

Transforming Care for People with Learning Disabilities - Next Steps



Progress Report from the Transforming Care Delivery Board -
3 July 2015

**This document has been produced jointly
by the following organisations:**

Association of Directors of Adult Social Services (ADASS)

The Care Quality Commission (CQC)

The Department of Health (DH)

Health Education England (HEE)

Local Government Association (LGA)

NHS England

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1. Summary

Transforming Care for People with Learning Disabilities - Next Steps, ([Next Steps](#)) outlined an ambitious programme of system wide change to improve care for people with learning disabilities and/or autism, and behaviour that challenges (learning disabilities).

Next Steps set out clear expectations that our six organisations - NHS England, Department of Health (DH), Local Government Association (LGA), Association of Directors of Adult Social Services (ADASS), Care Quality Commission (CQC) and Health Education England (HEE) - would work together more effectively, to drive forward change.

We now have a single shared Transforming Care programme that recognises the scale of the change required, and ensures that we address the underlying causes of why so many people remain in, and are continuing to be placed in, hospital settings.

As a result, and with the active engagement and commitment of professionals, commissioners, providers, and people with learning disabilities and their families, we are starting to see progress, but there is still much more to do.

In May, we completed a public consultation '[No Voice ignored, no right ignored](#)', on proposals to strengthen the rights of people with mental health issues, learning disabilities and autism, so they can live independently, be included in their community, and make choices about their own lives.



We are also ensuring that people in hospital settings are receiving the right care that meets their individual needs, with discharge plans in place for those that are able to, to move to a community setting. To 31 March 2015, we have carried out more than ¹1,400 Care and Treatment Reviews (CTRs) for people in hospital and more than ²650 people have now moved to a community setting. To the end of May 2015, we have delivered a total of ³1,700 CTRs for people in hospital.

This focused activity is beginning to have an impact on the overall numbers of people in hospital settings. Over a 14 month period, (March 2014 to May 2015), we have seen an overall reduction of ⁴140 people in in-patient care.

But we also recognise that there are still too many people being admitted to hospital, and too many people staying in hospital for too long. For example, in ⁵May 2015, 70 people were discharged or transferred to another setting, whilst 50 people were admitted to hospital in the same month.

To address some of these long standing issues, we have put in place the building blocks to radically change how and where we deliver

¹ NHS England's monitoring data, end March 2015

² Assuring Transformation data, end March 2015

³ NHS England's monitoring data, end May 2015

⁴ Assuring Transformation data, end May 2015

⁵ Assuring Transformation data, end May 2015

services across health and social care. This will enable more people to live within their local communities, close to home, and will see a significant and permanent reduction in the number of people in in-patient care.

Working closely with health and social care partners in areas where there are high numbers of people in hospital settings, we are establishing five Fast-Track sites, to accelerate service change.

Each Fast-Track will have access to additional support, including a £10 million transformation fund, to enable commissioners across health and social care to test new approaches, tackle some of the long standing issues and drive sustainable change. Learning from these early implementers, will inform the national roll-out of a broader transformation programme.

The Fast-Tracks will also help to develop a national approach to workforce planning, to support wider service re-design, ensuring that we have the right skills in the right place, to deliver services differently.

This report does not cover every activity that will improve the care of people with a learning disability. It aims to summarise progress across the key areas outlined in the Next Steps document, led by the six national partners, and working closely with commissioners, managers, practitioners, providers and people with learning disabilities and their families. Our aim is to ensure that where people are able, they can live within their local communities, with the right level of support, close to home.



2. Next Steps commitments

Our focus

The publication, Next Steps, set out an ambitious programme of system wide change, to drive forward improvements, at pace, for people with learning disabilities.

This work aims to ensure:

a substantial reduction in the number of people placed in inpatient (hospital) settings	a reduction in the length of stay for all people in inpatient settings
a better quality of care for people who are in inpatient and community settings	a better quality of life for people who are in inpatient and community settings

Our priority areas

Next Steps also outlined the work programme for the six national partners across five key priority areas:

1	Empowering individuals	Giving people with learning disabilities and/or autism, and their families, more choice and say in their care. This area is led by the DH and the LGA.
2	Getting the right care in the right place	Ensuring that we deliver the best care now, whilst re-designing services for the future. This area is led by NHS England, the LGA and ADASS.
3	Workforce	Improving care quality and safety by developing the skills and capability of the workforce to ensure we provide high quality care. This area is led by HEE.
4	Regulation and inspection	Tightening regulation and the inspection of providers, strengthening providers' corporate accountability and responsibility, to drive up the quality of care. This area is led by the CQC.
5	Data and information	Making sure the right information is available at the right time for the people that need it. This area is led by the DH, working closely with NHS England and the LGA.

Leadership and governance

In Next Steps, we set out our commitment to strengthen and improve the governance structure for the entire Transforming Care programme. We have established a cross-system Transforming Care Delivery Board (TCDB) that meets regularly, with senior representatives from NHS England, the LGA, ADASS, DH, CQC and HEE. This is chaired by Jane Cummings, Chief Nursing Officer from NHS England, with Ray James, President of ADASS, as Vice Chair, and has enabled more robust and effective partnership working, both across, and within, organisations.

The TCDB provides feedback to the Transforming Care Assurance Board that is co-chaired by the Minister of State for Community and Social Care and a self-advocate (who has direct experience of the services in the scope of this programme). Each individual organisation is also accountable to their own Board or via their individual governance arrangements.

Co-production and engagement

Each of the six partners has committed to ensuring that effective co-production, participation and consultation with key stakeholders, underpins and informs their work. This ensures that health and social care commissioners, providers, front line healthcare and social care professionals and individuals with learning disabilities and their families, are all actively involved in shaping our approach. We have set out examples of how each work area is doing this in section 3.



3. Delivering progress on Next Steps

3.1 Empowering individuals

Empowering people with learning disabilities and their families to have greater rights and say in their care, underpins the Transforming Care programme. We have been working with partners across the health, local authority and voluntary sectors to strengthen the collective voice of individuals with learning disabilities and their families, to ensure greater personalisation, increased choice about care, and greater influence over service design and delivery.

An important milestone this year was the public consultation issued by the Government, 'No voice unheard, no right ignored', to strengthen the rights of people with mental health issues, learning disabilities and autism, so they can live independently, be included in their community, and make choices about their own lives.

It sets out that people should:

- expect to be supported to live independently, as part of a community and in a home they have chosen;
- know their views will be listened to and be able to challenge decisions about them and about their care;
- have clearly-stipulated rights within the Mental Health Act;
- be able to exercise control over the support they receive with a personal budget, and expect that different health and local services will organise themselves around their needs; and

- know that professionals are looking out for their physical health needs as well as their mental health needs.

We received over 400 responses to the consultation which ended on 29 May 2015. The DH, working closely with health and social care system partners (including Transforming Care programme members), is aiming to publish its response to the consultation by autumn this year.

With NHS England, we have ensured that high quality advocacy is a core component of the new Service Model that is being developed for commissioners (see 3.2).

So far, the programme has:

- ensured that we are asking whether people are getting support from advocacy through the revised approach to Care and Treatment Reviews (see 3.2);
- reviewed the Assuring Transformation data to gather information that tells us what sort of advocacy a person is receiving; this is now informing the empowerment work area;
- designed and tested, with people with learning disabilities, clinicians, social workers and other partners, an accessible booklet on independence that supports people to plan for discharge from hospital and live in the community; this is due to be published in July 2015;

- set out what good advocacy should look like for people who are moving out of inpatient settings into community based services, as part of the future Service Model work; and
- continued work with key partners, such as Mencap and the Challenging Behaviour Foundation, to support the development of resources for people with learning disabilities and their families.

This work has been underpinned by ongoing co-production and engagement work with people with learning disabilities, their families and voluntary sector organisations.

We are currently:

- commissioning a series of Implementation Planning Sessions, made up of 30-40 people, including people with learning disabilities and autism, their families and organisations, working with them, to review the effectiveness of our programme to date; and
- with the National Forum of People with Learning Disabilities and the National Valuing Families Forum, developing a systematic way of sharing and gathering information about local implementation of Transforming Care, including dissemination of products produced by this work area, through their networks, and the development of a set of questions about how local areas are progressing on Transforming Care to feed back to the national delivery partners.



3.2 Right care, right place

Real progress has been made in this area to ensure that we deliver the best care now and support more people to move to community settings, whilst kick-starting service transformation in five areas, to inform national roll-out in late 2015.

Delivering the best care now

We have reviewed care plans for those individuals in hospital settings - using Care and Treatment Reviews (CTRs). By the end of March 2015, over ⁶1,400 people in hospital settings had received a CTR, with more than ⁷650 people transferring to community settings, whilst others have either been transferred to more appropriate in-patient care, or have complex needs that still require on-going hospital care. To the end of May 2015, we have delivered a total of ⁸1,700 CTRs for people in hospital.

Using the learning from the first phase of CTRs, we have further developed the approach to prevent both unnecessary hospital admissions by identifying people who are 'at risk' of admission, or where individuals do need short-term hospital care, ensuring that care plans focus on transferring them back to a community setting from the start.

The CTRs involve the commissioner, an independent clinician and someone with 'lived experience' (an individual with a learning disability or family member) to bring an external challenge to Care Reviews. Individuals and family members can also request a CTR if they are concerned about their care, contacting their care co-ordinator in the first instance. This approach is now being embedded locally across England to ensure a significant and permanent reduction

in the number of people receiving long-term hospital care and to reduce hospital admissions.

The CTRs have identified a number of areas that we are now working on, through the Transforming Care programme, to ensure that we have the right skills in the community across health and care, to support more effective and safe discharges where appropriate. For example, we are using the findings from the early CTRs to inform longer term planning on both service provision and staff training needs. Whilst this work is underway, Reviews are continuing, to ensure that there are care plans in place to meet individuals' needs.

Transforming services

Next Steps set out a clear ambition for a radical re-design of services for people with learning disabilities. A number of localities have already made substantial progress and have developed a range of community based provision, including additional support for those people who are at risk of admission.

It is our expectation that commissioners in all areas continue with this work, to put in place alternative provision; facilitating discharges and preventing the need for admission.

NHS England, the LGA and ADASS have been working closely with local and regional partners from across health and social care, to describe a transformation programme that will reduce

"The reviews would have been more clinical and process driven without input from an expert by experience. I was able to get some positive changes for the individual that took effect immediately or shortly afterwards."

Individual with 'lived experience' involved in CTRs.

⁶ NHS England's monitoring data, end March 2015

⁷ Assuring Transformation data, end March 2015

⁸ NHS England's monitoring data, end May 2015

the reliance on in-patient beds and lead to the closure of some in-patient facilities. We have started in areas with a high number of people with learning disabilities living in hospital settings, to review how we can best support local areas to test new models of delivering services and within this, ensure that they are getting the basics right.

We will be working with five locations in the North, and East and Midlands to test different approaches, to inform wider service transformation across England, in late 2015.

This work includes:

- Establishment of five Fast-Track areas, where Clinical Commissioning Groups (CCGs) and specialised commissioning, in collaboration with local authorities, will receive additional central support and a share of a £10 million transformation fund to accelerate service re-design, and help shape the national approach, which will be embedded in business planning for 2016/17. We will be sharing their learning with all health and social care commissioners to help inform their local plans.
- The five areas are: Greater Manchester and Lancashire; Nottinghamshire; Arden, Herefordshire and Worcestershire; Cumbria and the North East; and Hertfordshire. They have been chosen because they have high numbers of people with learning disabilities in hospital settings and have the potential to bring together a large number of local authority and CCG commissioners and

specialised commissioning, each with different challenges, so we can test different approaches and effect the biggest change.

"It was and is enjoyable and rewarding, especially if you manage to get even one person back into the community with the support they need."

Individual with 'lived experience' involved in CTRs.

- CCGs, local authorities and NHS England's specialised commissioning teams across the five areas are now drawing up joint transformation plans, by early September 2015, to start wider service changes later this year.
- This should ensure a significant and permanent reduction in the number of people who are being cared for in hospital settings.
- Workforce development will be part of the Fast-Tracks transformation plans and, as part of NHS England's 'Safer Staffing' programme, we have developed and are testing workforce planning tools to support services in assessing staffing requirements for learning disabilities community teams.

The Fast-Track sites will also help shape our overall approach to transforming learning disability services more widely across England, to effect more sustainable change, including ensuring that the funding flows enable and incentivise service transformation.

They are helping us to co-produce:

- the future model of care (a new Service Model) which will be available in July for people with learning disabilities, that will describe what good services look like, with clear patient outcomes and standards;
- national planning assumptions for re-designing services to be reflected in planning guidance for 2016/17; we will also be sharing the learning from the Fast-Track areas with all commissioners, to help inform their local plans;
- more flexible ways of using funding to get the best outcomes for individuals; and
- the central support package, to help commissioners deliver service transformation in their areas.

Future model of care

Developing a new Service Model for children and adults with learning disabilities, is central to our ambition for service transformation.

Working with an external reference group, with membership drawn from local authorities, CCGs, providers, voluntary sector partners and people with learning disabilities and their families, we are on-track to publish a draft Service Model in July, for Fast-Track areas to test on-the-ground, what a good service looks like. The Model will include how personal budgets and personal health budgets can enable people with learning disabilities to live independently in the community.

The Fast-Track areas will use the draft Service Model as a basis for their planning, enabling us to test and refine the model before publishing this autumn, for all commissioners across health and social care to use, to support their transformation plans.

Through the Fast-Track sites, we are also exploring outcome-based payments and linked social investment. We acknowledge that progress on taking forward the work on social investment, should have been faster. However, our focus has been on the immediate actions needed to establish the Fast-Track areas. Now that these are in place, DH has formed a small working group with NHS England, with assistance from the Cabinet Office social finance team, to inject pace into this work, and explore the practical feasibility of social investment at a local level through the Fast-Tracks.

Stakeholder engagement and involvement

To drive forward this work, we have been proactively engaging with a range of formal steering groups, forums and project specific consultation meetings, to ensure that key stakeholders have had the chance to help co-produce, input into and inform our proposals.

This includes:

- a Service Model Reference Group - to help shape how we commission and deliver services, and made up of a range of stakeholders from across voluntary, academic, government and health care sectors; as well as a forum of people with learning disabilities and their families to co-produce and help shape and refine our emerging new Service Model that is co-chaired by Professor Tony Holland (CBE), Department of Psychiatry, University of Cambridge, and Scott Watkin, from national charity SeeAbility and former national learning disability co-tsar for learning disabilities for the Department of Health.
- a series of 'expert' steering groups, including:
 - a clinical reference group
 - Providers Forum
 - Commissioners Forum
- a series of consultation meetings with key groups - to ensure that opportunities are in place to share learning and expertise across the programme.

3.3 Workforce

Since the publication of Next Steps, Health Education England (HEE) has been working with its Transforming Care partners, including Skills for Health and Skills for Care, to ensure that workforce development and planning supports the wider service re-design across health and social care. We have been actively engaging with key partners to develop and support our proposals. **This includes:**

- A new delivery network to inform workforce planning and training, with representation from 13 local education and training boards (LETBs), to support the local delivery of transformational education and training for the learning disability workforce.
- A Workforce Expert Advisory Group to review, advise and assure the learning disability workforce programme, led by HEE; the first meeting is currently planned for July, and is aiming to:
- Collaborating with the national skills councils (Skills for Health and Skills for Care) to get a holistic view on current and future workforce requirements.

Our work to date includes:

- Developing and testing a new Learning Disability Skills and Competency Framework that outlines the competencies that staff need to have, to fulfil certain roles, to ensure that we have the right skills in the right place. This Framework will be rolled-out in January 2016.

- Using this new Framework, alongside feedback from providers and professional networks, to map current skills against future requirements, to ensure that we can meet future service needs. This will be complete by September 2016.
- We are also focusing on reducing the use of restrictive practices by staff, that aim to control an individual's behaviour or freedom of movement, or invade their privacy. Working with the Department of Health, our delivery network and Skills for Care, we are rolling-out 'Positive and Safe' training across health and social care.

The training will include 'Positive Behaviour Support' training to help staff to better understand and reduce challenging behaviour in individuals with a learning disability, without the inappropriate use of physical or pharmacological interventions, and improve patient outcomes. It is expected that the training will be implemented across health and social care, and will be part of the Competency Framework (see above).

We are also supporting the longer term development of the disability workforce including:

- Working with DH and partners to ensure the implementation of recommendations in key national reports⁹ to strengthen the capacity, capability, quality and leadership of the learning disabilities nursing profession, to improve care outcomes.

⁹ The seventeen Learning Disabilities Nursing recommendations of 'Strengthening The Commitment - the Report of the UK Modernising Learning Disabilities Nursing Review' (DH 2012); 'Strengthening the Commitment One year on: Progress report on the UK Modernising Learning Disabilities Nursing Review' (DH 2014); Department of Health 'Strengthening the Commitment Work Plan 2015-2016'

- Reviewing the number of training places that have been commissioned for learning disability nursing and learning disability psychiatry roles, to help shape HEE's workforce investment plan for 2016/17. This will ensure that we can better predict and meet future workforce demands, in line with future models of care for learning disabilities.
- Supporting the recruitment, training and retention of Learning Disability Psychiatrists, working in partnership with the Royal College of Psychiatrists.
- Developing a national approach to further develop leadership training across health and social care, to foster an improving culture of innovation, change management and leadership. This work is being done with our Transforming Care partners and the NHS Leadership Academy, and early findings are expected by September 2015.

We will be testing the training with the five Transforming Care Fast-Track areas (see 3.2), working with the relevant local education and training boards and their local provider networks.



3.4 Regulation and inspection

Much of the focus of the programme's work on inspection and regulation is to ensure that the new inspection framework is being implemented as effectively as possible. The framework reflects CQC's new approach to inspecting health and social care services. The inspections assess whether services are safe, effective, caring, responsive and well led, and make greater use of the expertise of health and social care professionals. They also involve service users and carers as 'experts by experience' as part of the inspection process.

The CQC is working to ensure that its assessment methods are fully adapted to ensure robust inspections of hospital and community learning disability services.

This includes further developing how we obtain the views of service users about the nature and quality of the care they are receiving.

The CQC is further developing the work on registration, to ensure that:

- applications by any service provider to vary their 'service type', that describes the services that they offer, are only agreed when the new 'service type' accurately reflects a changed model of care. This will also ensure that any inappropriate models of care for people with learning disabilities do not continue after the 'variation' has been agreed; and
- new applications are only agreed when the application reflects the agreed model of care for people with learning disabilities, which is currently being defined by the Transforming Care programme and outlined in the new Service Model for commissioners.

The CQC will be consulting with partners to ensure that its new enforcement powers are as effective as possible. For example, we are currently reviewing how we can ensure that where enforcement action against a provider could result in closure, that an appropriate plan is in place to ensure that people who are living in the setting will be transferred in an appropriate and timely way to high quality services that can fully meet their needs. This includes ensuring that the relevant commissioners are informed in a timely way, to allow them to develop individual plans for those affected, and focused consideration of risks to the service user.

The CQC is also working closely with partners to ensure that good quality data is available on the location, type and numbers of inpatient services being provided to people with learning disabilities, and will work with partners to consider the quality of providers.



3.5 Data and information

Data is essential to tracking where and how people are being cared for and measuring progress, particularly on transferring people to a community setting.

We have made significant progress in the quality of the data, so that we have greater confidence that our information about individuals is robust and accurate. For the first time, this is enabling us to track the number of people who are in hospital for significant periods of time, to understand where people are being cared for before they are transferred to a hospital setting, and to both understand and remove any barriers which are preventing individuals being discharged when it is clinically appropriate to do so.

Data is now collected through a 'live' clinical audit platform, which allows us to publish top level national data every month, in addition to the detailed quarterly Assuring Transformation data.

Steps to improve the quality of the data include:

- working with commissioners to query all patients that are covered in the 2014 LD Census that were not included in the Assuring Transformation data submitted for September 2014 - to date over 650 queries have been resolved; and
- comparing the Assuring Transformation data with information that regional NHS teams collect on people with learning disabilities who are admitted to specialist hospitals.

We are also reviewing the content of the Assuring Transformation data, so that it includes information on CTRs - both pre and post admission - CTR outcomes, and information on planned and unplanned admissions. This should be in place by this autumn.

Work is also underway to:

- Help identify people that are at the highest risk of being admitted to inpatient care, so that local commissioners can meet their needs earlier by providing them with the right services to prevent unnecessary admissions. This is reflected in the new CTR process.
- Identify robust and relevant indicators to evidence the quality of care and quality of life for people with learning disabilities. This will be reflected in the new Service Model for commissioners that will be embedded in business planning for 2016/17.

4. Future work

The Transforming Care Delivery Board is continuing to focus on delivering the key activities under the five work areas outlined in the Next Steps document. We are also developing a road map which sets out how all the different elements that we need to change across health and care, to deliver service transformation, will impact on each other - and when these changes are likely to happen.

This will help partners and stakeholders to understand the overall pace and scale of the programme and set out a blueprint for key characteristics of system change, including deliverables in 2015/16, 2016/17, and in five years' time (2020/2021).

We will provide further updates over the coming months as this work progresses.

Key Transforming Care milestones for 2015/16

July to September 2015	• Publish draft Service Model (July) • Embed use of CTRs, pre-admission, across England (July - Aug) • Fast-Tracks develop local transformation plans (July-Aug) • Response to 'No Voice unheard..'consultation (autumn) • Publish final Service Model for all commissioners (Sept) • Fast-Tracks submit transformation plans (Sept) • Service transformation starts in Fast-Track sites (late Sept)
October to December 2015	• Service Model reflected in commissioners' business plans for 2016/17 (Dec)
January to March 2015/16	• New Learning Disability Skills & Competency Framework for staff (Jan) • Workforce investment plan agreed for 2016/17 (early 2016)

5. Case studies

Supporting moves to community settings

The transforming care programme aims to see more people transferring to community settings, ideally close to home.

1

One individual is now living in the community in a residential care home after 26 years in a hospital setting...

...with agreement from the funding authority and backed by sound clinical knowledge and experience. The individual has been supported throughout the transition and in the care home, by a nurse, support worker and a full multi-disciplinary team. The support team has encouraged the individual to visit the local GP, and the person has regular care reviews with representatives from the funding authority. The individual has settled in well, in the home; gets involved in activities and social groups, and is making good progress.

2

One individual is being supported to move to a community setting, after living in numerous secure facilities over the last 15 years...

...and demonstrating behaviour that is challenging. To support their transfer, the individual moved to a local step-down facility - with a robust risk assessment and contingency plans in place - and a review of their medication and behaviour triggers, and intensive resettlement support. A nurse visits weekly and rings on alternate days, and the new service provider is working with the individual two to three times a week. The person's progress has been good and the multi-disciplinary team is planning a move back to the community within six months, rather than 12-18 months as originally planned. The individual has enrolled in the local college on a maths and cookery course and is working with a nurse, looking at areas such health needs, social integration and motivation, and learning new skills.

Preventing unnecessary admissions

A pilot across five CCGs in the North West used Care and Treatment Reviews (CTRs) to see if hospital admissions can be diverted at the point of crisis. Of the six cases that were reviewed, four individuals remained in their community setting, with additional support:

3

One young man with moderate learning disabilities, who lived in a residential home had a CTR...

...following concerns raised by the care provider about staff safety and managing the on-going risks of providing his care in the current setting. This followed incidents of behaviour that challenges that had been attended by the police. The CTR team encouraged local services to work with the police, who had a good understanding of the individual, and the Community Learning Disability Team and care provider, to provide a short term solution as an alternative to admission, with training on Positive Behaviour Support for his care team. The Community Team continues to have an active role in overseeing his care, working with his mum. He continues to live in his residential home.

Feedback from experts by experience

The new Care and Treatment (CTR) review process brings an external challenge to care reviews, including an 'expert by experience' - someone with learning disabilities or a family member - who works alongside the commissioner and independent clinician, and the individual, to review care plans. Early feedback shows the unique perspective that experts by experience bring.

"I would like to see all patients having an option to see an expert by experience earlier in their admission process or at least six months into their admission, so that exit strategies can be sorted out earlier and their rights are taken into consideration."

Individual with 'lived experience' involved in CTRs.



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