

How well did Cambridgeshire and Peterborough provide services for adults with learning disability 2012-2013? Report to the Health and Wellbeing Board Cambridgeshire and Health and Wellbeing Board Peterborough

Dr Caroline Lea-Cox Clinical Lead for Mental Health and Learning Disability
John Ellis, Dawn Jones, Cambridgeshire and Peterborough CCG
Tracy Gurney

Deborah Gallacher



1.1 Context

With the formation of the new Cambridgeshire and Peterborough CCG and the Health and Wellbeing Boards for Cambridgeshire and Peterborough, it is opportune to reflect on how well as a region we are delivering services for adults with learning disability.

Total number of adults on the learning disability register 2012-13	Cambridgeshire		Peterborough
Age 18+	1478		701
Age 65+	Fens	25	44(5.9%)
	South	31	
	Hunts	15	
	City	21	
	East	19	
	Total	111 (7.5 %)	
Total	1589		745

Services are jointly commissioned through health and social care, with the local authority taking responsibility as lead commissioner. Well established Learning Disability Partnership Boards in both Cambridgeshire and Peterborough oversee the delivery of services for people with learning disability. However, it is the responsibility of all of us in the region to make sure that we are aware of the care of people with learning disability and know how to alert if concerns are raised. *'If we get it right for learning disability, then we get it right for everybody'*. Indeed, the ethos of care for learning disability applies to any vulnerable group of people within our society.

People with learning disabilities have often been invisible to mainstream health services and health professionals.

We need to give particular consideration to commissioning services for people with learning disabilities because they experience poorer health than the general population (*Confidential Inquiry into premature deaths of people with learning disabilities CIPOLD 2013*), differences which are to a large extent avoidable, and thus represent health inequalities.

Some health inequalities relate to the barriers people with learning disabilities face in accessing health care and health screening. These barriers are well documented in numerous reports including *Death by Indifference Mencap 2007*, which detailed the deaths of six people with learning disabilities while in the care of the NHS and the Disability Rights Commission's report *Equal Treatment*.

The recent report on *Hospital admissions that should not happen* (Admissions for Ambulatory Care Sensitive Conditions (ACSCs) for people with learning disability in the UK 2013) found that people with learning disability were 25% more likely to be admitted to hospital as an emergency compared to other people, and were 70% more likely to be admitted for an ASCSs. The ASCSs include

- Epilepsy and convulsions
- Constipation
- Complications of diabetes
- Influenza and pneumonia

Recent events at Winterbourne View (*Winterbourne Review Report 2012*) have also highlighted the importance of good quality commissioning for people who challenge services, and those with complex needs. We will need to work jointly with providers and others to ensure that good local services are available to support people who challenge services and those with complex needs to prevent the need for expensive and potentially risky out of area placements.

A review of how well we are delivering services cuts across public health, primary care, acute providers, learning disability partnerships, specialist learning disability teams, patient transport and ambulance system the criminal justice system and the third sector.

The health self-assessment framework (SAF) for learning disability services is a helpful tool as it involves specialist healthcare professionals as well as people with learning disabilities and family carers in assessing local services, and therefore provides good evidence of local involvement. It is used by most health communities on an annual basis and thus enables comparison on a year by year basis, and with other areas. The SAF brings together many standards for learning disability services that are in other documents, and

are included in this guidance under the appropriate section. Details of the SAF and assessment results can be found at: www.ihal.org.uk/self_assessment/

1.2 The HWBs of Cambridgeshire and Peterborough are asked to

1. Have a named Board level Executive Lead with responsibility for learning disabilities
2. Support the CCG in signing up to Mencap's "Getting it right charter" which sets out the key principles of care for people with learning disabilities. <http://www.mencap.org.uk/CCGcharter>
3. Ensure the local JSNA includes a needs assessment and corresponding plans are in place, which reflect policy and best practice guidelines.
4. Ensure there are well functioning partnership agreements between health and social care organisations.

1.3 Summary of how services for people with learning disability were delivered in 2012-13

Area
<p>How well has primary care delivered health checks for people with learning disability? Since 2009 directions were published by the Department of Health that required that Primary Care Trusts to offer GPs in their area the opportunity to offer learning disability health checks as part of a Direct Enhanced Service scheme. Since the restructuring of the NHS, NHS England through the Local Area Teams is responsible for commissioning services from General Practice</p>
<p>How well do the acute providers provide services for people with learning disability? In the East of England the acute hospital trusts have been working with their commissioners and Learning Disability Partnerships to carry out self assessments of their services for these patients and to agree plans for 2012-14 to improve these services</p>
<p>How well did the Learning Disability Partnerships meet their quality standards? Learning Disability Partnerships include representation from both social care services, health professionals, voluntary organisations, people with learning disability and their family carers or support workers. The Learning Disability Partnership Board covers employment, education, leisure, person centred planning, health, housing and other issues.</p>

1.3 1. Primary Care – Health checks for adults with learning disability who are eligible (moderate to severe learning disability)

We are currently doing fairly well across the CCG as benchmarked nationally, but we are doing less well than last year (78.5% of health checks completed) and there is wide discrepancy between practices/LCGs. However, if we include the number of patients who declined health checks then we have a 79.1% response rate. We have not reached the target of 90% except for the South Villages locality of Catch. We still have 6 practices not signed up to deliver health checks for 2013/14

LCG	Number of practices signed up for health checks	Number of patients with learning disability	Number of health checks Performed	Number of checks declined	% of patients who had a health check-Target 90%(including patients who declined a health check)
Peterborough	18/20 practices	192	169	12	88.0%(94.2)
Borderline	6/8 practices 2 Northants practices excluded	192	167	3	86.9(88.5)
Cam Health	9/9 practices	229	143	18	62.4 (70)
CATCH	24/25 3 Royston practices excluded	419	309	26	73.7 (80)
Hunts Health	10/10 practices	250	205	19	82.0 (89.6)
Hunts Care Partners	15/16 practices	350	241	33	68.8 (78.2)
Isle of Ely	10/10 practices	279	152	8	54.4(57.3)
Wisbech	3/4practices	122	101	4	82.8 (86)
Total	94% practices signed up (excluding 5 out of county practices)	2033	1487	122	73.1 (79.1)

1.3 2. Acute Providers- The Self Assessment RAG ratings for all objectives 2012

Leadership management and strategy	CUHFT Addenbrookes		HHT Hinchingbrooke		PSHFT Peterborough and Stamford	
There is a clearly identifiable Board and senior management engagement in embedding a strategy for adults with a learning disability or autism						
The Trust has policies in place that meet the specific needs of adults with learning disabilities or autism						
Partnership working takes place at all levels within the organisation						
Care Standards, Reasonable adjustments and service delivery	CUHFT		HHT		PHSHFT	
The Trust employs a registered healthcare practitioner for adults with learning disability or autism (Acute liaison Nurse) and identifies practitioners with extra skills and responsibilities						
The Trusts' plan to deliver the Public Sector Equality Duty and the NHS Equality Delivery System reflects the reasonable adjustments required for adults with learning disability or autism						
Adults with learning disability or autism receive high standards of fundamental care						
Patient safety issues are identified proactively. Risk assessment is comprehensive, taking into account individual support needs						
Adults with learning disabilities or autism receive appropriate nutrition and hydration						
Adults with learning disabilities or autism are identified prior to admission for elective cases or on admission through Emergency Departments						

Training and education on understanding the specific needs of people with learning disability and autism is provided to <u>all</u> hospital staff						
Pathways	CUHFT		HHT		PSHFT	
Adults with learning disability or autism attend outpatients and investigations appropriately						
Adults with learning disabilities or autism attend A&E appropriately						
Adults with learning disabilities and autism are discharged home in a safe and timely way						
Women and partners with learning disability or autism have a clear pathway for use of maternity services						
Involvement and representation of people with learning disability and their carers	CUHFT		HHT		PSHFT	
Adults with learning disability or autism and their family carers are fully involved in the planning of the Trusts learning disability strategy and in service evaluation						
Adults with learning disabilities or autism and their family carers are fully involved in pre admission planning, care planning and care delivery						
People with learning disability or autism are represented in the workforce						
Information for people with learning disability and their carers	CUHFT		HHT		PSHFT	
People with learning disability, autism and their family carers receive appropriate information prior to planned, emergency or outpatient admissions						
All departments have access to a range of resources to help in the production of easy read information. These are available to people with a learning disability or						

autism and family carers				
People with learning disabilities or autism and family carers, have appropriate information to help them make complaints, discuss concerns and give feedback				
Keeping people safe	CUHFT	HHT	PSHFT	
The Trust demonstrates learning from serious incidents, deaths of people with learning disability or autism				
The Trust demonstrates learning from other incidents involving people with learning disability or autism				
The organisation has ways of listening to adults with learning disability or autism and their family carers and learns from this				

Areas of good practice across the acute trusts

1. CUHFT have non executive Directors on the Trust board responsible for learning disability or Vulnerable Adults
2. CUHFT has agreed an Adolescent transition in Care Guideline
3. CUHFT have developed and audit tool which includes reasonable adjustments, fundamental care and the use of hospital passports
4. PSHFT have an electronic flagging system in place
5. CUHFT Maternity services use a learning difficulties screening tool, and there is a Maternity Services Learning Disability flowchart
6. PSHFT have a specialist midwife and a learning disability maternity pathway
7. CUHFT provide work placements for people with learning disabilities, some of whom have gone onto be employed in substantive posts.
8. PSHFT have volunteers with learning disabilities who act as hospital guides

1.3 3. Local Disability Partnerships

Quality Standard	Cambridgeshire LDP	Peterborough LDP
% of adults with learning disability living in appropriate accommodation i.e settled family accommodation or own/tenancy ownership reflecting personal choice	1199 of 1589 = 75.5% (Target 75%)	77% (Target 74%)
% of adults with learning disability receiving self directed support	1361 of 1589 = 88.6% (Target 80%)	271/745 = 36.4% (Target 60%)
% of adults with learning disability with paid employment	81 of 1589 = 5.1% (Target 7.5%)	49/745 = 6.6% (Target 6.0%)
% of adults with learning disability with something meaningful to do	85 of 1589 = 5.3% (unpaid voluntary work.)	73/745 = 9.9% (Voluntary work)
Timeliness of social care assessments within 28 days (Target 86%)	78 of 83 = 94%	Av 14 days (reported differently)
Timeliness of social care packages in place within 28days of assessment (Target 93%)	48 of 69 = 69.6% This is currently being closely looked at and a remedial plan in place	Av 26 days
Number of safe guarding issues/alerts	Total in the year of 266 alerts broken down as: 33 - not determined / inconclusive 61 - not substantiated 42 - partially substantiated 130 - substantiated	10 cases
Number of adults with learning disability who live out of area	Across health and social care provision the total is currently 139 of which 9 are in hospital placements (5 in secure units). There is active work with 23 people currently taking place around move on plans.	Work in progress
% of service users who live out of area who have had annual review by local team	100%	Data not available
% of Care Homes quality review	Data not available	Data not available
% of service user annual reviews	1168 of 1587 = 73.6% (Target 80%)	393/745 = 52.7% (target 100%)
% of carer reviews	327 of 1300 = 25.2% (Target 27%)	147/745 = 19.7% (Target 21%)
Number of people with transitions Plans	Data not available	Data not available

Areas identified for improvement

Area for improvement	How we move forward
Different targets for Learning Disability Partnerships in Cambridgeshire and Peterborough	This may wish to be discussed by the relevant HWB
Information sharing agreements between providers to improve quality of care	Collaboration between providers to ensure IT systems can communicate, but with firewalls to ensure confidentiality of data
Primary care contracting teams to gather data and compare with public health prevalence information.	Collaboration with public health
Maintain monitoring of improvements in services where user feedback is poor.	Look at the work by the EoE Managed Clinical Network to look at local family carer and user groups to form effective networks to feedback about services
Strengthen transitions work to prevent avoidable out-of-area placements of young adults.	EoE Managed Clinical Network led by Dr Lea-Cox is drafting standards for transition work
Implement Autism Action Plan, especially post-diagnosis support and for people not eligible for social care.	EoE Managed Clinical Network are developing guideline standards

Strengthen working relationships that have now been developed with local criminal justice agencies. Build on prison work to date and ensure continuity through transfer to NCB responsibility.	HWB
Regularly monitor individual provider plans to ensure LD-related issues are systematically reviewed.	Contracting.
Specialist care of epilepsy – whose responsibility? Quality of epilepsy reviews?	EoE Managed Clinical network Collaboration required between providers LDT and neurologists and primary care
We do not have data on the number of people with learning disability who have specific problems such as challenging behaviour, epilepsy, and dementia	LDP/CCG