What time is it?

Candesic's **Dr Joe Taylor** considers the journey ahead for learning disability services

Since the abuse of people with learning disabilities (PWLD) at Winterborne View came to light in 2011, we've had seemingly endless discussion about how to move those with LD out of inpatient hospitals and into community-based services.

Despite early political consensus, change has proven painfully slow. Over the past 12 months we have seen more people moving out of inpatient settings than entering between most months, but the net change has proven fluctuant and the numbers low (*figure 1*).

Sir Stephen Bubb, chief executive of ACEVO, was charged with understanding why service improvement was taking so long, and how outcomes for PWLD could be improved. Recommendations made in 'Time for change' ('The Bubb Report'), 2012, included:

1. A programme of inpatient facility closure, reflecting a move in commissioned activity towards community provision
2. A 'right to challenge' the nature and location of care provide, specifically admission or continuation in inpatient care
3. A new national commissioning framework to oblige Local Authorities to adopt common outcomes based around core service models and standards
4. Further training and development of staff to expand existing good practice, and deliver the community-based workforce new service models will need
5. Creation of a social investment fund to enable third sector organisations to deliver new community provision and build on existing services.

What has really changed, and what more is there to do to make this vision a reality? We're a long way from achieving the ambitions of The Bubb Report, and there is much more for commissioners and providers to do.

The nature and scale of the problem

All of us who work in the care sector share a desire to see better health outcomes and improved wellbeing for PWLD. We all recognise that we can do better than we have done in the past, and better than we are doing right now for this group of people.

However, what is not agreed upon is the proportion of people in inpatient settings who can be better supported in alternative environments. From my own experience working in the sector, and the analyses we've done, it appears that there are many people who continue to benefit from inpatient care (*figure 2*).

There will naturally be a continuing role for inpatient care. However, for the majority of people it should be seen as part of a pathway that addresses periods of significant need and is designed to equip people with the skills required to live as independently as possible closer to communities of their choosing.

Unfortunately, we do not yet have a precise understanding of demand for appropriate community placement, because the clinical profiles of PWLD in inpatient care are not aggregated and published. Therefore, it's not possible to know if ambitions for the wholesale transfer of LD care into the community are realistic and aligned with delivery of the best place of care for each person.

There is a balancing act to be struck between protecting right to privacy and data-control of this relatively small cohort of individuals, and enabling markets to appreciate the nature and scale of demand. The wishes of people who use services has to be at the very heart of their reconfiguration. It is often hard work to develop and gain informed consent in the context of LD, but this makes it no less central to achieving better outcomes and the right services. Obviously providers need a clear understanding of demand today and likely demand over the long-term, and that includes individual needs profiles for people who are languishing in inpatient care unnecessarily.

Until new models of community provision are tried and tested we can't know how what proportion of people can be supported in the community. Innovative care models, enabled by changing attitudes to the possibilities of community care, should enable the majority of people to leave inpatient care or preferably not enter it for any protracted period.

It seems likely that community providers will have to drive service development to demonstrate the efficacy of their models for the largest possible cohort of PWLD. Commissioners and inpatient service providers need to do more to equip community providers with the information necessary to invest in new services.

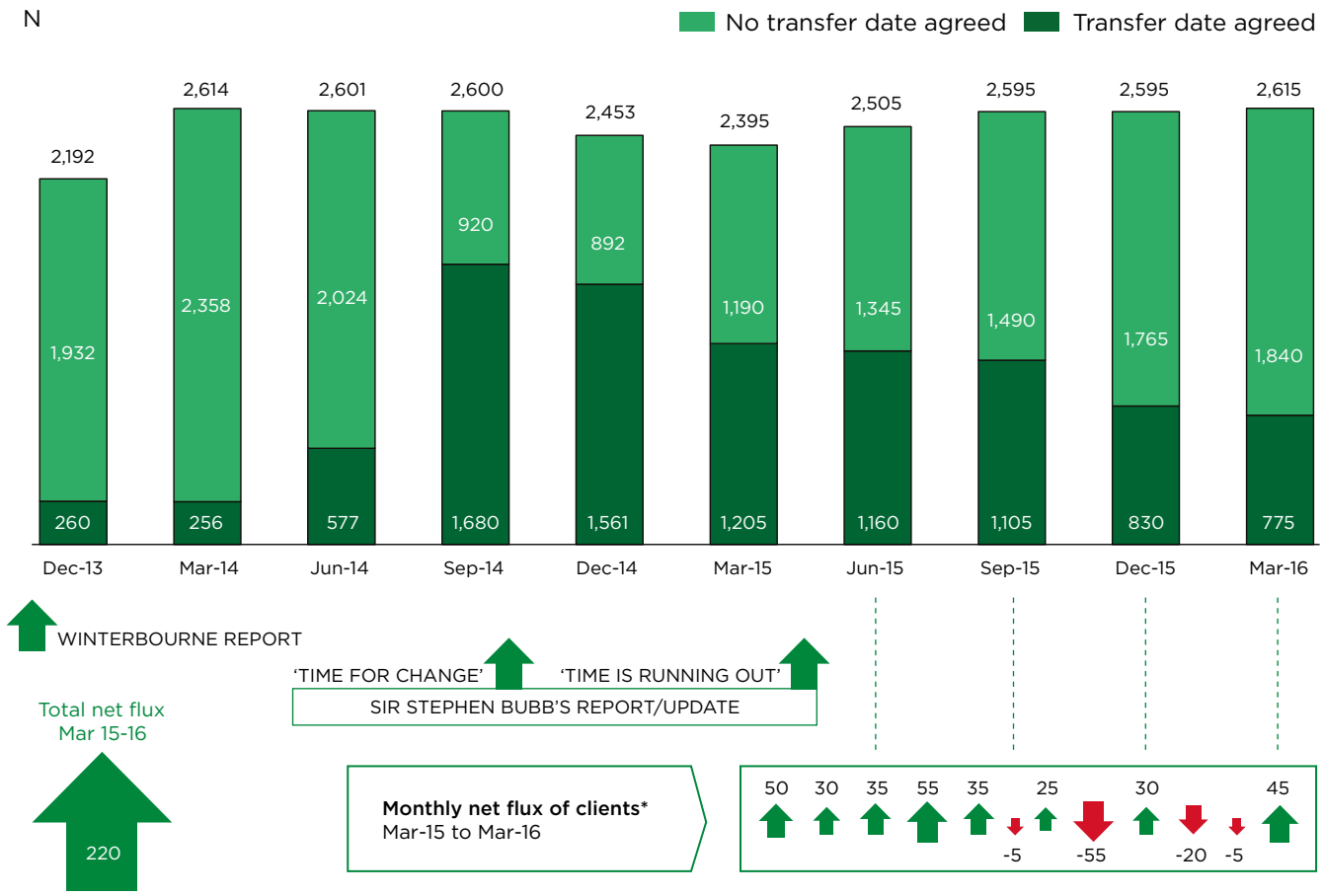
The continuing role of inpatient services

The Transforming Care Programme has not yet resulted in the development of new community facilities or yet seen the closure of inpatient facilities. The reality therefore is that much care for PWLD who have the most complex needs continues to be provided in inpatient hospitals.

Dominic Slowie, national clinical director for learning disability, recently said: "NHS Improvement and Care Quality Commission involvement in South Health suggest that we are not investigating the death of people with learning disability to the level we should be and learning the lessons." That's quite a damning statement.

Whilst we now have a very capable new chair in the form of Tim Smart at Southern Health, it continues to be essential that we promote better inpatient care nationwide

FIGURE 1: THE END OF LONG STAY HOSPITAL CARE FOR LEARNING DISABILITIES?



** Prior to 2015, the monthly 'experimental statistics' on LD are not published; arrow size is proportional to magnitude of net flux*

Sources: HSCIC 'Learning disability services monthly/quarterly statistics'; NHS England 'Assuring transformation quarterly data'; Candesic analysis

for those people who currently need it and are likely to do so for the long-term. We need to look both to the quality of newly commissioned community services alongside existing inpatient services. There is a risk that as focus moves to better services outside of the hospital we forget that there is still much to be done in our wards to safeguard people and make sure they are being equipped for their ongoing care journey.

Providers should not be dissuaded from investing in inpatient facilities, and considering how to improve care within them. They will carry on being a key part of the care mix for PWLD.

Transition into adult services

The 2014 Children & Families Act recognised the value of diagnosis and therapy that started from the earliest years of life, and also recognised that there is a challenging period of transition into adult services. Consequently, Education, Health & Care Plans (EHCPs), now cover children between 0 and 25 years of age.

The challenge is to enable young people at the cusp of entering adult services to become active curators of their own care. There is a risk that the assumption of continuing placements into people's 20s undermines their autonomy during that key transitional stage. In theory, the extension of childrens' service funding beyond 18 can provide an opportunity for development of and transition into the most appropriate care packages.

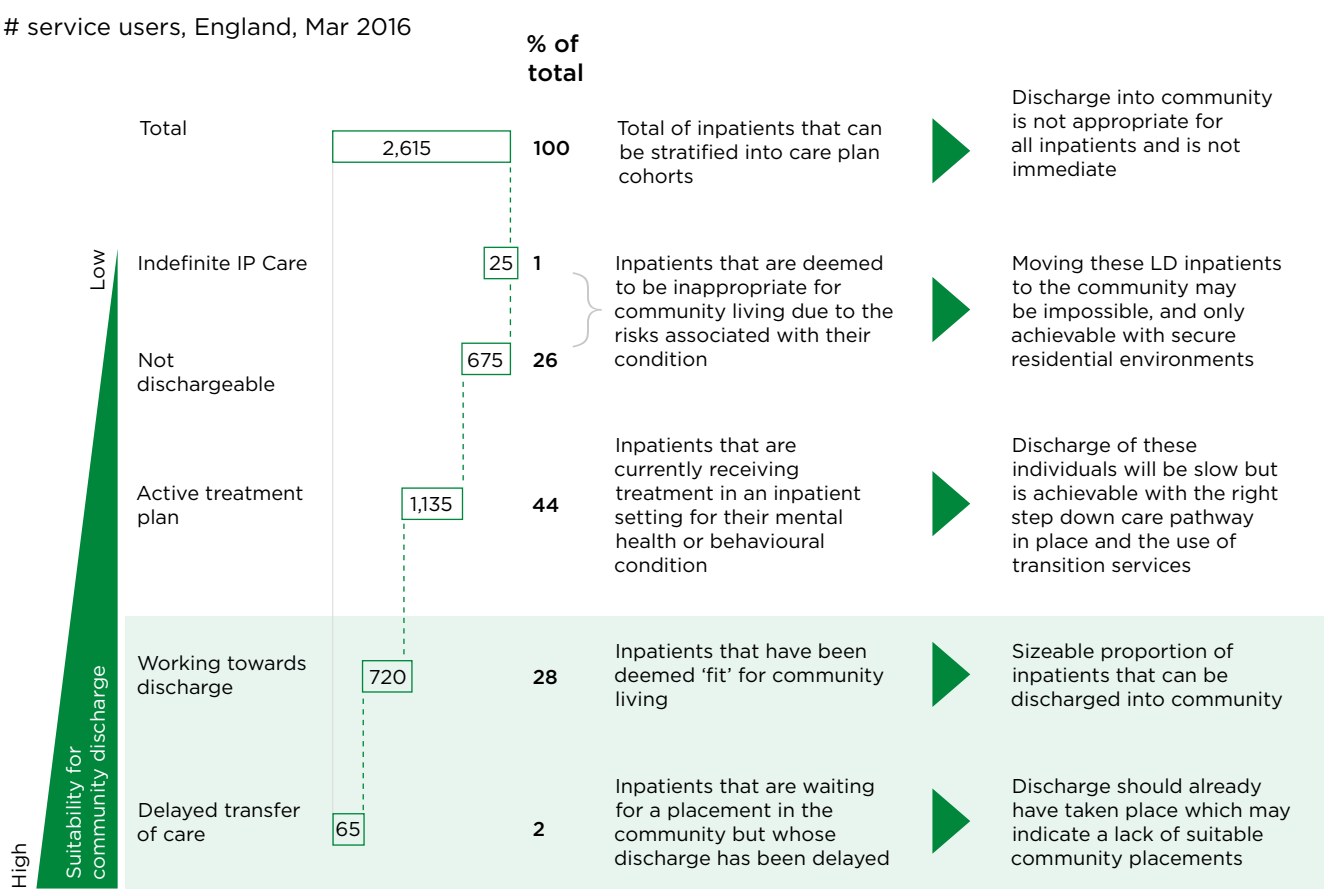
To develop adult care services best suited to PWLD, providers will have to work together to develop appropriate options for individuals moving out of children's services, and that means early engagement with people to understand their needs and objectives. This natural progression between services is a key time to develop community provision that can reduce demand for inpatient services and improve placement stability.

Provider engagement and capacity development

There is a need to generate new community services in order to meet the needs of people anticipated to move out of inpatient facilities as the closure programme progresses; building capacity in community provision cannot happen overnight.

There is a lack of agreement regarding the features of new infrastructure demanded of care models able to support service users with a variety of complex needs in the community. So there are three key areas commissioners and providers must address: ▶

FIGURE 2: BREAKDOWN OF CARE PLANS OF CURRENT LD INPATIENTS (C. 2,600)



Sources: HSCIC 'Learning disability services monthly statistics March 2016'; Candesic analysis

1. Capacity

We find ourselves in a Catch-22 senario. We need to develop more community capacity to enable inpatient services to be scaled back, but until the closure programme moves forward there is little additional demand in the market.

It will be important to de-risk the required additional investment in community services by providing greater forward-looking demand certainty. Commissioners could look to guaranteeing minimum service levels and payments to generate confidence amongst those seeking to increase community-based care capacity.

The recent establishment of the Provider Delivery Taskforce, charged with supporting the development of new community services, is a welcome move, but success in this sector is likely to depend on the commitment and vision of individual provider groups.

2. Innovation

Unfortunately, we've seen the enablement of PWLD as a fairly static enterprise, but in our work at Candesic we've visited services that have adopted innovative models of care, often supported by new technologies, that have delivered greater independence and improved outcomes.

In one service, a simple and inexpensive pressure sensor by a person's bed triggered a series of lights to be switched on enabling them to locate the toilet when getting up in the night. This eliminated the need for a waking staff member 24/7.

Other services have made use of purpose-built homes with annexes for those of greatest need and more communal environments for others of lower acuity. This model enables flexibility in staffing, and opportunities for people who find the company of others difficult at times to still socialise when it's right for them.

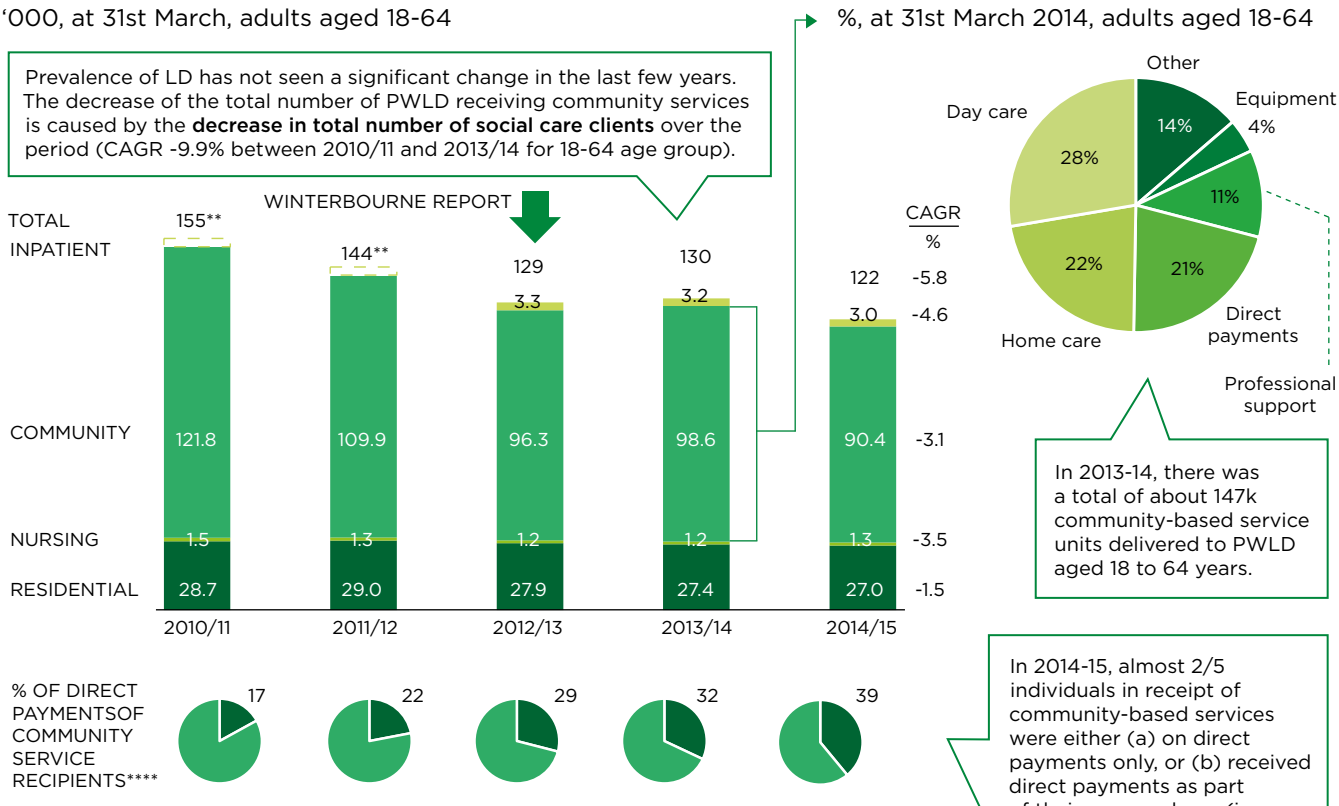
These hidden gems of great quality innovative care need to be more widely known about and their impacts, financial and clinical, better understood. Commissioners need to recognise and incentivise new models of care that enable community providers to address the high acuity needs of PWLD currently in inpatient services.

3. Workforce

Service transformation is naturally about much more than bricks and mortar; developing a skilled workforce able to deliver community services will be key step in enabling PWLD whose needs are complex to move out of inpatient services.

Here providers have a clear role in generating and supporting their valuable human resource. In addition to training they also need to understand that pay and conditions are essential considerations.

FIGURE 3: LONG TERM TREND IN CARE



* *This includes placements commissioned by other UK countries in hospitals in England*
** *No censuses conducted in 2010-11 and 2011-12. 'Count me In' finished in 2010.*
*** *Units of service count rather than per person (as many people are in receipt of multiple services)*
**** *As a proportion of all individuals receiving community care on the 31 March by year*

Sources: HSCIC 'Learning disability censuses', 'Referrals, assessments and packages of care (Table PS2)'; CQC 'Count me In'; Candesic analysis

Care staff churn is high. It's understandable – the job is often as challenging as it can be rewarding. However, we know that the success of services depends on consistent staffing.

In contrast to the divisive attacks this government has made against nurses and doctors, introduction of the national living wage (NLW) has the potential to positively impact care staff. Commissioners need to understand this is an additional cost and readjust fees to reflect that. Providers should avoid the temptation to reconfigure reward packages, such as weekend working rates, to mitigate the impact of the NLW.

Well-compensated staff will stay in post for longer, improving placement stability and providing system-wide cost savings by reducing expensive inpatient admissions.

The changing balance of power

Government leadership has been weak in the care of PWLD, but there is a grass-roots movement to drive forward community repatriation.

A group of parents of children with complex needs are in the process of launching a legal challenge, claiming the Department of Health has failed to provide appropriate community placements for their children. This reflects growing unhappiness with the glacial pace of service innovation.

Access to and uptake of direct payments has grown significantly over recent years (*figure 3*). The result being that commissioners will increasingly be bypassed by families who consider alternative models of care to be best.

It seems inevitable that 'a change is gonna come' and it's now time for us to plan and prepare for it so that we can provide the high quality community services deserving of people who live with complex needs and whose ambitions for a good life are so often thwarted. ■

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