

Integrated Care Board

Date of meeting	1 February 2023
Title of paper	Learning Disability and Autism: Current position
Presented by	Professor Sarah O'Brien, Chief Nursing Officer
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Agenda item	11a
Confidential	No

Purpose of the paper

At previous Board meetings the variation and low delivery of annual health checks to people with a Learning Disability has been discussed. The purpose of this paper is to present to the Board current performance across all key areas and highlight the associated challenges, risks and required service improvements.

Executive summary

The ICB has statutory responsibilities in relation to people with a Learning Disability and Autism and the accountable Executive is the Chief Nursing Officer.

The Long-Term Plan (2019) specified areas of focus and improvement in relation to people with a Learning Disability and or Autism and there are also nationally driven programmes with a focus on the developments required to reduce health inequalities. These are: the need to improve the uptake of Annual Health Checks in primary care; reducing over medication through the Stopping the Over Medication of People with a learning disability, autism or both (STOMP); Supporting Treatment and Appropriate medication in Paediatrics (STAMP); taking action to prevent avoidable deaths through learning from the lives and deaths of people with learning disabilities and autistic people (LeDeR).

The NHS (led by the ICB) and system partners have a crucial role to support people with a Learning Disability and / or Autism live longer, happier and healthier lives.

The ICB has a dedicated Learning Disability and Autism team that support delivery of all these programmes and report trajectories to NHS England on inpatient admissions and discharges, completion of annual health checks and Learning from the Lives and deaths of people with learning disabilities and autistic people (LeDeR).

However, there were challenges to achieving performance against NHS trajectories across the CCGs and these still exist and whilst there are some mitigating actions in place with more planned, it is evident that further service developments and potential investment will be required to ensure the ICB can deliver on this agenda and commit to support people with a Learning Disability and / or Autism live longer, happier and healthier lives.

Recommendations				
The Integrated Care Board is requested to:				
<ol style="list-style-type: none"> 1. Note the responsibilities of the ICB in relation to people with a Learning Disability and or Autism and the current challenges and risks 2. Note the service developments required to improve this area of delivery and the potential investment required. 3. Endorse the requirement for a future report to consider the impact of proposed service developments. 				
Governance and reporting (list other forums that have discussed this paper)				
Meeting	Date			Outcomes
ICB Executive Team	24 January 2023			Supported the paper for the Board
Conflicts of interest identified				
Not applicable				
Implications				
If yes, please provide a brief risk description and reference number	Yes	No	N/A	Comments
Quality impact assessment completed			x	
Equality impact assessment completed			x	
Privacy impact assessment completed			x	
Financial impact assessment completed		x		
Associated risks	x			
Are associated risks detailed on the ICB Risk Register?	x			

Report authorised by:	Professor Sarah O'Brien, Chief Nursing Officer
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Integrated Care Board – 1 February 2023

Learning Disability and Autism: Current Position

1. Introduction

- 1.1 There are several key areas in Learning Disability and Autism where it is evident that the NHS and system partners have a crucial role to support people with a Learning Disability and / or Autism to live longer, happier and healthier lives. Responsibility passed from CCGs to Integrated Care Boards (ICBs) in July 2022.
- 1.2 The ICB Learning Disability and Autism team report trajectories to NHS England regarding delivery in these key areas which are: inpatient admissions and discharges, completion of annual health checks and Learning from the Lives and deaths of people with learning disabilities and autistic people (LeDeR).
- 1.3 At previous Board meetings the variation and low delivery of annual health checks to people with a Learning Disability has been discussed. The purpose of this paper is to present to the Board current performance across all key areas and highlight the associated challenges, risks and required service improvements.

2 Background: Key drivers in Learning Disability and Autism

- 2.1 The Long-Term Plan (2019) directs a focus on improving community-based support and reducing reliance on specialist hospitals so that people can lead lives in their own homes. The plan also highlights the requirement to ensure all commissioned services provide good quality healthcare and treatment for people with a learning disability and Autistic people and their families.
- 2.2 There are also nationally driven programmes with a focus on the development required to reduce health inequalities. These are: the need to improve the uptake of Annual Health Checks in primary care; reducing over medication through the Stopping the Over Medication of People with a learning disability, autism or both (STOMP); Supporting Treatment and Appropriate medication in Paediatrics (STAMP); taking action to prevent avoidable deaths through learning from the lives and deaths of people with learning disabilities and autistic people (LeDeR).
- 2.3 It is explicit that support should be provided to services to develop their workforce to have the necessary knowledge and skills to apply reasonable adjustments including accessible information, to ensure that people with a learning disability and Autistic people have equal access to care and treatment.

- 2.4 The importance of recognising the value of including people with lived experience and their families in this work is recognised, including developing a workforce that is representative of our learning disabled and autistic population.
- 2.5 Co-production is evident and highly valued within Lancashire and South Cumbria. The Learning Disability Strategy and Autism Strategy were co-produced and we work together at the Confirm and Challenge Group to identify what has worked well and where improvements are required. There are also people with lived experience on the Local LeDeR panel and expressions of interest for health inequalities steering group will be requested imminently.
- 2.6 The Confidential Inquiry into the deaths of people with learning disabilities (CIPOLD), 2013 investigated the avoidable or premature deaths of people with learning disabilities through a series of retrospective reviews of deaths. The conclusions from the inquiry provided key recommendations for the NHS and system partners on the reasonable adjustments and infrastructure required to improve the outcomes for people.
- 2.7 The LeDeR programme was developed as a further service improvement programme to review why people with a learning disability and autistic people are dying prematurely and to identify if there is anything that is required within local service delivery to reduce health inequalities.
- 2.8 Integrated Care Boards are now responsible for ensuring that LeDeR reviews are completed based on the health and social care received by people with a learning disability and autistic people (aged four years and over) who have died, using a standardised review process. This enables ICBs to identify good practice and what has worked well, as well as where improvements in the provision of care could be made. Local actions should be taken to address the issues identified in reviews. Recurrent themes and significant issues are to be identified and addressed at a more systematic level, regionally and nationally.
- 2.9 Oliver McGowan Mandatory training in Learning Disability and Autism has been developed following the preventable death of Oliver McGowan in 2016 which highlighted the requirement for health and social care staff to undergo enhanced training in learning disability and autism. The training was launched on the 1/11/2022 and is fully co-designed and co-delivered with people with a learning disability, autistic people, family carers and people working within learning disability and autism services.
- 2.10 The training has been identified as mandatory within the Health and Care Act, 2022 and requires the ICB to ensure identification of staff that may encounter a person with a learning disability and autistic people as part of their role and ensure they receive training to improve the social care and health outcomes they provide.

2.11 Building the Right Support (HM Government, 2022) has the aim that people with a learning disability and Autistic people are equal citizens able to fulfil their potential. They are supported to live full lives in their community, in their home, with access to the care that is right for them, when and where they need it.

3 Current Performance

3.1 Inpatient care

3.11 The current trajectory for inpatient care for Lancashire and South Cumbria (LSC) is that by March 2024 no more than 30 adults with a learning disability and/or who are autistic per million adults and no more than 12–15 under 18s with a learning disability and/or who are autistic per million under 18s are cared for in an inpatient unit. We are not meeting this trajectory, there are a number causative factors but the two main ones are a lack of capacity in community accommodation and an increase in people receiving a diagnosis of autism whilst in an acute mental health bed.

Current Inpatient Performance:

Inpatient Category	2022/23 Trajectory	Current	Gap
Non secure adult inpatients	47	56	9
Secure adult inpatients	37	44	7
Total adult Inpatients	100	84	16
Inpatients within LSC	-	49	
Inpatients out of area	-	51	

*there are 3 people on extended S17 leave

3.12 There are some mitigations in place to improve the position against trajectory but we do not expect to meet the 2022/23 target:

- The use of NHSE transformation funding to improve community services is beginning to show improvements in planned discharge performance and unnecessary admission avoidance.
- Development of a Supported Living Framework where 39 providers have been selected through competitive tendering to provide supported living to people with a learning disability and /or autism for individuals leaving hospital or at risk of needing a hospital admission.
- Close work has been completed with a range of providers to develop services based on the needs of people with a learning disability and/or autism and by managing the referrals into these services and leading mobilisation meetings to accelerate progress.

3.13 Out of area placements for people with a Learning Disability and / or Autism are too high and the aim is to have more acute adult inpatient beds within LSC.

- 3.14 £32 million capital investment has been allocated by NHSE ‘Capital Bed Gaps Programme’ - subject to Care Quality Commission (CQC) and full business case approval (£8m 23/24 £25m 24/25).
- 3.15 A coordinated programme of work is underway with the ICB and LSCFT to deliver a HM treasury approved full business case for the beds including an agreement on location/s and any required public consultation. A review and plan for revenue requirements will also be included highlighting potential running costs.
- 3.16 A Model of care has been coproduced and shared with CQC for initial consideration and feedback. NHSE National LDA Director has been supporting negotiations with CQC and in NHSE National Team. There has been some challenge and delay by the CQC which is a risk to delivery. Capital funding can start to be accessed from 2023/24 with the aim of the service being ready for 2025/2026.

3.2 Annual Health Checks

3.2.1 The target is for 72% of people that are on the learning disability register at GP practices to receive a health check by the end of March 2023. Our current position across LSC (variation across practices is recognised and low performing practices are being targeted for improvement) at the end of November was:

Category	Current position	November 2021 position
Offered or declined a health check	2184 (24%)	
Received health check	3339 (37%)	3011
Received health check & health plan	2961 (32%)	2659

- 3.2.2 Reducing health inequalities is a key focus and there has been close working with the health facilitation team to address this area. There is support being provided to GP’s to offer a quality health check through training sessions which are held fortnightly, advice and information on making reasonable adjustments and resources offered to GP practices. Training sessions that are held highlight feedback from people with a lived experience.
- 3.2.3 A Learning Disability Strategy and Autism Strategy have been co-produced with people with lived experience to highlight key areas that people with learning disability and autistic people want us to address.

3.3 Learning from lives and Deaths of people with a learning disability and Autistic people (LeDeR)

3.3.1 The responsibility for allocating and ratifying the LeDeR reviews now lies with the ICB (transferred from CCG’s). The CCG’s acknowledged that there was a significant number of reviews that had been submitted and there was a delay in decision making. The current position at the end of November was:

Number of reviews	Activity
451	Archived / completed
76 new reviews	54 have been assigned
24 finalised requests for sign off	2 on hold
8 notifications received	Allocation being completed

3.3.2 To address previous challenges in this area additional capacity has been introduced and it is anticipated that the new post of Senior LeDeR review and Senior Health Inequalities Manager will improve learning. The development of a Lancashire and South Cumbria LeDeR Quality Panel and Health Inequalities Steering Group is in progress where there will be clear actions and accountability and this group will also feed into the regional LeDeR group.

3.4 **Children and Young People (CYP) assessment performance**

3.4.1 In Lancashire and South Cumbria, there is unwarranted variance in statutory compliance of completed Children and Young People autism assessments and waiting lists in line with National Institute of Clinical Excellence (NICE) guidance. There is currently only two areas (East Lancashire and Blackpool) with a commissioned service, other areas of the ICB do not hold a recurrently funded contract with a provider (NHS or independent) for the delivery of CYP Autism assessments.

3.4.2 It has been identified that the inherited budget from CCG's does not meet current and perceived future demand for CYP autism assessments and support pathway. An Autism Capacity and Demand analysis has been commissioned from NICHE which is scheduled to complete on 20th January and will indicate the scale of the issue from an independent perspective.

3.4.3 Initial joint discussions with CYP/SEND ICB colleagues have been completed to identify further actions required which include the development of an ICB agreed pathway, an agreed investment plan and commissioning of a suitable provider.

3.5 **Adult Autism Assessment**

3.5.1 The Adult Autism Assessment service is not currently meeting statutory compliance against NICE guidance for assessment waiting times. There has been ongoing concerns regarding delivery of this agenda which has resulted in the termination of contract with two previous providers. The ICB has approved a new Adult Autism assessment provider but there is a total waiting list of 1600 assessments inherited plus approx. 130 new referrals per month. The trajectory is for the backlog to be cleared by May 2023, non -recurrent funding was used to complete this and ensure compliance with NICE guidance regarding waiting times.

3.5.2 The budget Inherited from CCG's for adult autism assessment does not meet the demand – circa £3m gap after May 2023.

- 3.6 The recommission does not include pre and post diagnosis support – therefore does not meet NICE compliance. The only existing post-diagnostic support offer available is in East Lancashire through the Voluntary, Community, Faith and Social Enterprise sector and recent communication has been circulated that this service is due to cease.
- 3.7 The ICB team are reviewing all the areas of challenge outlined in this paper and continue to work with system partners on the service developments. A further report to the Board will be required when this work is complete outlining any recommended developments and financial impact.

4 Conclusion.

- 4.1 The ICB has a statutory responsibility for Learning Disability and Autism and there are risks that need addressing as a priority. There are several service developments highlighted in this paper that are already in progress and it is anticipated that these will improve performance against NHSE trajectories, however it is unlikely that the threshold will be met this financial year. The Autism capacity and demand analysis as well as the potential for development of acute inpatient beds in Lancashire and South Cumbria indicates there will be a request for further financial investment in the future. This investment will be essential to enable the ICB to move forward to progressing discharges from hospital and to ensure people are receiving the assessments and care they require to lead longer, happier and healthier lives. It will also allow progression of the integrated work that has been started in Lancashire and South Cumbria.

5.0 Recommendations

- 5.1 The Integrated Care Board is requested to:
- Note the responsibilities of the ICB in relation to people with a Learning Disability and or Autism and the current challenges and risks.
 - Note the service developments required to improve this area of delivery and the potential investment required.
 - Endorse the requirement for a future report to consider the impact of proposed service developments.

Debbie Wardleworth

16th January 2023