



CHOICE IS KEY

**Where next for accommodation and support
for people with learning disabilities?**

NEW DIALOGUES
MAY 2017



“There should be no doubting the commitment from providers to play their part in bringing about the necessary change”

Imagine a ship on the open sea. Rain is lashing down and waves are pushing the ship off course. On board the crew are battling to ride out the storm but just over the horizon the storm clouds give way to brighter skies.

That ship, says Neil Revely, the co-chair of ADASS's Housing Network, is where those tasked with transforming accommodation and support for people with learning disabilities currently are.

The destination is clear: a future where people with learning disabilities or autism or both – including those with challenging behaviour - have more choice and control over their lives. “The direction for many years now has been towards securing independent living options, so moving in that direction is a constant,” says Revely. “But sometimes you get a bit blown off course.”

What is different today is that health and social care are heading in that direction with more determination than ever before. “Health and social care have been talking about doing this for the past 20 years,” says Simon Leftley, Southend's director of adult social services and co-lead of the ADASS Learning Disabilities Network. “What is different now is that there is a political will to do this.”

The organisations that provide accommodation and support to people with learning disabilities are also determined to make the difference, says James Allen, the managing director of learning disability provider Consensus.

“There should be no doubting the commitment from providers to play their part in bringing about the necessary change – they have after all been engaged in innovating and investing in new community based services for years, often at risk to themselves,” he says.

Yet, while the will is there, progress is patchy says Leftley. Big strides have been made when it comes to people with more predictable and manageable learning disabilities, he says, but there is still “a long way to go” for the so-called Winterbourne View cohort; the individuals with complex and challenging behaviours most likely to wind up in institutional care.

Steven Rose, chief executive of the learning disability charity Choice Support, feels little progress has been made. “When the Winterbourne View scandal broke in 2011 there were somewhere around 2,500 to 3,000 people in inappropriate private hospitals and NHS assessment and treatment units and my understanding is that the numbers remain much the same today,” he says.

WIDENING CHOICE

Central to delivering change is ensuring there are more ‘settled accommodation’ options that give people control over where they live and how they are supported.

NHS England, ADASS and the Local Government Association's *Building the Right*

Home guidance uses the Cabinet Office's definition of settled accommodation; namely accommodation in the community where individuals have security of tenure in the medium to long term.

That definition includes multiple models: owner-occupier schemes where individuals own or part-own their home; supported living services where people's needs are met by separate providers of housing and care; and tenancies in accommodation owned by friends, family or providers of social housing.

What these models have in common is that the individual's status as an owner-occupier or tenant allows them to access certain benefits and, if they wish, change their care provider without having to move home.

But what is explicitly excluded from the definition is the model that has long been the default support and accommodation option for people with learning disabilities or autism or both: residential care.

Residential care is not included in the definition of settled accommodation because the occupant does not own the accommodation or hold their own tenancy.

Despite this residential care still has a role to play says Amy Swan, the national housing lead for Transforming Care.

“Residential care has a really important role to play as part of a housing pathway, as one of a number of different options available to people,” she says. “First and foremost

ABOUT THIS REPORT

In adult social care it is essential to reflect on our thinking and that is why ADASS is pleased to bring you this provocative report on accommodation and support for people with learning disabilities or autism or both.

This report brings together a range of views – and not all of them are ones that ADASS members will agree with.

Nor, for that matter, are they

necessarily views shared by the learning disability provider Consensus, whose sponsorship made this report possible.

But as we all continue with our efforts to improve the lives of people with learning disabilities or autism or both, it is important to maintain an open debate.

Challenging our notions is helpful. We might not change

our minds but it is always worth questioning our beliefs so that we do not fall into lazy oversimplification of complex problems.

Exchanging ideas is vital if we are to develop personalised services that enable people with learning disabilities and autism or both to live more independent lives.

I hope you find this report as stimulating and useful as I did.



SEAN MCLAUGHLIN
ADASS LEARNING
DISABILITY CO-LEAD



“We need to recognise the importance of ensuring the workforce understands the difference between registered care and supported living”

Transforming Care is about choice and what is important right now is widening the accommodation and support options that are available.

“It does not feel like there is the choice of accommodation options available yet for people with learning disabilities. What we’re trying to do with Transforming Care is to work with the communities and providers to develop more options for settled accommodation.

“To do that we have to try and move away from developing new residential care, which we have a lot of, and ensure there are different options available.”

BESPOKE ENVIRONMENTS

Some providers of accommodation and support, however, feel that in the push to widen choice, good quality residential care is being dismissed as an option even when supported living schemes are inappropriate.

“Currently, the focus is all about the model and how people are perceiving registered and non-registered care and the perceived advantages and disadvantages of each,” says Allen of Consensus, which provides residential and supported living services for people with learning disabilities.

“We’ve been struck by some of the conversations we’ve had with commissioners about the very different perceptions of what modern residential care and supported living looks like. Some people do not recognise that many providers are investing in quality bespoke environments that in many cases don’t look much different to supported living.”

Peter Kinsey, chief executive of care and support provider CMG, says the effort to move on from residential care means issues with supported living services are being overlooked. “It’s like *The Emperor’s New Clothes*. Everybody’s too frightened to say anything other than supported living is wonderful, but there can be two very important downsides to supported living that nobody ever mentions.”

The first problem, he says, is that supported living requires a separation of housing and support so that individuals can change their care provider without losing their home in the process.

“That separation is absolutely a good idea, but usually you get a housing association providing the accommodation and many housing associations are poor at maintenance,” says Kinsey. “In supported living the care provider has no control over the housing provider and so the environment can be damaged for a long time before things are repaired or replaced.”

Kinsey’s second issue with supported living schemes is that he feels the Care Quality Commission does not monitor them to the same degree as residential care.



“First and foremost Transforming Care is about choice and what is important right now is widening the accommodation and support options that are available”

Supported living services are inspected in a similar way to domiciliary care. Usually a head office is registered and the CQC inspects that and a sample of the services that office runs.

Kinsey says that means many supported living services go uninspected: “People with learning disabilities, particularly those with complex and challenging behaviour, are the most at-risk group when it comes to abuse and poor care but they are being moved to services where they may never have an inspector walk through the door.”

Rose, however, says the regulation regime is up to the job: “Yes it is a sample the CQC looks at but, generally, if you’ve got a good care provider you’ll see that reflected in the sample and if you’ve got a poor care provider you will see that reflected in the sample.”

DEREGISTRATION

There are concerns that some residential care homes are rebranding as supported living but doing little more than deregistering from the CQC.

“We would encourage any residential care provider to see supported living as

more than de-registering a service with the CQC and fixing locks onto bedroom doors,” says Kaysie Conroy, the principal strategic commissioning officer at Central Bedfordshire Council. “We need to recognise the importance of ensuring that the workforce understands the difference between registered care and supported living and provide the necessary training for staff to shift the culture and mindset.”

Mike Ranson, director of development and partnerships at Consensus, says labels can be misleading. “The perception of residential care is institutional care where individuals have no control over where they live, eat, what they share, etc. but some supported living environments are in fact like the old residential care models,” he says.

Rose says this is happening less following the mainstreaming of Supporting People funding. “When Supporting People funding came in there was a huge rush of this,” he says. “There was a huge financial incentive in claiming Supporting People funding and not being registered, and people did change the sign outside but the practices didn’t change. That incentive isn’t around so much now so the trend has

slowed down, but it still happens.”

Ranson says: “Whilst Supporting People funding ceased to be a significant influencing factor in 2009, more recent commissioning strategies, since Winterbourne View, have seen some local authorities actively encourage ‘in-situ’ de-registration of residential care.”

Even when providers truly embrace the supported living model, delivering such a service for the more complex and challenging individuals can be difficult. “We did supported living for about 18 months and then we pulled away from it,” says Richard Smith, managing director of residential care provider Homes Caring for Autism.

There were multiple reasons why Homes Caring for Autism abandoned supported living but the primary issue was that the model made it hard to support a client base that requires at least one-to-one support at all times. “Each one required a sleep-in seven days a week and the staff were required to lone work with no immediate support available,” recalls Smith.

As an example of the challenges of doing supported living without clustering services together, Smith tells the story of a



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young man in one of their residential homes who ripped his toilet out ten times over a three-week period. “If that happens in one of our clustered services we can make sure that we’ve got staff support on hand to help de-escalate and divert,” he says. “You transport that person into his own home with no other staff support than the person who is working with him on that day and you have the same situation, where does the lone staff member get support?”

HOUSING SLOWDOWN

These challenges have led Homes Caring for Autism and some other providers to develop residential care services for people with complex and challenging behaviours that offer greater levels of choice and control and more individualised environments.

“Residential care homes these days look very different,” says Ranson. “It can be that

some have shared living space, some can be individual flats in a registered service where you have your own front door, lounge, kitchen, bathroom and bedroom. It’s not about the label, it’s about the quality and values of the management, the approach and the capability of that environment to consider what the individual requires and to provide that outcome flexibly and sustainably.”

Some providers expressed uncertainty about future service developments. They are aware that the CQC has completed a consultation on guidance relating to registration of learning disability services (*Registering the Right Support*). This considered *Building the Right Support*, national Transforming Care policy and accepted good practice, which followed on from the scandal at Winterbourne View and supports the development of smaller-scale



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Conroy notes: “Whilst we fully support the notion of smaller and more bespoke service provision, we need to acknowledge that there are some excellent services that are provided in larger schemes.”

Ranson notes that the policy could also hamper efforts to modernise existing residential care services. “If a provider wants to change what they are currently providing to a more innovative or bespoke service by taking a 10-bed service down to an eight beds there’s a risk they won’t get registered,” he says.

Further uncertainty surrounds housing benefits. The government has delayed plans to cap the local housing allowance for supported housing until 2019/20 but what happens after that remains unclear. This, says Swan, has led to reports of “a bit of a slowdown on new developments”.

NEW THINKING NEEDED

In addition local services are still grappling with the financial pressures of austerity and rising demand for health and social care. Solving these kind of financial challenges may mean thinking differently about public money, suggests Leftley.

“If someone has been in a 52-week school and then a residential placement, by the time they reach 30 we’ve probably spent £2m to £2.5m,” he says. “With that life cost you would be better off working with the family to buy that person a house and provide them with support in a different way. It would be really interesting to challenge the government to create a small fund where you could bid in to do it and see if that made a difference.”

Another tough problem for the Transforming Care agenda is how to support those with challenging and complex learning disabilities to move into settled accommodation.

Nonetheless Rose of Choice Support,

which provides services to this group, that while there are challenges in moving this group out of institutional care it can be done. “It’s a lot more complex to support people with that level of need or challenge but it is quite possible to do and to do very well if it’s approached properly,” he says.

“There remain a number of blockages. There is a huge financial incentive for the private providers not to support or encourage people to move on. Some local authorities still put them in their ‘too difficult’ pile or are risk adverse and don’t want to risk a scandal.

“But all of the evidence is that when the work is done properly, as evidenced in the Association of Supported Living’s *There is an Alternative* report among others, it is often significantly less expensive than private hospitals and assessment and treatment units, and people have long-term, happy placements in the community.”

FORENSIC SUPPORT

Southend, Essex and Thurrock’s Transforming Care Partnership is hoping to achieve just that through the creation of a multi-disciplinary community forensic service that works across the three local authority areas. The goal is to help people whose behaviours and disabilities have led to them experiencing very extended stays in secure hospitals, move into community based accommodation.

“It is a peripatetic service that can be mobilised to a number of different locations,” says Simon Dickinson, the programme manager for the Essex Transforming Care Partnership. “Its purpose is to allow us to discharge people who have a risk or history of forensic behaviour and keep them in the community. Most usually this involves sexual behaviour; people who because they have a learning disability and/or autism may be more at risk of behaving inappropriately. The

services. The outcome of the consultation, which closed in February, was due to be published in May and will now be published after the general election. Some providers have expressed fears that an application for registration of a new care home may be refused if the service is too large.

In the light of this, Homes Caring for Autism has scrapped plans to develop a registered care service in Somerset that would have given residents their own flats. The development would have consisted of several apartment blocks, each with six flats.

“It wasn’t the six person bit that was the problem, it was that we would have had more than one of those blocks on the site,” says Smith. “The CQC won’t look at your proposals in advance. Instead they say you do it and we’ll then come and decide. Well, that’s just financial nonsense so we pulled out.”



function of the service is to provide that assurance to the responsible clinician and commissioners that there is an appropriate support role that the individual can access to help manage those behaviours and perceived risks.

“The role of the community forensic service in reality is twofold. It provides some short, sharp training up of the individuals who will provide the core community care; and second, they will provide an ongoing case management role meeting with and supporting the individual to make sure their behaviours are being monitored and maintained in a way that is appropriate.”

Coupled with additional support from social workers and other professionals at local authority level, the intention is that the

“Let’s not get hung up on models – let’s focus on outcomes”

service can respond should an individual’s behaviours start to escalate in ways that could start to endanger them or others in the community.

The service has a caseload of just 18 to 20 across the partnership. As such, the scale of the service is not really viable to be commissioned on an individual agency footprint, says Dickinson. Instead the service is currently being funded by the seven clinical commissioning groups (CCGs) in the three local authority areas on a “risk share basis”, with the costs shared between CCGs as a block service rather than based upon usage by each individual CCG.

TACKLING ISOLATION

Creating stable community placements is one thing, but ensuring people with learning disabilities or autism or both are happy there is quite another.

One of Leftley’s biggest concerns about the Transforming Care agenda is whether enough is being done to help people find employment and access mainstream services once they are in settled

accommodation. “That could lead to what people see as a good thing - people living independently - becoming people trapped in their own homes without a lot of access to local community assets,” he says.

Conroy shares his concern: “We’ve had occasions where people wanted to move back to residential. I recognise the importance of having a range of housing options for people as I don’t think one size fits all works.

“We need to be thinking about the design and model of accommodation because if you get that right it can really help in maximising people’s independence and can improve people’s quality of life. We need to ensure that we are providing people with good opportunities through commissioning the models of accommodation, care and support that enable people to feel well connected within their local community, with good access to local services, amenities and transport.”

Communal space shows how design can affect people. Accommodation that lacks communal space can leave individuals with



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Allen. “It works really well when you can get people with learning disabilities and their families involved in the planning right from the beginning,” he says. “If commissioners can say this is the group of individuals we think this service will be for then providers such as us can get them involved at appropriate stages and truly provide control for the individual.”

Central Bedfordshire Council is developing a transition service that will support 16 to 25 year olds with a learning disability. Conroy says the service will focus on helping individuals develop their skills and confidence to help “maximise their level of independence”.

CHANGING THE CULTURE

Culture and mindset issues are also an ongoing challenge for efforts to re-engineer accommodation and support for people with learning disabilities or autism. “There is still a lack of ambition around social workers in terms of seeing where people can go and the potential people have got,” says Leftley. “As local authorities, we spend a lot of time making social workers follow forms and do assessments and all the rest of it. We need to get them back to where they want to be. In my experience social workers want to do

it and so often it is our processes and risk-adverse policies that prevent them from doing it. Once you get people enthused about it, social workers will become the best advocates.”

But it is important not to view those who resist change negatively, adds Revely: “Some of the mindset issue is there for very good, genuine reasons. The people who struggle with the mindset are not bad people, they are not trying to do the wrong thing, but sometimes they are not aware of or open to the possibilities.”

Nor is that resistance limited to professionals. Often the resistance comes from the families. “For very good and proper reasons family members want to protect their loved ones,” Revely says. “They probably fought very hard to get whatever service they currently have and to move on from what they see as safe and secure placements is a concern. They are not necessarily comfortable with their loved ones taking a few risks as we all do in life. We don’t want to be maverick about that but in a controlled way we can give people new leases of life.”

In order to overcome these mindset barriers, real-life examples of the benefits of independent living and more risk taking are

mobility issues feeling isolated.

Conversely, big communal areas can create flash points for people with challenging, complex behaviours. “People with learning disabilities have such varied needs I don’t think one size fits all works,” she says. “We really need to be thinking about the design of the property because if you get that right it can really help in maximising people’s independence and minimising their deprivation of liberty.”

There is also a need to think about how accommodation is going to be used in the future, adds Sarah Cavill, a team manager with Central Bedfordshire’s adult learning disability team.

“It’s really positive that housing partners are working with services to provide good accommodation that is flexible to the needs of individuals now and in the future,” she says. “We would want to avoid investing in developments that were unable to respond environmentally to changes in people’s needs by reason of age or disability.”

Gaining the input of people early in the design process can help with this, adds





“There has been a stalling of people building the housing we need at the moment because people are unsure about the ongoing sustainability of what they build”

necessary, he adds, recalling an example of a plan to move a young man out of a long-stay hospital when he was a director in Sunderland. “We were told he couldn’t have anything other than nurses looking after him literally 24-7, two people at a time,” he says. The man subsequently moved to home in a group of six bungalows to live independently with floating care, one-to-one care during the day and ‘on call’ overnight support. “I was told previously that no one could visit him unless you had been slowly introduced to him because of his behavioural difficulties but when I visited him he showed me his video diary of him going to the supermarket, etc. And the people who were most against the move became the advocates of doing this sort of thing, but if staff hadn’t persevered it would never have happened.”

Sean McLaughlin, the learning disability co-lead at ADASS and the corporate director of housing and adult social services for the London Borough of Islington, says involving families and individuals early is key.

“Our experience in Islington is that if you engage people in a grown-up conversation early, the people who are your biggest opponents become your strongest advocates,” he says.

“And it’s not just about doing that because it’s the right thing to do. Getting that energy behind you instead of against you is really helpful. It helps with planning applications, with political approval, with discussions with providers and more.”

Swan says that more examples of success are needed to win people over: “We don’t have enough good practice to be able to share with commissioners and clinicians to show them that it is possible and to make them comfortable with some of those choices.”

More open dialogue between providers and commissioners is also important, says Allen: “Commissioners need to find the time to go out and engage in a conversation with providers about what they have delivered. That enables a relationship to be developed with some consistency and that gives confidence to providers to take some risks about funding and find new solutions.”

NO GAME STOPPERS

The challenges in delivering more choice and control for people with learning disabilities or autism or both are many. Funding, commissioning, culture, regulations and scale issues are all helping to whip up the storm that is threatening to blow the ship off course. But, says Revely, what is important is to understand that none of these are insurmountable problems.

“We will emerge out the other side of this,” he says. “Necessity is the mother of invention and the necessity for us in the sector is to find ways to support people to live independently and therefore we will find a solution. I see some of the issues people see as game stoppers as just being almost a transition point to find our way through.”

It’s quite often about those important but not fundamental things like where do we find the money?”

Putting the outcomes for individuals first will be paramount to overcoming the challenges, says Allen. “The challenge for commissioners and providers really is as it has always been. We need to work together with individuals and their families to find the best outcomes whilst not being bound by ideology. Let’s not get hung up on models – let’s focus on outcomes.”

And there are developments on the horizon that could accelerate progress towards giving people more independence too, Revely adds. “People talked about how you can’t get robots to do personal care tasks for disabled people. Well, the Japanese are doing that. It’s a practical issue we are solving internationally. That tech is potentially applicable to people with learning disabilities if they also have physical disabilities. What impact will driverless cars have? People might not have the cognitive ability to drive but what if the car drives itself?”

“There has been a stalling of people building the housing we need at the moment because people are unsure about the ongoing sustainability of what they build. But in the huge, grand scheme of things - if you think in decades rather than months or the odd year - then we will get over this. I am optimistic and confident that we will get through this storm.”

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directors of
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This think piece report is designed to stimulate debate and discussion and as such it does not necessarily reflect the views of ADASS. The report is sponsored by Consensus but ADASS retained editorial control of the content.

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