

**BOARD PAPER - NHS ENGLAND**

**Title:**

Transforming Care for People with Learning Disabilities including an Update on the New Service Model and Framework

**From:**

Jane Cummings, Chief Nursing Officer and NHS England National Director Sponsor for the Learning Disability Programme

**Purpose of Paper:**

- To provide an update and continuing assurance on NHS England's activity to support its corporate priority of transforming care for people with learning disabilities.

**The Board is invited to:**

- Consider the update, and to assess the progress made since the last report and the level of assurance provided by the paper.

**Transforming Care for People with Learning Disabilities including an Update on the New  
Service Model and Framework  
NHS England Board - 23 July 2015**

**1.0 PURPOSE**

1.1 This paper provides an update to the Board on the progress made by the NHS England Learning Disability Programme (“the Programme”) to deliver our corporate priority of transforming care for people with learning disabilities since the May 2015 Board meeting.

**2.0 PROGRESS AGAINST OUR CORPORATE PRIORITY COMMITMENTS**

2.1 The NHS England 2015/16 Business Plan sets out the five commitments that will enable us to achieve our corporate priority.

**Commitment 1:**

***Throughout 2015/16 improve the independence, wellbeing and health of people with learning disabilities by continuing to roll out care and treatment reviews to manage discharge and prevent inappropriate admissions, ensuring annual health checks to support physical health, and extending the offer of personal budgets.***

**Rolling-out of Care and Treatment Reviews**

2.2 The last update on the Programme, submitted to the NHS England Board for its meeting in May 2015, explained that we have completed the development of a health and care pathway for the specific group of people who are in a hospital, for specialist learning disabilities care or at risk of admission to such a hospital. This pathway sets out how the principles underpinning care and treatment reviews (CTRs) should be applied across the patient journey.

2.3 £3.2 million of central Programme funding is now being distributed to regional teams to manage to support the implementation of the new pathway. This is in addition to £5.5 million of central Programme funding which is being used to provide staff and support to change in the regions.

2.4 To help roll-out of the pathway, the central Programme has supported 26 regional and national events that have reached around 350 stakeholders comprising NHS and Local Authority commissioners, providers, Experts by Experience, clinicians and colleagues from social care. The events, designed to raise awareness of the cross-system Transforming Care Delivery Programme (“the cross-system Programme”), included detailed information on the new care pathway. The latest iteration of the pathway (revised following learning), will be published after it has been through the Gateway process.

2.5 The involvement of Experts by Experience is integral to the CTR process and we are carrying out a learning exercise on their involvement in the pathway including:

- i. How they are involved in the set-up and delivery in CTRs
- ii. What value they add to the CTR process and its outcomes
- iii. How we can take from the learning from the involvement of Experts by Experience in CTRs to think about how to involve them in other areas of the Programme
- iv. The exercise includes talking to Experts by Experience and regional colleagues. Preliminary feedback indicates that Experts by Experience add a valuable voice which is unique to the reviews offered by CTRs.

**Annual Health Checks**

2.6 The Programme is finalising plans for work that will support the increased uptake and quality of enhanced annual health checks for people with learning disabilities. This will include promoting annual health checks to patients and clinicians, and using data to help reduce regional variations in annual health check delivery. Our proposals were shared with the ministerial Learning Disability Programme Board, which met on 7 July 2015.

**Extending the Offer of Personal Budgets**

2.7 Personal Health Budgets and personal budgets will feature in the new service model, which is being published for consultation this month. In addition, the CTR process ensures that the use of personal budgets is considered for all reviewed.

**Commitment 2:**

***By March 2016 all young people with a learning disability leaving residential school, leave with an Education, Health and Care Plan to support their transition to adult services.***

- 2.8 Joint meetings between NHS England, Association of Directors of Children's Services (ADCS), and Department for Education (DfE) have been held to ensure CTRs properly meet the needs of children who are
- i. in-patients identified in the Assuring Transformation data, and
  - ii. in 52 week residential school placements as identified in the NHS England Business Plan.
- 2.9 Reviews are aligned with Education Health, and Care Plans, and the work will feature as part of the NHS England Children with Complex Needs Board.

**Commitment 3:**

***During 2015/16 work with partners to develop a national framework to close inappropriate facilities and commission more appropriate local and community-based alternatives.***

- 2.10 The service transformation work has four key elements:
- i. Supporting five fast-track areas to transform services – helping them achieve change at pace and 'learning as we do', so that all other elements of our national approach to transformation is co-produced with local commissioners and based on real experience.
  - ii. National transformation plan by October 2015, including: service model, planning assumptions, bed closures, credible timeframes for transformation, financial underpinnings, and plans for workforce development (linked to 'safe staffing' commitment)
  - iii. Improvement programme, similar to Vanguard approach, aiming to build capability, share good practice and change culture amongst commissioners (from clinical commissioning groups (CCG), local authorities (LAs) and specialised commissioners) and providers
  - iv. Support and assurance programme for areas to plan for and execute transformation.
- 2.11 Progress on each of these areas is summarised below.

**Fast Tracks**

- 2.12 In the past month, five 'fast-track' areas (Greater Manchester & Lancashire; Cumbria & the North East; Nottinghamshire; Arden, Herefordshire & Worcestershire; Hertfordshire) have been launched. In these areas, collaborations of commissioners (CCGs, LAs, specialised commissioning hubs) will receive extra support to work with providers, families and patients to draw up service transformation plans by the first week of September 2015.
- 2.13 The aim is to achieve real change in these areas at greater pace, but also to build our understanding and refine our approach to transformation, addressing questions such as:
- i. What should the planning assumptions be for in-patient and community based services?
  - ii. What should the service model look like? (Fast Tracks are sighted on the draft national service model and we hope to refine and enhance it with them over the summer.)
  - iii. Building on co-commissioning with specialised commissioning, what mechanisms are needed to flexible use of the budget along pathways and to promote integrated personalised budgets? (We intend to work with the North region in particular on building financial models.)
  - iv. What support is required to bring about transformation and resettlement?
  - v. What is the right time-frame in which to expect transformation?
- 2.14 Fast Track areas will each receive up to £100,000 in technical support to draw up their plans. They will also be able to bid for access to £10 million transformation funding to kick-start service transformation in the second half of 2015/16.

## **Service Model and Other Aspects of the National Transformation Plan**

- 2.15 By October 2015, we will articulate a national transformation plan, covering: service model, bed reductions, planning assumptions, credible timeframes for transformation, financial underpinnings, and plans for workforce development (linked to 'safe staffing' commitment). Elements of this will be reflected as appropriate in the 2016/17 planning guidance.
- 2.16 National work is underway to finalise a future service model – i.e. what services we expect to be in place, meeting what standards. This work is being taken forward by a virtual team of staff from NHS England, the Local Government Association (LGA) and Department of Health (DH), supported by an external reference group bringing together clinicians, people with learning disabilities, family carers, academic experts, commissioners and third sector groups. Consultation events/focus groups have been held with clinicians, commissioners, people with learning disabilities and family carers. We intend to publish the final draft by 27 July 2015, further discuss with stakeholders, test with the Fast Tracks and publish a final version in the autumn which will be linked to the 2016/17 planning guidance.
- 2.17 The service model includes a focus on:
- i. Providing more proactive, preventative care, with better identification of people at risk and early intervention
  - ii. Empowering people with a learning disability and/or autism, for instance through the expansion of personal budgets and personal health budgets and independent advocacy
  - iii. Supporting families to care for their children at home, and the provision of high-quality social care with appropriate skills
  - iv. Providing greater choice and security in housing
  - v. Ensuring access to activities and services that enable people with a learning disability and/or autism to lead a fulfilling, purposeful life (such as education, leisure)
  - vi. Ensuring people with a learning disability and/or autism whose behaviour challenges are able to access mainstream health services (including mainstream mental health services in the community)
  - vii. Providing specialist multi-disciplinary support in the community, including intensively when necessary to avoid admission to hospital
  - viii. Ensuring that services aimed at keeping people out of trouble with the criminal justice system are able to address the needs of people with learning disabilities and/or autism, and that the right specialist services are in place in the community to support people with a learning disability and/or autism who pose a risk to others
  - ix. Providing hospital services that are high-quality and assess, treat and discharge people with a learning disability as quickly as possible.
- 2.18 Work has started on planning assumptions (i.e. assumptions of what reduction in in-patient usage will be achieved) with Fast Track commissioners. We are also undertaking modelling work at a national level to understand what kind of reduction in hospital usage and therefore in in-patient bed numbers could be expected if the right services in the community were in place.
- 2.19 Work is also underway to agree how the transformation should be funded. We anticipate that the costs of the set of services we have in future will need to be met from the current budget spent on health and social care services for people with a learning disability and/or autism. This may involve shifting spending from some services along the pathway to others, and a range of financial mechanisms may need to be used to do this, including pooled budgets where appropriate and NHS-funded dowries for people being discharged after very long spells in hospital. We anticipate that the costs of transitioning to the future mix of services will need to be funded out of existing allocations, though the five Fast Track areas will also have access to a £10 million transformation fund in 2015/16 to help with some of these transition costs. We intend to issue further guidance on how we expect the finances to work (including dowries) as part of the autumn transformation plan.
- 2.20 As a result of the recent announcements regarding safe staffing, national work will be undertaken on workforce issues. The brief is under development and work will commence with

Fast Tracks by the autumn. This work is expected to focus on competences and future state and include social care.

### **Improvement programme**

2.21 An improvement programme, similar in approach to the New Models of Care Vanguard, is being considered and will be initiated building collaborative learning communities of commissioners and providers through networks, sharing good practice, accelerating change, readying the system for the 2016/17 planning round expectations.

### **Support and Assurance**

2.22 Working with LGA and the Association of Directors of Adult Social Services (ADASS), we will provide support and assurance for commissioners to plan for and execute service transformation – starting with the Fast Track areas and adapting our approach having learnt from working with them.

2.23 We have procured technical support for Fast Track areas to draw up robust transformation plans. We also intend to provide practical resources for commissioners (e.g. how-to guides, sample service specifications).

2.24 We are building the assurance process of commissioners for their transformation plans, and against delivery on those plans. Given the need for NHS and local government commissioners to act together to close inpatient services and strengthen community support, discussions are underway with the LGA to design those assurance processes.

### **Commitment 4:**

***Building on preliminary work in 2014/15, establish a national learning disability mortality review function in 2015/16, to inform how we shape future services.***

2.25 NHS England, the Healthcare Quality Improvement Partnership (HQIP) and the University of Bristol have announced the world's first national programme to review – and ultimately reduce – premature deaths of people with learning disabilities.

2.26 The three-year project will be the first comprehensive, national review set up to understand why people with learning disabilities typically die much earlier than average, and to inform a strategy to reduce this inequality. The new function will support commissioners to review and act on their local premature mortality.

2.27 This work will be led by Dr Pauline Heslop, Reader of Intellectual Disabilities Research at University of Bristol. Formal work began in June 2015 and has initially focused on recruiting staff and development activities. The University is planning to establish a Programme Board for this work, which will meet for the first time in July, and a Learning Disability Representatives meeting in August. They also participated in a recent workshop in the North East, hosted by Dr Dominic Slowie, the National Clinical Director, to develop the local mortality review process for people with Learning Disabilities.

### **Commitment 5:**

***Throughout 2015/16 use reliable real-time data to track progress and inform learning disability work.***

2.28 We have made significant improvements in the provision of data on people with learning disabilities in inpatient care. Management of the Assuring Transformation data collection has successfully transferred to the Health & Social Care Information Centre. Data is now published monthly, and the in-built validations in the Health & Social Care Information Centre's (HSCIC) clinical audit platform mean the quality and accuracy of the data have improved significantly. We continue to improve the completeness of the data set, most notably by investigating the differences between Assuring Transformation and the Learning Disability Census – to date over 650 differences have been resolved.

2.29 Data and Information work stream supports all other work streams in the Programme. Examples of this include in-patient modelling to support the Future Care work stream and the Fast Track sites, and operational dashboards to monitor admissions, discharges and CTR delivery. We also play a leading role in the cross-system Transforming Care Data & Information group, developing Quality of Care and Quality of Life indicators and working to improve the flow of information around the care system.

### **3.0 OTHER WORK TO SUPPORT THE CORPORATE PRIORITY**

#### **Clinical Leadership and Assurance Activities**

- 3.1 The clinical governance of the Programme has been strengthened to ensure alliance between the central and regional teams. The clinical leads in each area meet monthly to assess, discuss, and mitigate clinical risks. Programme 'products' such as the CTR policy, Clinical Risk Register etc. are scrutinised and agreed by the group.
- 3.2 A central process of quality assurance is in place for CTRs to support their delivery, and a data collection to support the outcomes of reviews is currently being agreed with HSCIC for implementation from October 2015. Regional processes to quality assure CTRs are being developed and are informing regional trajectories for delivery.
- 3.3 Clinical leadership to support the Fast Track areas is being developed as part of the supporting infrastructure and a clinical governance and assurance quarterly report is provided to the NHS England Learning Disability Programme Board.

#### **Stakeholder Involvement**

- 3.4 The service model reference group and fora for the four different constituencies described in the May 2015 Board paper (commissioners, providers, patients/carers and clinicians) have all met at least once. The groups are currently focused on providing their views on the draft service model.
- 3.5 The Public Patient Voice Team hosted a successful learning disabilities week in June. The theme this year was 'Hear My Voice'; for NHS England, this means ensuring that people with lived experience of learning disabilities influence and co-produce work across the range of our activities.
- 3.6 July will see the new Learning Disability Engagement Team, working within Public and Patient Voice and funded by the Programme, starting work to put the 'Hear My Voice' aspiration into practice. This team will work to ensure that people with lived experience of learning disabilities influence and co-produce work across the range of NHS England's activities.
- 3.7 The team is made up of six people: a Public Engagement Manager, four Learning Disability Network Managers and a Business Support Assistant. For the first time, NHS England will use the co-worker model in this team, where a person with a learning disability job shares with a person without a learning disability, giving a complementary combination of skills, strengths and experience. The team as a whole will use a combination of lived experience, subject matter expertise and a passion to make a difference in healthcare for people with learning disabilities.

### **4.0 RECOMMENDATION**

- 4.1 The Board is asked to consider the update, and to assess the progress made since the last report and the level of assurance provided by the paper.

**Author:** Jane Cummings, Chief Nursing Officer and NHS England National Director Sponsor for the Learning Disability Programme

**Date:** July 2015