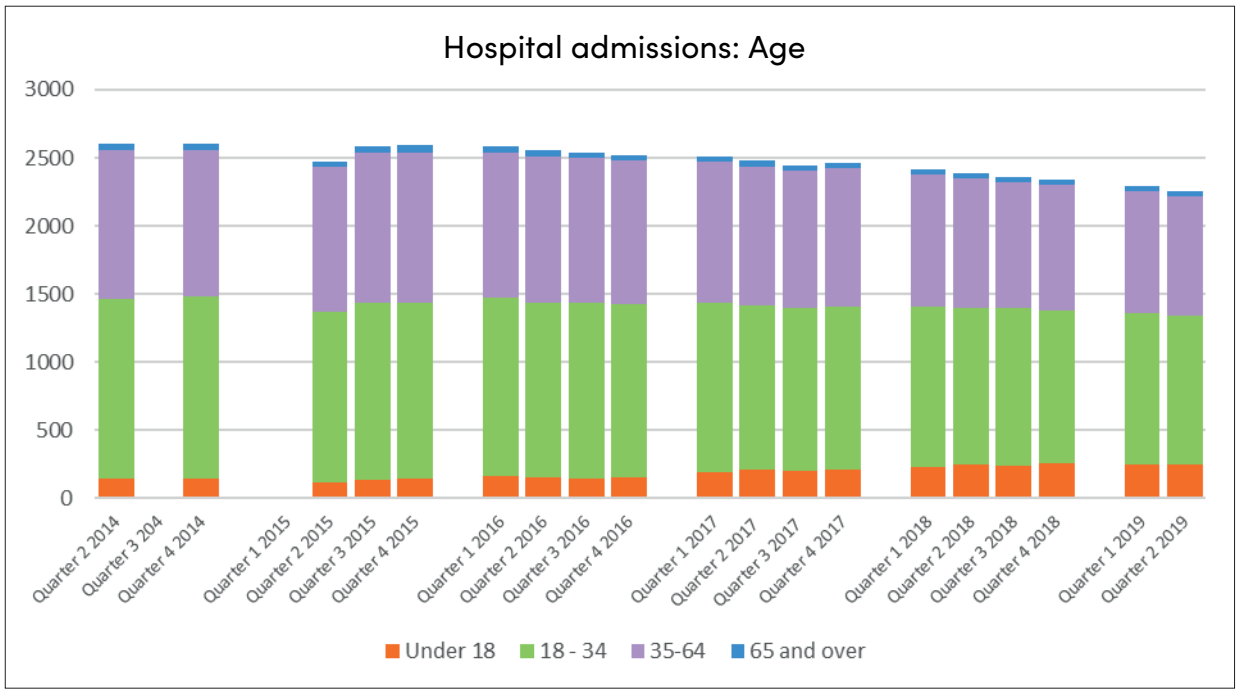
Housing	
Working	**Not working**
Housing was mostly challenging but not everyone saw this as a particular issue of transforming care so much as a more general difficulty in securing the right property at the right price in the right place.	Difficulty finding suitable housing for individuals coming out of ATUs, particularly where relatively tight geographical locations were specified. Housing Associations sometimes appeared to be short of stock and sometimes unwilling to give assured tenancies. Funding levels and arrangements seem to discourage new-builds, which can make delivering a truly bespoke solution difficult. Difficulty accessing NHS grants for housing. Many providers perceived the conditions for NHS grants as onerous.

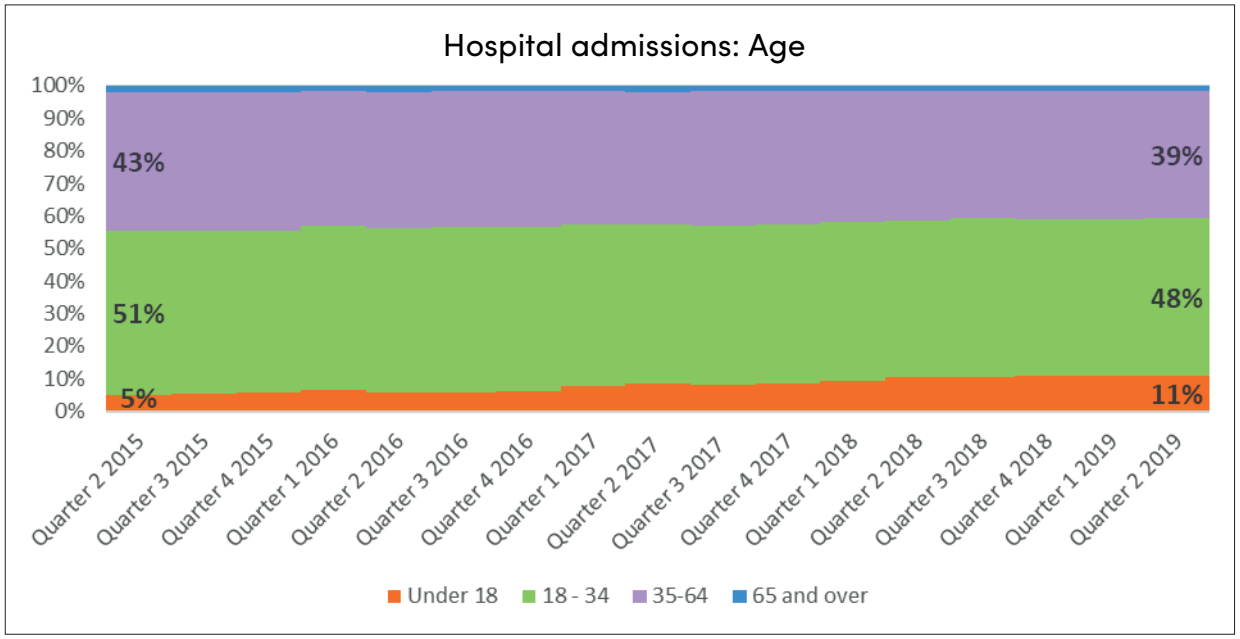
Relationships with hospitals and clinicians	
Working	**Not working**
Some providers reported hospitals being almost too keen to get people out, possibly driven by concerns about bed blocking. Initially risk adverse clinicians responding well to thoughtful and evidenced arguments, growing in confidence and cooperating. Establishing and maintaining relationships with clinicians, which is crucial for discharge as well as for sustaining the person in the community.	Clinicians unwilling to let people go and putting barriers up. Private hospitals showing a financial conflict of interest. NHS hospitals proving too risk averse and skeptical about whether social care providers can manage. Difficulties getting in to the ward to get to know the individual and plan for the move. Many reported problems with the information that was shared about an individual, to the point where some providers are only willing to look at discharge if they have had the opportunity to undertake their own assessments. A lack of strong central leadership, who can hold clinicians to account.

Commissioning	
Working	**Not working**
Some good examples of commissioning showing in-depth understanding of the issues and a commitment to collaborate. More creative approaches to commissioning being taken as a result of collaboration across local areas.	Some 'professional commissioners' lacking understanding of services. Commissioners not always sure what they want – flip flopping. Commissioners only thinking about the 'usual suspect' large providers. A lack of forward planning and unrealistic timescales to organise placements and obtain housing solutions. Not being given time and certainty to invest in developing capacity. A need for commissioners to work with you from the start to develop a bespoke s olution together. Too many hoops for providers to jump through.

There are around 2,250 people currently included in the TCP, which in terms of the total population of England is small, but to put it into context this equates to nearly half the population of a town like Keswick.

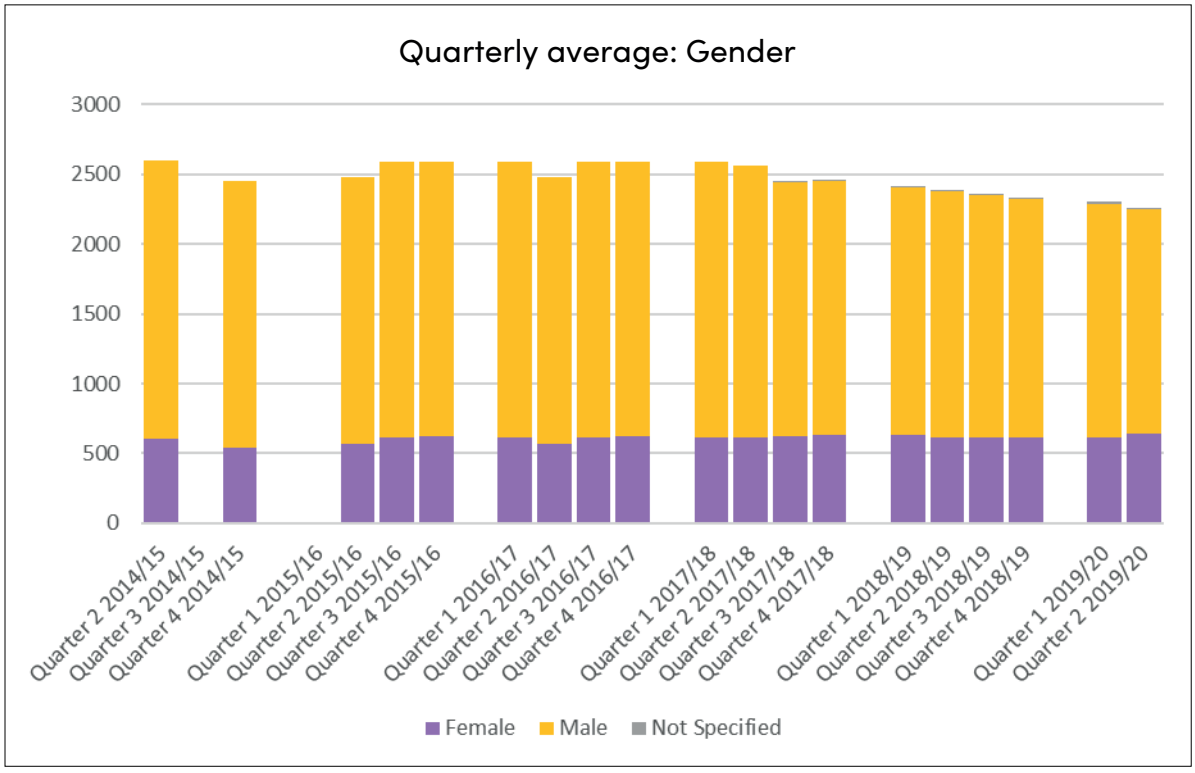
The majority of these people are of working age (87% in Q2, 2019/20), with a very small group aged 65 and above. Worryingly, the number of people aged under 18 is increasing and becoming a growing proportion of the remaining total. Under 18s have moved from representing just 5% in Q2, 2015/16, up to 11% by Q2, 2019/18. This is, in part, almost certainly down to some historical miscounting but accepting this, the later trend between Q1 of 2017/18 and Q1 of 2019/20 shows an increase of over 30% for this group of young people.





In other words, even with a clear acknowledgement that the placements are inappropriate, and the mission of the programme is to reduce detention of people in these settings, more younger people are being admitted. The simplest explanation for this is that the services needed to properly assess and support young people in the community are becoming less readily available.

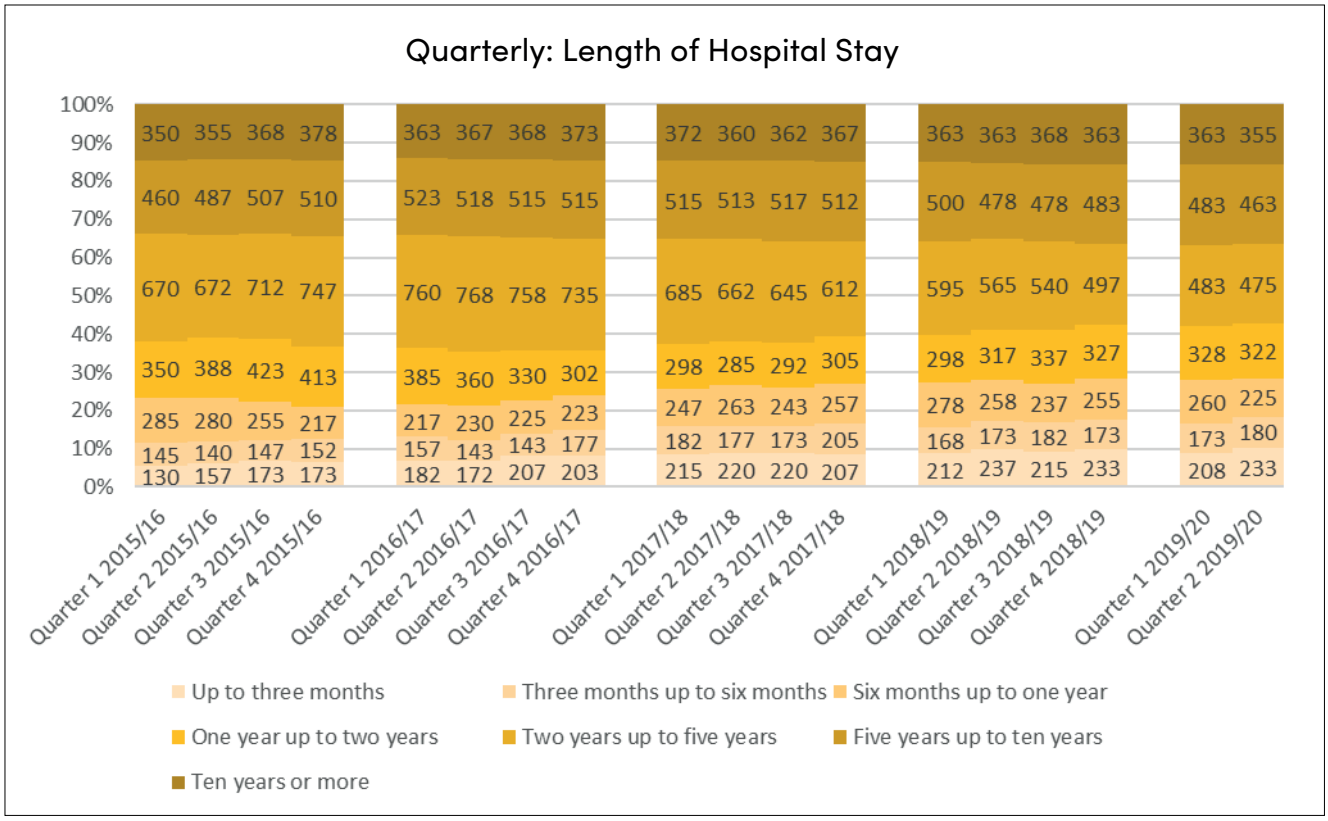
Women have always made up the minority of this group, but it would appear that even with an increase in the rate of people successfully moving back to live in the community, women are markedly less likely to do this. In 2014, the number of women detained was estimated to be around 600 or 23% of the detained population at that time, by 2019 it is still around 600 women although it may be slightly higher. As a proportion of the total people detained, this figure has risen to 28%. There is no clear explanation for this. It is a statement of the obvious that it appears to be far harder to get discharged from NHS care if you are a woman.



People detained in hospital as part of the TCP are not the only group of people detained indefinitely by the state. When the coalition government came to power, they decided that indeterminate prison sentences, where no end date is fixed, were 'indefensible'[10] and repealed the legislation.

There are around 463 people that have been NHS accommodation for more than five years and 355 people who have been there for more than ten years.

Nearly 60% of the people covered by TCP have been in NHS accommodation longer, on average, than a prisoner spends in prison. However, no legislative response has been forthcoming from government even though the circumstances of people's detention has been judged unacceptable.



10 House of Commons Hansard (2010) *Prison Places.* Accessed:https://hansard.parliament.uk/commons/2010-06-15/debates/10061522000022/PrisonPlaces

How did we end up here?

What happened at Winterbourne view was sadly not in any way exceptional in the context of the history of secluded and segregated hospital-based provision for people living in vulnerable circumstances.

From the late 1960s onwards, a series of abuse scandals focused around long-stay hospitals and wards began to emerge, starting with Friern Hospital in 1967 which was quickly followed by reports of further instances of institutional abuse at Ely and Powick Hospitals.

This pattern continued into the 1970s with abuse scandals at Farleigh, Whittingham, South Ockendon and Normansfield Hospitals. The response of government to these events at the time could at best be described as 'defensive', with ministers determined to try and present each occurrence as an isolated and unconnected event. Even after the broadcasting of the documentary 'A silent minority', which exposed the poor treatment of children with disabilities at Boroughcourt and St Lawrence's hospitals in 1981, the immediate response of government was to downplay what had been shown.

It was a further seven years before the government brought forward the green paper 'Community Care Agenda for Action' proposing the closure of long-stay hospitals and the development of community-based services. This was quickly followed by the white paper 'Caring for people', which directly led to the National Health Service and Community Care Act 1990 becoming operational in 1993.

From the scandal at Friern Hospital it had taken 25 years to get to this point.

The pattern of abusive settings continued, however. As NHS facilities closed, the problem began to emerge in privately operated services as well, In 1998, the Long Care Inquiry exposed two privately operated care homes where systematic abuse of people with a learning disability took place, 2006 saw the investigation into abuse of people with learning disabilities and autism in the Cornwall Partnership Hospital and then in 2011 the BBC Panorama programme on Winterbourne view was broadcast.

In 2012, the Department of Health published a concordat outlining a programme of action. When progress was seen as being too slow, the chief executive of NHS England asked the chief executive of the Association of Chief Executive of Voluntary Organisations, Sir Stephen Bubb, to investigate and report. The publication of 'Winterbourne View – Time for change' followed in 2014.

Although in the last two years the pace at which people leave these institutions has increased, there is a growing sense that NHS is shifting its priorities away from the TCP to other areas, albeit equally important issues such as the early deaths of people with a learning disability from entirely preventable conditions.

In the same week that Panorama reported on the abuse scandal at Whorlton Hall Hospital, the Care Quality Commission[11] brought forward the publication of their interim report into segregation in mental health wards for children and young people and in wards for people with a learning disability or autism. This provided further evidence of children and young people living in appalling conditions in both directly managed NHS and independent sector provision. CQC plan to bring forward a final report in the spring of 2020. Earlier in 2019 the Joint Committee on Human Rights initiated two inquiries into conditions in learning disability inpatient units and into the detention of children and young people with learning disabilities and/or autism.

VODG sees a pattern of further reviews and enquiries with a continued reluctance to either propose or to take more radical steps for change. VODG believes that if the current approach is maintained that it will probably take another fifteen years for concrete action. During this time there will be positive steps forward and for some people their lives will be transformed for the better. Sadly, many people will simply experience a lifetime of wholly unacceptable depravation, living in institutions that the government has already judged unacceptable.

11 Care Quality Commission (2019). *Segregation in mental health wards for children and young people and in wards for people with a learning disability or autism.* Accessed: www.cqc.org.uk/sites/default/files/20190626_rssinterimreport_full.pdf

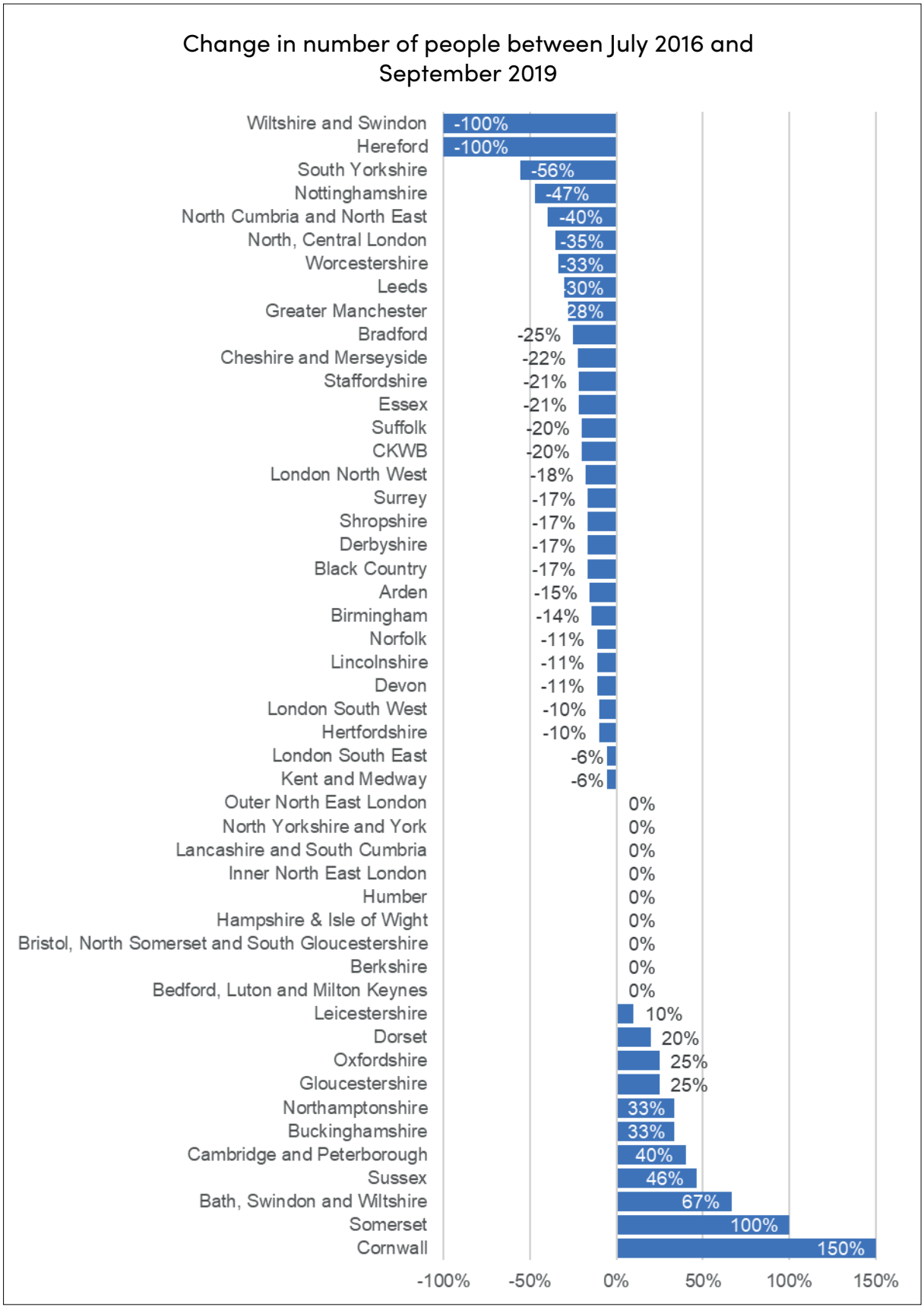
A matter of perspective

NHS England believes good progress has been made since the start of the TCP in 2012. In the NHS ten-year plan, it states:

Since 2015, the number of people in inpatient care has reduced by almost a fifth and around 635 people who had been in hospital for over five years were supported to move to the community.

Given the poor quality of the data, it is difficult to understand how NHS England can be so certain. Data from NHS England indicates that the rate at which people are being discharged has increased, which VODG members recognise is a positive step, although this has to be qualified by four critical points of concern:

- The number of people under the age of 18 in these units is rising in absolute terms as well as becoming a larger proportion of the group overall.
- Women appear far less likely to be discharged from NHS care then men with the total remaining broadly constant for the last four years.
- People who have been in these setting for in excess of 10 years appear highly unlikely to be discharged with their numbers remaining broadly constant.
- Looking at the data between July 2016 and September 2019 it would appear that there is highly variable performance amongst the partnerships. Just over half of TCPs have actually achieved discharge from hospital, with the rest either failing to achieve any overall change or increasing the number of people. Only fifteen TCPs managed to move 20% or more of the people for whom they are responsible and only seven managed to move more than 30%.



It is possible of course that this data is not correct. However, it would be surprising if data errors are only supportive of a narrative of success.

A matter of perspective

It is unclear if commissioners see it as problematic that over half the people within the TCP are currently supported by independent sector providers, both for profit and charitable. It is only possible to provide a broad estimate of income for these providers based on a figure of around £170,000 per person per year. On this basis, it would appear that the five largest providers, Acadia Health Care, Universal Health Care Inc, St Andrews Health Care, BC Partners and H/2 Capital Partners support some 955 people with an estimated income of around £162million per annum for the five largest providers.

VODG finds its difficult to understand what would motivate these large American corporations and private investment vehicles to be positively engaged in discharging people from their care back into the community given the level of resources associated with their continued detention.

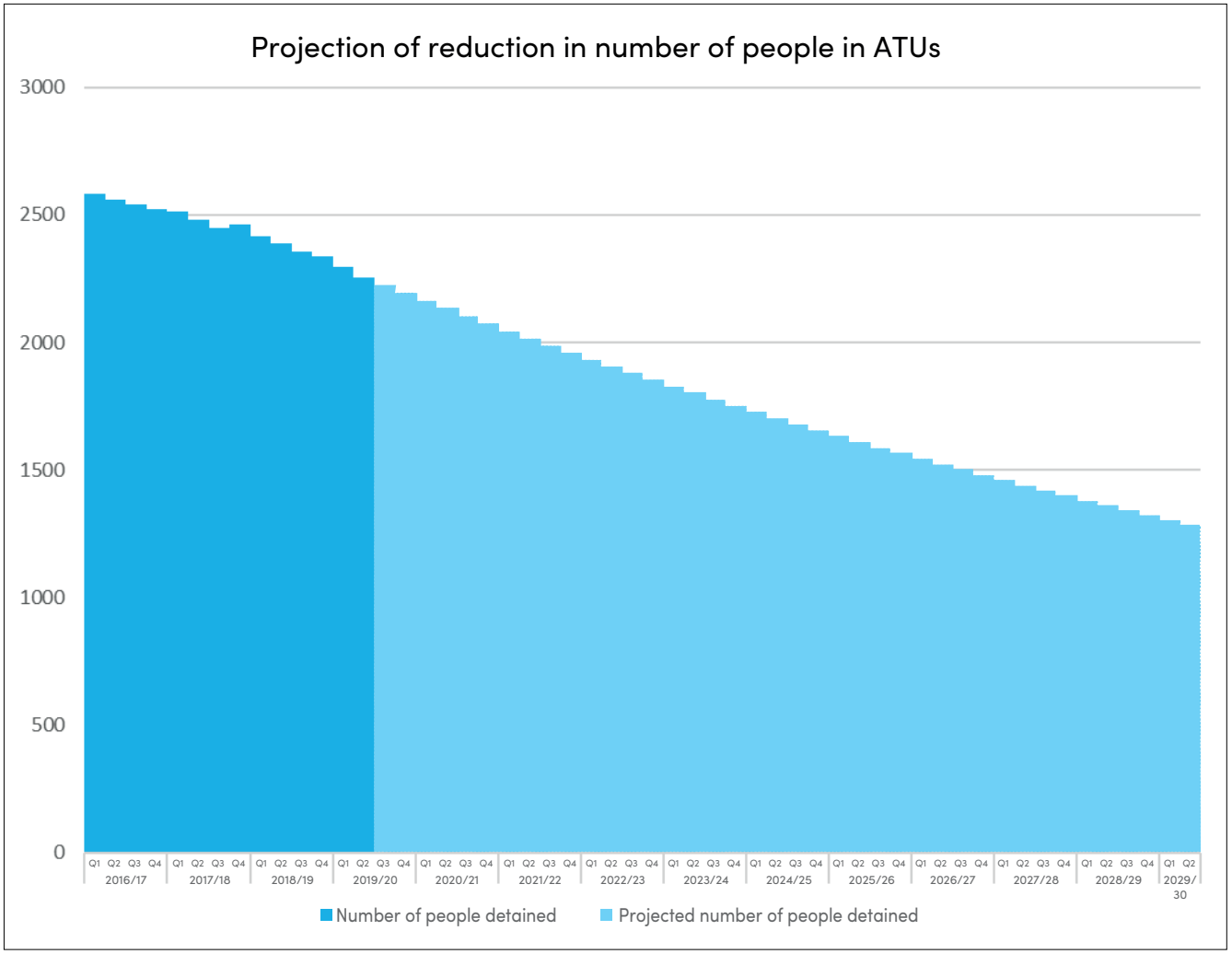
VODG cannot understand how services which are meant to be for assessment, treatment and then discharge continue to be rated as 'Good' by CQC when they are clearly failing to deliver on their core registered purpose.

Ultimate owner	Subsidiary company	Total number of people	Estimated income by subsidiary
Arcadia Health Care	Priory Group	155	£26,350,000
Arcadia Health Care	Partnerships in Care	170	£28,900,000
Subtotal Arcadia Health Care		**325**	**£55,250,000**
Universal Health Care	CAS Behaviour Health Limited	65	£11,050,000
Universal Health Care	Danshell Group	80	£13,600,000
Universal Health Care	Cygnet Health Care	120	£20,400,000
Subtotal Universal Health Care		**265**	**£45,050,000**
St Andrews Healthcare		**170**	**£28,900,000**
BC Partners	Elysium Health Care	90	£15,300,000
BC Partners	Lighthouse Health Care	25	£4,250,000
Subtotal BC Partners		**115**	**£19,550,000**
H/2 Capital Partners	**The Huntercombe Group**	**80**	**£13,600,000**
	Total	**955**	**£162,350,000**

VODG members and other providers from the independent sector report numerous examples of independent sector providers proving uncooperative in the process of discharge. Although there were notable exceptions to this as well of reports of lack of co-operation from directly managed NHS provision.

VODG wants to stress that there are also many positive experiences of interagency co-operation and support, but organisations that have direct and positive experience of supporting people to leave institutional care and establish themselves in the community report many challenges in the operation of the programme.

VODG members do not dispute that the rate of discharge has increased and indeed it is recognised that is a positive turn of events. If the current rate of discharge maintained it means that by early 2030 the population will have halved from 2015.



However, this also means that if this is achieved, two decades will have passed since the abuse scandal of Winterbourne View. For those one thousand people, it will represent a hugely positive outcome which should be celebrated. For the thousand people it leaves behind, it will be a personal tragedy and a national disgrace.

More action less words

VODG does not accept that the current rate of discharge represents acceptable progress. A rate which only halves the population after twenty years of action is simply not good enough.

Secluded institutional care is fundamentally wrong and exposes some of the most vulnerable citizens to serious risk of harm. There are no excuses for this type of provision in the 21st century.

The current situation is a sustained and inexcusable failure by successive governments to properly protect vulnerable people who have been deprived of their rights and detained by the state. The current situation is in part sustained by the profits accrued by large American corporations and private investment vehicles which have no incentive to support the programme.

Re-providing care away from long-stay institutions should be about achieving an irreversible change to publicly funded provision for people with a learning disability and autism not about making private investors richer.

VODG is opposed to any further general reviews. There is no debate or disagreement that the placement of people in assessment and treatment units (ATUs) for extended periods of time is damaging to their wellbeing.

VODG is committed to the closure of all institutional settings for people with learning disabilities and autism and the development of comprehensive, effective and safe provision in the community.

VODG has just three proposals for action:

VODG asks that the Secretary of State for Health and Social Care direct CQC to rate all ATUs as 'Requiring Improvement' if any person has been living there for more than 12 months. The rating should be downgraded to 'Inadequate' if anyone has been living there for more than 24 months and all new admissions halted until the rating has improved.

VODG believes that funding needs to be invested immediately in developing community provision that can support people with the most complex needs. Without this approach, the excuses for refusing discharge will continue. VODG therefore asks the Treasury to establish a community development fund (allocated on the basis of the TCP cohort through existing pooled budget arrangements) of £400m over four years to pump prime the development of community facilities.

VODG asks that the Secretary of State for Health and Social Care require the National Audit Office to publish an annual report to be presented to parliament on the progress of Transforming Care.

In the end

It is often said that the true measure of a society is how it treats its most vulnerable members.

If the behaviour of the government is measured in 2019, the concluding judgement must be that it does not value the people detained, it does not care enough to use the power of law-making to actively protect these citizens, it is not willing to use its powers to directly intervene in even the most modest of ways.

When the government's own regulator can share Adam's[12] story as part of an introduction to an official report, and no one lose their job and no contract be withdrawn, then VODG believes that something has gone terribly wrong.

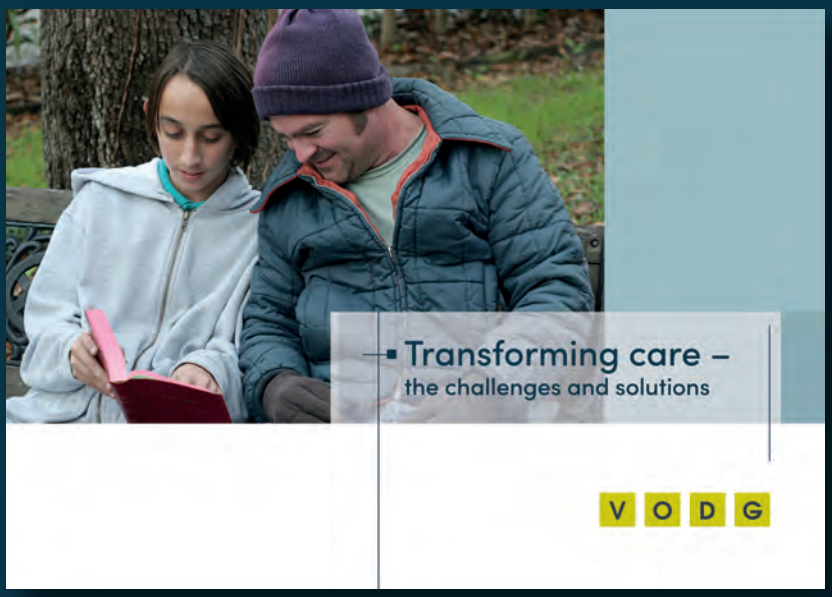
"Adam was admitted to his current hospital when he was 10. Since admission, Adam has been confined to a seclusion room with dimmed lighting. ... The walls of the seclusion room are padded because Adam often throws himself at the walls and bangs his head on them. ...

Adam soils himself, sometimes smearing faeces. Staff have abandoned attempts to help Adam to learn to use the toilet after early attempts had not been successful. ...

[M]ost of the staff who care for Adam have only received basic online training in autism. There is no plan to remove Adam from long-term segregation or support him to leave hospital."

VODG believes that it is only through the leavers of government and realistic investment that substantial progress can be made. Previous governments acted on the scandal of long stay hospitals with legislation and funding. If today's government does not do the same, then the message is crystal clear, 'these people do not matter to us and we do not care'.

12 Adam's story is shared as a case example at the start of a Care Quality Commission (2019) report, *Segregation in mental health wards for children and young people and in wards for people with a learning disability or autism.* Accessed: www.cqc.org.uk/sites/default/files/20190626_rssinterimreport_full.pdf



Read an earlier report describing the learning and lessons from community providers delivering transforming care in the London region: https://www.vodg.org.uk/publications/transforming-care-the-challenges-and-solutions/

Published 2019
Voluntary Organisations Disability Group

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

V O D G