Agenda Item 15

HEALTH AND WELLBEING BOARD: 8 JULY 2021

REPORT OF THE DIRECTOR OF ADULTS AND COMMUNITIES AND LEICESTERSHIRE PARTNERSHIP NHS TRUST

TRANSFORMING CARE FOR THOSE WITH LEARNING DISABILITIES AND/OR AUTISM

Purpose of report

1. The purpose of this report is to present to the Health and Wellbeing Board an update concerning the current activity and progress of the LLR Transforming Care Design Group in achieving the ambitions of the National Transforming Care Programme (TCP) of Change, which includes the Learning from Deaths of people with Learning Disability (LD) Review Programme (LeDeR) Annual Report and the System 3 year plan to improve outcomes for service users with a learning disability and/or autism.

Link to the local Health and Care System

2. This work links to a number of national strategies and local improvements. Transforming Care is a national programme of work launched in 2012 following the report into the failings at Winterbourne View hospital.

3. This work also links into LLR joint system plans and has been a focus of improvement over the last 12 months.

Recommendation

4. The Health and Wellbeing Board is asked to:

   a) Note the Learning from Deaths of people with Learning Disability (LD) review programme Annual Report and support the work being undertaken to promote good health and wellbeing for service users with a learning disability and improve service design and delivery;

   b) Note the Transforming Care in Leicester, Leicestershire and Rutland 3 year road map which seeks to improve outcomes for the LLR population with a learning disability and/or autism and aid service development.

Background

5. In May 2011, Panorama broadcast an undercover exposé concerning Winterbourne View, a private hospital in Bristol that provided assessment and treatment for adults with learning disabilities and challenging behaviour. Winterbourne View was owned and operated by Castlebeck Care (Teesdale) Limited. Castlebeck also ran a number of other hospitals around the UK providing care to some of the most vulnerable people in society. The programme showed the residents being physically assaulted

and humiliated by members of staff at the hospital. The programme also alleged that records were being falsified, there was deprivation of liberty, excessive use of physical restraint, a poor quality of life for the claimants and breaches of their human rights. In 2012, 11 members of staff were convicted of over 40 offences between them.

6. In light of the publicity surrounding the actions of the CQC in relation to its role in investigating allegations of abuse at Winterbourne View, the CQC reviewed its inspection programme and changed the way it responded to whistle blowers and allegations of abuse.

7. Following the revelations around Winterbourne View, the Government introduced a "Transforming Care" programme which was intended to prevent further abuse on the level of that found at Winterbourne.

8. The LLR vision is that "All people with a learning disability and/or autism will have the fundamental right to live good fulfilling lives, within their communities with access to the right support from the right people at the right time."

9. The primary purpose of the Learning from Deaths of people with Learning Disability (LD) review programme (LeDeR) is to review the care each person has received leading up to their death and make recommendations that could help improve the care for other people and reduce premature deaths. Recommendations from each review are intended to highlight best practice and thereby support health and social care professionals and policy makers to implement positive change for people to have better experience of their care.

LeDeR Annual Report

10. The Annual Report, which is appended to the Report as Appendix A, was published on July 1 and is also available in easy read format.

11. The core principles and values of the LeDeR programme are as follows:

    (a) The programme overall must effect change and make an identifiable difference to the lives of people with learning disabilities and their families.

    (b) We value the on-going contribution of people with learning disabilities and their families to all aspects of our work and see this as central to the development and delivery of everything we do.

    (c) We take a holistic approach, looking at the circumstances leading to deaths of people with learning disabilities and don't prioritise any one source of information over any other.

    (d) The key principles of communication, cooperation and independence will be upheld when working alongside other investigation or review processes.

    (e) The programme overall strives to ensure that reviews of deaths lead to reflective learning which will result in improved health and social care service delivery.

12. The report highlights that partners can make big differences to the care of people if the following 11 points below are adhered to:

    1. Listen to people with Learning Disabilities and their families and carers;

    2. Ensure everyone is fully up to date with training;

    3. Everyone having a clear understanding of the difference between Learning Disability and learning difficulties ;

    4. Carry out Mental Capacity Assessments in every relevant case;

    5. Ensure patient records are fully accurate and changes are recorded correctly;

    6. Communicate more effectively, in particular:

        - with people with LD
        - across providers about Care Plans
        - discharge planning
        - advocacy
        - decision making
        - end of life
        - DNACPR

    7. Make no assumptions, particularly about LD being related to cause of death;

    8. Check procedures to ensure nothing is missed in any process;

    9. Ensure Annual Health checks are provided for every eligible person;

    10. Support people to attend appointments, especially for Annual Health checks and screening programmes;

    11. Ensure the correct versions of documents are used and completed accurately, including death certificates.

13. Partners have improved service outcomes across LLR in the last 12 months, moving from the 44th of 48 systems in the country to 27th of 48 systems. We have reduced the number of people in hospital, we have completed timely reviews when people have died and we have met the national target for providing health checks to people with a Learning Disability, something which had not been achieved across LLR previously .

3 Year Roadmap

14. The 3 Year Roadmap, attached as Appendix B to the report, outlines what ‘good’ will look like for people with learning disability (LD) and autism who use community and inpatient services in Leicester, Leicestershire and Rutland (LLR). The Roadmap will focus on addressing health inequalities for people living with a learning disability and/or autism.

15. Key Priorities and Pathways for Year 1

- Increased focus on co-production with people with LD and Autism.
- Admission avoidance for CYP and Adults.
- Integrated team working – development of TCP Hub – joint working across LLR.
- Continue to improve Annual Health Checks (AHC) completion rates – look to developing ASD AHCs.
- Provide community and inpatient support for people with Autism without LD.
- Learn from LeDeR – make service changes.
- Provide better support for our forensic cohort.

16. How Things Will look

(a) In year 1:

- Integrated working;
- New processes and protocols embedded;
- Learning from LeDeR;
- Dedicated Support Pathways;
- Reduced number of admissions;
- New Teams; and
- New models of care for individuals with ASD, LD and Forensic needs.

(b) In year 2:

- Timely discharges;
- Reduced reliance on inpatient care;
- Alternatives to admission;
- Early intervention to support wellbeing;
- Highly capable workforce.

(c) In year 3:

- Person centred and proactive intervention approaches;
- Designated key workers for CYP;
- Co-ordinated health and care support;
- Long term plans in place and achieved.

17. The Annual Reports and 3 year plan have been circulated to all TCP governance groups and will be used to inform future service development and improvement by LLR organisations and Participants Groups involved in the TCP programme

Patient and Public Involvement

18. Service users and their families have been engaged and supported the development of this work and will continue to be so through the duration of the programme.

Resource Implications

19. Partners now have a unique opportunity with additional NHS England funding, good system working to continue to build on better outcomes for our population.

20. The final funding allocation for LLR Learning Disability and Autism (LDA) Programme under the NHSE/I System Development Fund is outlined below. All of this is committed through the new LLR LDA 3-year road map developed with all key stakeholders in April 2021 and approved by NHSE/I in June.

Funding Line	Allocation Methodology	Amount (£)
SDF - Community	System Fair Shares	£487,000
SDF - LeDeR (Mortality Reviews)	System Fair Shares	£39,000
SDF- Care and Treatment Review	System Fair Shares	£33,000
Total SDF Funding 2021/22		£559,000

21. The Government published a COVID-19 mental health and wellbeing recovery action plan in March this year, with £31m allocated to support specific challenges faced by individuals with a learning disability and autistic people. LLR has been allocated £150,000 under the Spending Review funding for 3 specific service areas, as listed below.

Funding Line	Allocation Methodology	Amount (£)
SR – Autism Diagnostic Waiting Times	System Fair Shares	£68,000
SR – Champion in ICS	System Fair Shares	£24,000
SR – Community Respite Care (CYP)	System Fair Shares	£58,000
Total SR Funding 2021/22		£150,000

22. Proposals for the spending of these 3 pots are being developed by the TCP Collaborative and will be submitted to NHSE/I by 30 June. There is also an opportunity to bid for additional funding through an Expression of Interest process. LLR has put a bid in for £100,000 under the Accelerating Autism Diagnostic Pathway (Children and Young People) and a bid for £152,990 under the Piloting Autism Diagnostic Pathway (Adults), we are awaiting the outcome from the NHSE/I regional team.

Appendices

Appendix A Learning from Deaths of people with Learning Disability (LD) Review Programme (LeDeR) Annual Report

Appendix B Summary of the 3 year road map.

Appendix C – Transforming Care in LLR – Annual Report

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Relevant Impact Assessments

Equality and Human Rights Implications

23. This work is important to addressing health inequalities and supporting the residents of Leicestershire to live a long and fulfilling life