King's Health Partners Learning Disability Strategy

King's Health Partners

2020-23

Vision

- "Work with our health and care system partners to improve the health outcomes and experience of people with a learning disability when in hospital or in the community [inclusive of all levels of need] with the dual aim of improving quality of life and reducing the 16-year mortality gap(1)."

1 - http://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf

Life expectancy | People with learning disabilities

Age at time of death (cumulative) of people with learning disabilities compared with the population of England and Wales

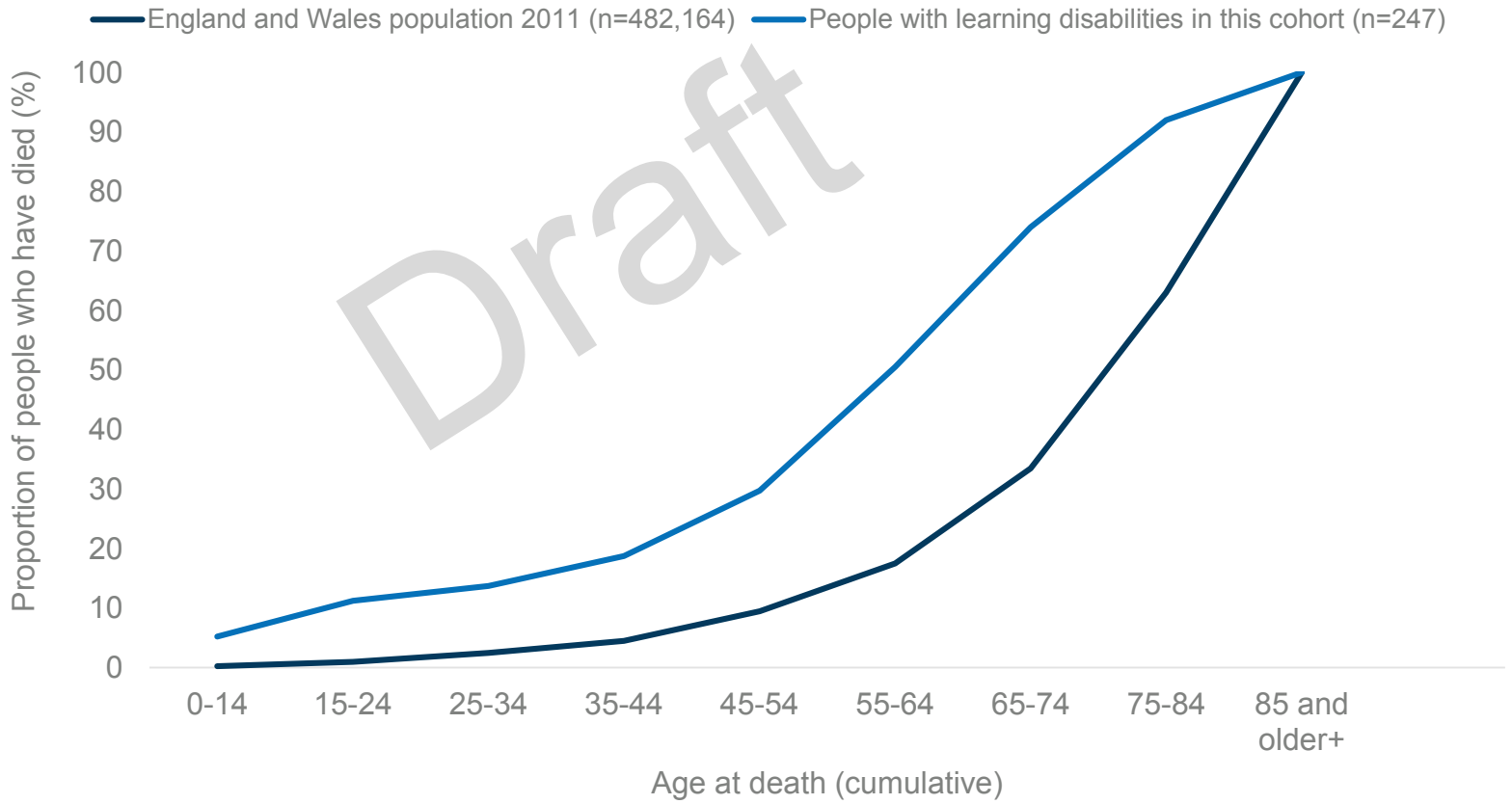
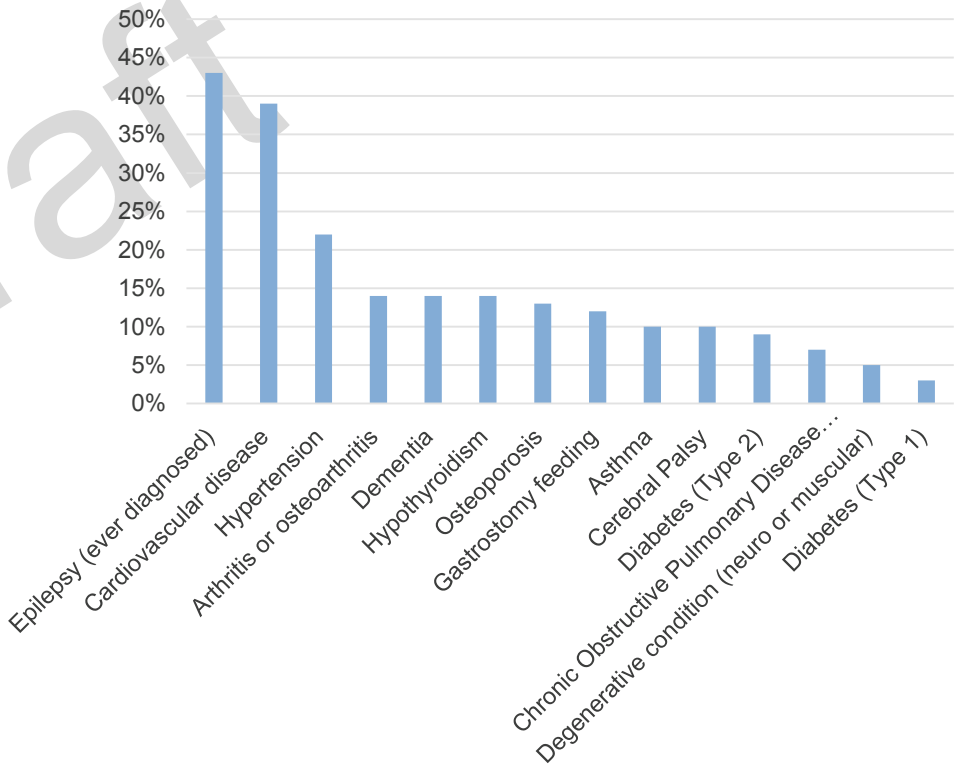


Chart reproduced from data in the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD), *Final Report,* available at: http://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf

Mental Health and Physical Health | People with learning disabilities

- Prevalence rates for schizophrenia in people with learning disabilities are approximately three times greater than for the general population (3% vs 1%) (1)
- Reported prevalence rates for anxiety and depression amongst people with learning disabilities vary widely, but are generally reported to be at least as prevalent as the general population (2), and higher amongst people with Down's syndrome (3)
- Challenging behaviours (aggression, destruction, self-injury and others) are shown by 10%-15% of people with learning disabilities, with age-specific prevalence peaking between ages 20 and 49 (4)

- 98% of people with learning disabilities had one or more long-term health condition or treatable medical condition



Source – 1 - Doody et al, 1998; 2 - Stavrakaki, 1999; 3 - Collacott et al, 1998; Emerson et al, 2001
Charts reproduced from data in the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD), *Final Report,* available at: http://www.bristol.ac.uk/media-library/sites/cipold/migrated/documents/fullfinalreport.pdf

Why is addressing the needs of people with Learning Disabilities important? (1 of 2)

- On average, adults with a learning disability die 16 years earlier than the general population – 13 years for men, 20 years for women;
- Over 1.2 million people in England have a learning disability and face significant health inequalities compared with the rest of the population;
- It is estimated that 20-30% of people with a learning disability also have autism;
- Despite suffering greater ill-health, people with a learning disability, autism or both often experience poorer access to healthcare;
- In 2017, the Learning Disabilities Mortality Review Programme (LeDeR) found that 31% of deaths in people with a learning disability were due to respiratory conditions and 18% were due to diseases of the circulatory system; and
- Psychotropic medicine is more likely to be inappropriately prescribed to people with a learning disability or autism.

Source: NHS Long Term Plan

Why is addressing the needs of people with Learning Disabilities important? (2 of 2)

- In 2017/18, 2,531 people with learning disabilities were living in Southwark and Lambeth (0.3% of the total population) (1) and we know they often experience poorer access to healthcare than the general population (2);
- People living with learning disabilities receive fewer screening tests and fewer health investigations and are less likely to get the healthcare they need (3);
- A person with a learning disability is 58 times more likely to die before the age of 50 than someone without (4);
- Physical and mental health co-morbidities are more prevalent in those with learning disabilities than the general population (5) and between 25-40% of people with learning disabilities also experience from mental health problems (6); and
- Evidence shows 3-4 times more likely to be admitted to hospital than general population with increased length of stay and re-admission rates.

Sources: 1 - PHE Fingertips, QoF, 2017/18; 2 - NHS England and NHS Improvement 2019; 3 – Equal Treatment; Closing the Gap 2006; 4 - Emerson and Baines, 2010; 5 - Cooper et al, 2015; 6 – Mental Health Foundation

There are a number of challenges in delivering the highest quality care for those with learning disabilities

- The learning disability **workforce is declining** locally and there are shortages in specialist roles where there is less uptake of trainees i.e. learning disability specific psychiatry;
- We believe there is a **lack of understanding and confidence amongst our workforce** which would enable them to appropriately meet the needs of our patients with learning disabilities within mainstream services;
- It can be **difficult to engage meaningfully** with our patients with learning disabilities across the system in order to inform service development;
- The nature of national pilot funding can create **challenges with delivery of sustainable services** whilst ensuring that we focus on delivering local initiatives that support national priorities;
- The **functionality of IT systems** across our partnership and with primary care does not always allow for sharing patient data which means often, people with learning disabilities and their carers have to tell their story multiple times and there is a lack of awareness in secondary care of the outcome of Annual Health Checks and early identifiers; and
- Local research often has a **complex rather than population/practice based focus** and we could be better at attracting local funding for learning disability specific research.

But by looking at the experiences of some of our patients, we know there are areas of exceptional practice across the system (1 of 3)

KCH Dental and GST Community Patient Story

Profile
27 year old gentleman with a Moderate Learning Disability, Autism, Social anxiety. He lives at home with supportive family and attends day services, phobic of professionals (in both the community and health service) and phobic of health setting (previous bad experience) with no health investigations to date

Pre-admission
Stopped eating, lost 4 stone in weight, referred under 2 week wait cancer pathway to upper GI, community dentistry- day centre check up with very limited success, carried out using photographs and looking from a distance, needed full check up

Challenges
Family circumstances limit their ability to support, managing clinical risk to patient i.e. community sedation, ambulance support, managing risk to the patient (likely to try to run, behaviour due to fear / anxiety), indemnity, anxiety around extensive cost i.e. transport, clinic booked out for the day

Actions:
Best interest and planning meetings, DoLS application made, reasonable adjustments made (co-ordinating investigations under 1 GA, working outside usual working protocols i.e. CLDN adapted hours, anaesthetist visited patient at home and accompanied into hospital, transport Sedation / GA / Recovery, HDU ambulance booked to wait, clinic booked out for the morning, team waiting to receive patient

Outcomes:
Successful - no evidence of cancer found, follow up required 1 year (Cyst), decayed tooth extracted, teeth filled

What went well:
Coordination and communication, specialist networking and liaison between departments, personable approach effective in achieving outcome, flexibility of services and professionals, positive risk taking

"This is a truly great example of health and social care professionals working together in the best interests of the patient"
Rob Hale, Clinical Director in Community Special Care Dentistry

But by looking at the experiences of some of our patients, we know there are areas of exceptional practice across the system (2 of 3)

KCH Psychology Patient Story

Profile

- 63 year old gentleman
- Mental health: Undiagnosed but probable mild learning disability, Attention Deficit and Hyperactivity Disorder (ADHD),
- Physical health: severe Chronic Obstructive Pulmonary Disease (COPD), and well-managed HIV.
- Reports difficulties with reading and writing and managing daily activities such as washing, dressing, cooking and cleaning around his home. Receives 24/7 care from his partner, who supports him with managing all aspects of his affairs and daily life (e.g. medication and medical appointments, arranging transportation, managing his finances, bills and other paperwork).
- Specialist input from the Integrated Respiratory Team (IRT) at King's College Hospital, from a team of physiotherapists, respiratory nurses and he sees a Respiratory Consultant for regular reviews. Referred to a psychologist at KCH for support with anxiety and low mood in the context of his COPD.

Challenges - complexity, staff knowledge and awareness

- Admitted as an inpatient on several occasions, and has many appointments and contacts with other health care professionals (smoking cessation, psychiatry, GP, respiratory and HIV consultants, physiotherapists etc).
- Most interactions are positive, but there have been several occasions where miscommunication led to considerable distress for the patient and his partner.
- The patient often reported feeling overwhelmed by the complexity of his needs and the sheer number of appointments, clinicians, interventions and medications involved in his care. He also reported feeling "unheard" or confused about how an appointment had gone, and that his mental health needs, literacy and attentional difficulties had not been considered in the interaction. There were also occasions where he wished for Mr Y to be present to support him with a conversation and this was not arranged or respected.

What worked - reasonable adjustments and integrated care

- ***Sharing information –*** *S*hared information about patients complex needs and care across systems to ensure his needs are fully understood and easily accessible to people who might be working with him in a range of contexts (e.g. GP records, EPR, EPJS and PIMS)

- ***Questions surrounding medication*** – Patient was on a number of psychotropic medications, and he was not aware of why or how long he had been on all of these. The psychologist worked with a Consultant Psychiatrist from 3DLC to review Mr X's mental health needs and his existing psychotropic medication.

- **In clinical sessions** – Partner was encouraged to attend both physiotherapy and psychology session. Information was communicated in smaller chunks whilst checking back for his understanding, videos rather than written materials were used to provide information, audio recordings were made about important things to help him to remember.

But by looking at the experiences of some of our patients, we know there are areas of exceptional practice across the system (3 of 3)

Project: Physical Health Assertive Outreach for Adults with Learning Disability, Mental Illness and Behaviours That Challenge - SLaM

Background

Community nurses identified that service users accessing the specialist mental health in learning disability (MHLD) community team at SLaM had poor access to primary care annual physical health checks. This was impacting mental health recovery. Nurses, taking in to account reasonable adjustments, set up a person-centred assertive outreach physical health clinic. The Clinic engaged this client group, their family and carers to individually tailor assessment and interventions.

Implementation

The Clinic completed 33 physical assessments between November 2018 and March 2019, leading to:

- Increased engagement with patients and family/carers
- Several reasonable adjustments including development of an accessible appointment template, a physical health assessment tool and a physical health information pack to support patients to understand and communicate their physical health needs during assessments
- A vital signs automated machine was made available for patients who may not tolerate close body contact by the health professional
- Sexual health issues were identified by SHRINE as a particular problem area and extra training was provided for community nurses.

Outcomes

- Detection of multiple health needs, such as blood in stools and constipation which impact upon improved quality of life, experience of health services and reducing health inequalities
- Patients who previously found clinics highly distressing engaged with the physical health assertive outreach group. For example, some service users previously refused physical health checks and sometimes displayed violent behaviour. One carer commented on this being a '*break through achievement*' and hopefully a building block to improved access to health services and the community
- Nurses reported feeling more confident and skilled in providing physical health checks and skills were maintained over time
- Improved relationships and communication between the project and primary care.

Next Steps

- A Quality Improvement method is being used to evaluate the Clinic using PDSA cycles to test and implement change
- A database is being maintained of all attendance and non-attendance and what health issues are being identified as a resource to identify themes; guiding improved and targeted clinical practice.
- The quality of Community Health Care plans from the physical health clinic will be compared to those completed by other means
- An evaluation will be shared with service users, their family and carers, and amongst local health and learning disability services and the Trust to share and embed learning
- The team are awaiting the outcome of a Nursing Times Award for which they were nominated for the Learning Disabilities Nursing category.

So where are we now, and where do we want to be…

Areas of good practice	Areas for Improvement
Dedicated resources are available across KHP and we have many examples of outstanding practice, for example in dental services at both GST and KCH.	…however the LD workforce is declining and there are shortages in specialist roles, such as LD specific psychiatry, where there is less uptake of trainees. In addition, there is a lack of wider trust understanding and confidence in meeting LD patients needs.
Good links already exist with service user groups and third sector organisations such as Mencap and we have good access to contacts via the involvement register.	… however additional workarounds need to take place to ensure meaningful engagement with patients and their families/carers. Ensuring resources are available to engage across the system is not always a key priority for everyone.
Across KHP, we have strong involvement in national programmes such as LeDeR and the Capital Nursing Programme and there are many opportunities for national influence and specialist IoPPN research.	… however national pilot funding isn't sustainable and funding flows do not always support national priorities. Requests for responses to national incidents can counter local population improvements as a whole.
KHP has valued membership across acute, community, mental health and academic organisations which is of great benefit to our LD patients and there are many LD service improvement initiatives already taking place.	... however we need to share data on LD patients across primary care and link with health check targets/early identifiers. Local research tends to have a complex rather than population/practice based focus and we need to attract more local funding for research.
Through e-noting, GST staff can access KCH and SLaM records for staff training.	…however not all internal and external IT systems are compatible and flagging systems need to be improved. Data collection needs to be standardised across organisations.
Good opportunities for research across the partnership…	… however we need to ensure that research has a population-based clinical-academic focus on the needs of patients with LD.

…How KHP is uniquely positioned to deliver a strategy that goes beyond delivery of one individual partner organisation

- Greater access into research at the Institute of Psychiatry, Psychology and Neurosciences (IoPPN)
- Focus on innovation and new models of care
- Expertise around co-design and co-delivery of education and training for health and social care staff together with service users and families
- Better able to represent learning disabilities across South East London as a collective rather than as individual Trusts
- Sharing best practice and expertise
- Ability to network across our organisations
- Addressing the mental health and physical health of people with learning disabilities and autism

…And how can a joint KHP strategy help us?

As a partnership, we are able to share our expertise and resources to support work which is of value to each of the partners but also helps to go beyond what any one partner can achieve alone.

Given where we are and some of our challenges, we have identified our key priorities. Through delivery of the King's Health Partners Learning Disability strategy, we aim to improve health outcomes and experience for our local learning disability population through:

1. Ensuring person-centred care & improved involvement with people with learning disabilities and their families and carers
2. Improving the consistency of our pathways across primary, community and secondary care
3. Focussing on workforce development across all partners, and sharing expertise
4. Development of a single dataset for everyone with learning disabilities living locally
5. A commitment to population-based clinical-academic research focussed on the needs of those with learning disabilities

- We will take a phased approach to implementation with phase 1 focussing on people living with learning disabilities over the age of 18, including children and young people-adult transition
- Whilst the strategy does not focus on autism specifically, the needs of people living with learning disabilities and autism will be addressed through this strategy

Our 5 key priority areas

1. Person-centred care & User Involvement	2. Consistency of Pathways	3. Workforce	4. Single LD dataset	5. Quality Improvement and Research
• Make information more accessible • Raise the profile of learning disabilities services (with support from local MPs) • Streamline the hospital passport • Gain more feedback from patients and carers about their experience of care • Identify health and social care needs of carers early and ensure they feel well equipped to provide care • Engage with the voluntary and community sector and local colleges	• Improve communication and handover between primary and secondary care • Review partnership offer/thresholds • Make reasonable adjustments to improve access and uptake of assessment and treatment • Use flagging systems and share information across all hospital services (beyond emergency departments) • Timely planning for child to adult transitions • Improve inter-professional direct clinical care • More signposting to voluntary and community services	• Improve our retention schemes across the partnership • Attract more nursing associates • Consider shortages of learning disability specialisms when planning for future workforce demands • Improve the education and training offer using a tiered approach /make it everybody's business • Improve recruitment processes i.e. more LD representation on panels • Develop LD Champion roles and create structured JDs • More support for workforce with learning disabilities • Greater resourcing for MTDs	• Link into STP data including social care • Develop a joint Risk Register • Improve use of the Dynamic Risk Register • Agree outcomes and measurements for improvement • Standardise data collection process • Develop a joint return for NHSI Benchmarking	• Through Quality Improvement approaches, improve frontline care • Learn from best practice in areas of excellence • Increase funding for and profile of research and quality improvement to address LD needs across all settings including mainstream • More practice-based research – develop a framework or guidance • Map all existing work

- See our 1-2-3 year deliverables as outlined in the implementation plan (NB. In development)

The KHP Learning Disabilities Strategy is aligned with wider system ambitions

- *NHS Long Term Plan:* 75% target for health checks in primary care, expand Stopping over medication of people with a learning disability autism or both (STOMP), continue to fund the Learning Disabilities Mortality Review Programme (LeDeR), By 2023/24, a 'digital flag' in the patient record will ensure staff know a patient has a learning disability or autism;

- *Beyond the High Fence: G*uidance for commissioners, local authorities and forensic services - funded support for bridging, transition and after discharge, less restraint in prison and hospitals, importance of community support to enable people with learning disabilities to stay out of hospital, good communication around discharge planning;

- *Death by indifference: Following up the Treat me right report* – safeguarding concerns, recognising distress cues, professional v's patient's opinion of their own quality of life, more proactive intervention and assessments, issues around consent and capacity, professional requirement to ask for help, dangers of delaying or deferring action, simplify complaints procedures;

- *South East London LD and Autism Programme (formally Transforming Care Partnership)* - reduce long term inpatient care, improve quality of life and/ or care, enable community living;

- *King's Health Partners 5 Year Strategy (currently in development)* – proposed priorities include Population Health, Outcomes and Workforce Sustainability; and

- *Any interdependent trust strategies* – Guy's and St Thomas' Learning Disability Strategy, SLaM Physical Health Strategy, SLaM's Reducing Restrictive Practice' Strategy and GST and KCH Mental Health Strategies.

NHS Long Term Plan; Beyond the High Fence, 2019; South East London Transforming Care Partnership 2018-19:

How we will know if the strategy has been successful:

Based on national priorities and what people have told us locally, we want to see improvements in patient care delivery and improved service/system delivery in the following areas:

- Improved patient (and family/carer) experience
- Improved care planning approach
- LeDeR measures including cancer, constipation, respiratory, sepsis, medication and DNACPR & cause of death
- STOMP measures including regular reviews, less inappropriate prescribing and reduction in side effects of psychotropic medication (weight, tiredness, serious physical health problems)
- Reducing Restrictive Practices
- Greater confidence and enhanced skills amongst our workforce (including greater understanding of the Mental Capacity Act)
- Greater sharing of Annual Health Check data from Primary Care
- More patients owning a Learning Disability Passport (greater consistency across the system)
- Reduction in ED attendances
- Reduction in inpatient admissions and reduced length of stay
- Start to routinely screen LD patients in line with the Vital 5 outcome measures, through the Improving Mental and Physical Health, Research, Training and Services (IMARTS) programme:
  - BMI/weight
  - Blood Pressure
  - Alcohol intake
  - Smoking
  - Mental Health: anxiety and depression