

<b>Health and Adults Scrutiny Sub-Committee</b>  Thursday 29 <sup>th</sup> April 2021	 <b>TOWER HAMLETS</b>
<b>Report of</b> Denise Radley, Corporate Director of Health Adults and Community	<b>Classification:</b> Unrestricted
<b>Adults Learning Disability Health Scrutiny Challenge Session Report</b>	

<b>Originating Officer(s)</b>	Jamal Uddin, Strategy & Policy Officer and Matthew Richardson, Integrated Learning Disability Commissioner
<b>Wards affected</b>	All wards

### Summary

A Health scrutiny challenge session took place on the 10<sup>th</sup> March 2020 reviewing “How health and social care is supporting adults with a learning disability to live independent lives in Tower Hamlets”. This scrutiny session focused on three main areas of the Learning Disability Strategy: Health, Accommodation and Employment. The challenge session report was compiled providing documentation of the sessions and including recommendations to be actioned upon, however sign-off of the report was delayed due to the outbreak of the Covid-19 pandemic in the UK.

Due to the profound impact the pandemic has had on the country, this report has been updated against the 10 March 2020 position and includes an impact assessment of the pandemic for the learning disability population.

Following discussions on this at the 8 February 2021 meeting, a number of new recommendations have been added to the final report.

### Recommendations:

The Health and Adults Scrutiny Sub-Committee is recommended to:

1. To note the report which covers the spotlight session held on 10 March 2020 and following scrutiny meeting held on 8 February 2021.
2. To note the final report and recommendations
3. Agree to delegate decision-making on any final minor amends or additions to this report to the chair of the sub-committee.

## **1 REASONS FOR THE DECISIONS**

- 1.1 This is a final report which includes the scrutiny challenge session held in March 2020 and - following the outbreak of the Covid-19 pandemic - considers the impact the pandemic has had on the learning disability population. As the original report was not signed off in 2020 the committee heard the findings of the spotlight session and expanded the report and built upon the recommendations from the initial challenge session to conclude a final report.
- 1.2 The updated report was discussed at the Health & Adults Scrutiny sub-committee meeting held on 8 February 2021 and several new recommendations have been considered by the sub-committee.

## **2 ALTERNATIVE OPTIONS**

- 2.1 Not Applicable

## **3 DETAILS OF THE REPORT**

- 3.1 Refer to attached report for details.

## **4 EQUALITIES IMPLICATIONS**

- 4.1 People with learning disability face a number of inequalities across the system from health to employment. Individuals experience a higher than average prevalence of a range of health conditions and have a much lower life expectancy than the general population. These inequalities are the result of the interaction of several factors including increased rates of exposure to common 'social determinants' of poorer health (e.g. poverty, social exclusion), experience of overt discrimination and barriers in accessing services.
- 4.2 Proposals in this report aim to improve the health and social care provisions for people with a learning disability with particular focus on improving the population's health, access to employment and increasing the range of accommodation options in Tower Hamlets.

## **5 COMMENTS OF THE CHIEF FINANCE OFFICER**

- 5.1 The Adult Learning Disability Strategy, supporting action plan and market position statement will need to be within the Council's medium-term financial strategy (MTFS) and the CCG's financial plan budgets.
- 5.2 The HAC Directorates 2020-21 budget for Learning Disability Services is £28.453m, representing 20% of the current total HAC directorate revenue

budget of £142.333m. At period 9 of the current financial year, The Learning Disability Budget was forecast to overspend by £2.420m (£30.873m forecast outturn position against the budget of £28.453m). Representing 64% of the overall projected forecast variance at period 9 (£3.758m projected at period 9 for the HAC directorate in total), the Adult Learning Disability Services are facing increasing packages of care, particularly in the 65+ age category, and increasing costs of packages being delivered, as clients' needs are increasing. The long-term needs on care arising from long-term covid, are yet to be factored into projections.

- 5.3 The progression of further work on the Learning Disability Strategy action plan and market position statement will endeavor to identify cost avoidance measures that can be introduced to alleviate the pressures being faced on the HAC directorate budgets.

## **6 COMMENTS OF LEGAL SERVICES**

- 6.1 Part 1 of the Care Act 2014 imposes a number of duties on local authorities in respect of provision of support for individuals, preventing or reducing the needs of individuals for care and support, and promoting an individual's well-being in relation to accommodation, health, and employment. The proposals set out in this report comply with the above legislation.

### **Linked Reports, Appendices and Background Documents**

#### **Linked Report**

- NONE

#### **Appendices**

- Appendix 1 - Health Scrutiny Challenge Session report - 10 March 2020

#### **Background Documents – Local Authorities (Executive Arrangements) (Access to Information) (England) Regulations 2012**

- NONE

#### **Officer contact details for documents:**

Or state N/A



**How is health and social care  
supporting adults with learning  
disability to live independent lives in  
Tower Hamlets?**

**Health Scrutiny Challenge Session with progress  
updates from December 2020 including impact of Covid-19**

**10 March 2020 & 8 February 2021**

## **Foreword (March 2020)**

Supporting people with learning disabilities to live independent lives is a high priority in Tower Hamlets. There is a real focus on improving better outcomes for people with learning disabilities and we are seeing an upward trend in many areas. I am particularly pleased to see priorities and aspirations that reflect the needs of the local learning disability population set out in the first ever Adults Learning Disability Strategy 2017-20.

In the context of a growing population and challenges associated with comorbidity and complex health needs, the sub-committee took part in a challenge session to examine how services in Tower Hamlets are supporting adults with learning disabilities to live independent and meaningful lives. The focus of the scrutiny challenge session was to assess how services are meeting health and wellbeing needs of adults with learning disabilities; how they are being supported into paid employment; and how they are being supported to live locally amongst family and friends.

I hope the findings and recommendations will support the strategic planning for adults with a learning disability, including any future strategy refreshes.



**Councillor Kahar Chowdhury**  
**Chair of Health and Adults Scrutiny sub-committee, 2018-2020**

## **Foreword (April 2021)**

The report covers two sessions: a spotlight session held on 10 March 2020 and a further session held on 8 February 2021. Given that the original spotlight session was held at the beginning of March 2020 at the onset of the Covid-19 pandemic, by the time the report was presented to the committee on 8 February 2021 the landscape had substantially changed. The committee recognise the level of work and dedication Tower Hamlets Council Staff have maintained during the crisis and this report notes the work undertaken by a number of teams and hopes to offer a timely response to the Adults Learning Disability Health Scrutiny Challenge Session Report.

As a committee we believed we could not sign off a report that was so out of time and did not address the effects of the Covid-19 pandemic. It seems that many changes have taken place with the directorate as a result of Covid-19 and the transformation of services. The changes to services and staff were outside of the

original scope of this report. However, the committee have concerns around mortality numbers and would ask that the council consider reviewing the provision and support on offer to people with learning disabilities living at home so as to get the right care to people at the right place.

The committee is concerned by the high mortality rate during Covid-19. It is of the upmost importance that any future adults' learning disability strategic/action plans should have a key set of performance measures to be published and reported to the sub-committee every six months.



**Councillor Gabriela Salva-Macallan**  
**Chair of Health and Adults Scrutiny sub-committee, September 2020 – to date**



**Councillor Mohammed Pappu**  
**Vice Chair of Health and Adults Scrutiny sub-committee, September 2020 – to date**

## **Introduction:**

People with disabilities have the same rights and needs as everyone else. The government and many organisations have introduced a number of initiatives and strategies that have aimed to improve the lives of people with learning disabilities through improved support, services, and advocacy. The white paper 'Valuing People' (2001) and 'Valuing People Now Strategy' (2008) are two such examples of this.

Since the Human Right Act 1998 became law in 2000, the rights of children and vulnerable adults in particular have been bolstered by the added legal effect the Act. For instance, human rights are at the very core of 'person-centred planning in health and care services, which aims to give people with learning disabilities the right to be treated and live life with the same rights, choices and opportunities as anybody else.

## **What are Learning Disabilities and support needs arising from this?**

Valuing People (2001) defines a learning disability as the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills (significantly impaired intelligence).
- A reduced ability to cope independently (significantly impaired social functioning); which started before adulthood (before the age of 18), with a lasting effect on development

People with learning disabilities do not learn certain skills as quickly as other people and may therefore need extra support in certain aspects of their lives. The specific skills in question will depend upon the type of disability. People with mild learning disabilities may live alone, travel independently, and work. They may not require any support from their local authority or may just need support in managing their finances.

Other people may require more regular support to ensure their safety and health on a daily basis. Those with more severe or complex needs may need extensive, hour-to-hour help in performing basic skills, such as eating, dressing, and washing.

With the right support people can live full and meaningful lives. However, if this support is not provided, they may face problems in gaining independence or a home of their own, in accessing leisure and recreation activities, and/or in developing friendships and relationships.

Tower Hamlets Council and its health partners are responsible for commissioning and delivering appropriate care, support, and assistance to people with learning disabilities that live in the borough. This is based on eligibility and the council is committed to enabling people with learning disabilities and learning difficulties to maintain their independence at home and in the community, with services ranging from giving advice and information through to long-term residential care.

## **Purpose of report:**

In 2020 the Health and Adults Scrutiny sub-committee felt that, based on service level information and targets related to adult learning disabilities presented to the committee in January 2019, that outcomes for adults with learning disabilities needed to improve faster. The committees' conclusion is in light of a growing population, and people having greater needs with more mental health issues and communication difficulties.

In the context of increasing demands on services and complex health needs the sub-committee agreed 'to examine how services in Tower Hamlets are supporting adults with Learning Disabilities (LD) to live independent lives and prevent people going into hospital, needing long-term support and high intensity social care intervention'.

### Areas for investigation in 2020:

The Chair of the committee is aware that Learning Disability Strategy 2017-20 came to an end in October 2020. This is a joint strategy with the Tower Hamlets Clinical Commissioning Group (TH CCG) and agreed by the Health and Wellbeing Board. The joint commissioning team is currently considering refreshing future strategic plans for people with learning disabilities.

In early 2020, the sub-committee was interested in investigating the extent to which better outcomes were being delivered for adults with a learning disability in the following three areas, which are priorities in the current Learning Disability Strategy:

1. Physical health management of adults with LD.
2. Adults with LD are supported into paid employment.
3. Adults with LD are supported to live locally.

These areas are the main focus of the report, and an initial challenge session and report into the key areas of focus was produced in March 2020.

### Areas for investigation in 2021:

The committee were interested in revisiting these three areas – physical health management, employment and accommodation for adults with a learning disability – in light of the Covid-19 pandemic, recognising that the pandemic has impacted on every aspect of life and therefore the priorities to be focused on. As a result, each section of the report that describes the findings of the committee has a 'December 2020 update' and a number of new recommendations have been added.

## **National and Local Context**

### The number of people with a learning disability

There are approximately 1.2million people in the UK with a learning disability. Comprehensive national data on the number of people with learning disabilities across the lifespan in England is unavailable. It is estimated by Public Health England that in England in 2011 1,191,000 people have a learning disability. This includes 905,000 adults aged 18+ (530,000 men and 375,000 women)<sup>1</sup>.

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<sup>1</sup> People with Learning Disabilities in England 2011



In March 2020 it was reported Tower Hamlets has around 1359 people (0.4% of the population) registered to have a learning disability with their GP. Public Health England estimates that 7,413 people (2.17% of the population) have a learning disability (based on national projections) of which 4,848 people are aged 18 and over. This group of people will experience poorer life outcomes than the general population, including for physical health, mental health, employment, and life expectancy.

### Life expectancy and health

According to Learning Disabilities Factsheet 2016 (JSNA), on average people with learning disabilities have poorer health and die younger. In part this is because they are more exposed to causes of ill health through greater levels of material deprivation, poorer health related behaviours and physical conditions often associated with causes of learning disabilities. It is also partly as a result of poorer understanding of physical changes and problems that indicate illnesses or conditions that could be treated and of how to get help from health services<sup>2</sup>. This means that many people with learning disabilities have health problems for which they do not seek help. In addition, some people with learning disabilities with specific genetic or chromosomal syndromes are subject to age related health risks, e.g. Downs Syndrome and an increased risk of early dementia of the Alzheimer's type.

People with learning disabilities experience higher than average prevalence of a range of health conditions, most notably diabetes, asthma, epilepsy, and stroke. The prevalence of mental health problems in people with learning disabilities is considerably higher than the general population. In addition to mental illness, people with learning disabilities often have coexisting autistic spectrum disorders, behaviours that challenge services, offending behaviour, or physical health conditions. It is often hard to distinguish between these conditions especially when people have more severe intellectual impairments.

People with learning disabilities also have a high prevalence of dementia even when specific at-risk groups such as people with Downs Syndrome are excluded. It can be difficult to distinguish between mental health and other conditions particularly among people with more severe intellectual impairments<sup>3</sup>. This can be further complicated by problems with communication of feelings, poor detection, misdiagnosis, and the effects of medication.

### Care and accommodation

Following Winterbourne View, there has been a significant drive in national health and social care policy to improve outcomes for this group of people, with a particular focus on those who have behaviour which can be challenging for services. The Transforming Care programme<sup>4</sup> is focused on addressing the specific needs and inequalities they face.

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<sup>2</sup> Kenney A, Turner S, Glover G & Hatton C (March 2014) Making reasonable adjustments to primary care services – supporting the implementation of annual health checks for people with learning disabilities London: Public Health England

<sup>3</sup> Joint Commissioning Panel for Mental Health (May 2013) Mental health services for people with learning disabilities

<sup>4</sup> NHS national plan, Building the Right Support, published in October 2015 sets out what commissioners are doing to make sure this change happens.

## Covid-19 Update

Since the March challenge session the Covid-19 pandemic has affected every aspect of life. This impact can be summarised as follows, and is described in more detail in the remainder of the report:

The clearest impact of Covid-19 is in the infection and mortality rate in Tower Hamlets. A national report published in November 2020 indicates that the death rate for people with learning disabilities from Covid-19 was at least 4 times higher than the general population<sup>5</sup>. The higher prevalence of physical health problems, such as diabetes, in adults with a learning disability is thought to be a key contributing factor to this. The LeDeR Covid-19 Report found that 4% of the learning disability Covid-19 deaths were in adults aged 85+, compared to the national average of 47% further indicating the mortality inequality faced by the population. The report further noted concerns around shielding and care homes which could affect the population.

The pandemic is likely causing significant indirect physical health impacts too. Disruption to 'business as usual' health and care services will have impacted people with a learning disability. Adults with Down's syndrome are considered Clinically Extremely Vulnerable to Covid-19 and were advised to 'shield' during lockdown, potentially at a greater risk of worsening physical and mental health as a result of stricter social distancing guidelines. Meanwhile, the wider determinants of physical and mental health (e.g. employment levels) are changing. There is a risk that health inequalities in the borough – already faced by adults with a learning disability in a number of areas - will increase and that many will be living in poorer health. This is likely to be a national trend, but Tower Hamlets may be hit harder given our existing health inequalities.

A number of health and care services have been impacted by closures or reduced capacities and increased waiting times. While services adapt to offer online and virtual appointments, this can be challenging for some individuals who experience digital poverty, may be unable to interact or even access online appointments, or may not wish to attend in person due to the risk of catching the virus in the community or on public transport.

We know that people have been reporting negative impacts on their mental health and wellbeing as a result of the pandemic and lockdown. This includes stress, anxiety and social isolation. Some will have experienced traumatic events or changes in their lives from Covid-19 which mean they now need support with their mental health. Adults with a learning disability may have experienced additional stress, worry or social isolation as a result of shielding, concerns and visitor restrictions to care homes or disruption to routines such as attending day services in social care.

Changes to the economy and the job market as a result of the pandemic has also impacted adults with a learning disability – particularly given that the hospitality sector in particular has been hard hit, and it is this sector that accounts for a large proportion of employment opportunities for the learning disability population.

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<sup>5</sup> <https://www.gov.uk/government/news/people-with-learning-disabilities-had-higher-death-rate-from-covid-19>

Overall, the pandemic has had a significant impact on the health, wellbeing and employment of adults with a learning disability and therefore the recommendations arising from this report are to be noted but the Committee feel that urgent action is needed so as to understand how to better support people with learning disability

## **The Approach**

The 'Living Well: Adults Learning Disability Strategy 2017-20' was the first ever strategy developed alongside other strategies and work programmes in Tower Hamlets to improve outcomes for adults with learning disability. The strategy was developed with the Learning Disability Partnership Board, reflects what adults with LD said was important to them and sets out a number of key actions for improving them. The strategy outlines six priorities:

- **Be happy and healthy.**
- **Live locally.**
- Be part of the community and be involved in activities.
- **Work or volunteer.**
- Have choice and the right support.
- Be respected and safe.

As previously noted, the chair of Health and Adults Scrutiny sub-committee agreed to examine three key priorities of the Adults Learning Disability Strategy 2017-20 and work programme to inform the future refresh of the strategy. These three are highlighted in bold above.

To effectively scrutinise the three areas identified in the scope of the review the sub-committee agreed to carry out challenge session(s). This would enable the group to carefully examine the work programme and performance related to the areas of investigation and inform the future strategic approach to supporting adults with a learning disability.

Table 1 (below) is a summary of the Tower Hamlets Adults Learning Disability priority action plan for 2019/20 focusing on the three areas the sub-committee identified for further investigation. Progress against these activities – as of March 2020 - was reviewed by the Sub-Committee ahead of the challenge session and the conclusion is that outcomes are not being met in a timely way.

A challenge session took place on 10 March 2020. A presentation was pulled together by joint commissioners of local health and social care which was used to develop Key Lines of Enquiry by Health and Adults Scrutiny sub-committee members to explore with participants at the challenge session.

The updated meeting on 8 February 2021 reviewed an updated report and agreed to update the report in light of the Covid-19 pandemic and due to officers' capacity the committee agreed not to widen the scope of the review. Updates – provided as of December 2020 and reviewed at the February meeting – are included throughout this report.

<b>Table 1: Summary of Tower Hamlets Adults Learning Disability priority action plan for 2019/20 (focusing on the three areas)</b>		
<b>LD Strategy</b>	<b>Priority actions for 2019/20</b>	<b>Key progress to date (March 2020)</b>
<b>Be happy and healthy</b>	<ul style="list-style-type: none"> <li>• Make sure Health Action Plans are implemented &amp; encourage people to have their cancer screening tests.</li> <li>• Promote healthy living messages to reduce obesity which has risen to 36%.</li> <li>• Complete the hospital passport business case development.</li> <li>• Increase the GP LD register by 473 patients to 1565, as NHSE require.</li> </ul>	<ul style="list-style-type: none"> <li>• Primary and Secondary Care have increased the Learning Disability GP register by over 200 individuals. Partnership between Children's and Adults services will aim to further increase this by 240+ and develop a transitions pathway and guidance so that annually ~50 individuals are identified.</li> <li>• The Learning Disability Mortality Review outlined recommendations for Health and Social Care. It found that: 1) the annual health check requires improvement and increased uptake across the borough, 2) Staff need better understanding and training on Mental Capacity assessments, 3) All staff need better awareness and understanding of learning disability and, 4) Organisations and partners need to provide better interagency collaboration and communication.</li> <li>• The programme also has a lack of trained reviewers with the majority being placed with the Community Learning Disability Team. Other providers such as Barts Health should aim to increase their reviewer pool across the system.</li> </ul>
<b>Live locally</b>	<ul style="list-style-type: none"> <li>• Continue to assess people out of borough and arrange moves into in borough accommodation (target of 59 returns).</li> <li>• Ensure people progress along the accommodation pathway to independence and the quota of 20 units per annum agreed with Lettings is utilised.</li> </ul>	<p>A four-year programme to reduce the number of out-of-borough placements and bring individuals back into borough is underway. This will increase the number of adults with a learning disability further impacting upon health services with additional individuals requiring annual health checks and presenting with challenging behaviour and high needs.</p>

	<ul style="list-style-type: none"> <li>• Finalise, agree, and implement plans to create additional in borough accommodation, including in the upstairs of Sewardstone Road.</li> <li>• Ensure Shared Lives starts to offer long term and overnight placements.</li> </ul>	
<b>Working and volunteering</b>	<ul style="list-style-type: none"> <li>• Continue to identify and support people to start skills development &amp; employment support; the target for each is 55 new people per annum.</li> <li>• Encourage more employers to offer jobs to people so they have choice. Focus on encouraging people with long term social care support into employment so 11% are employed by October 2020.</li> </ul>	<ul style="list-style-type: none"> <li>• Preliminary figures indicate that the percentage of people with a learning disability in long term social care who have secured paid employment during 19-20, is currently at 9.2% (end of quarter 3), this is an increase of 3.3% since 2017. We aim to increase this to 11% by the end of this financial year.</li> </ul>

## **Attendance at the Challenge session – 10 March 2020**

### Health and Adults Scrutiny committee members:

- Chair, Cllr Kahar Chowdhury (Chair)
- Cllr Marc Francis
- Cllr Denise Jones
- Sue Kenten (co-optee)
- David Burbidge (co-optee)
- Cllr Amina Ali (Lead Member for Health and Wellbeing)

## **Attendance at the follow-up report session – 8 February 2021**

### Health and Adults Scrutiny committee members:

- Chair, Cllr Gabriela Salva-Macallan (Chair)
- Cllr Kahar Chowdhury (former chair)
- Cllr Mohammed Pappu (Vice Chair)
- Cllr Denise Jones
- Cllr Andrew Wood
- David Burbidge (co-optee)
- Sue Kenten (co-optee)

### Service providers and stakeholders:

- Carrie Kilpatrick, Deputy Director of Mental Health & Joint Commissioning
- Diane Barnhardt, Senior Joint Commissioning Manager LD, and Autism
- Claudia Brown, Divisional Director of Adults Social Care
- Richard Baldwin, Divisional Director of Children's Social Care
- Mary Marcus, Service Manager of Community Learning Disability Service
- Sarah Murphy, Joint Strategic Safeguarding Lead
- Dr Jason Crabtree, (Consultant Clinician, Tower Hamlets Community Learning Disability Service (CLDS))
- Matthew Richardson, Integrated Learning Disability Commissioner
- Francis Paul, Support worker Create day centre
- Richard Fullerton (service user- Create day centre)
- Andros Attoungatre (service user- Create day centre)
- Jack Kerr, Strategy & Policy Manager
- Jamal Uddin, Strategy & Policy Officer

## Findings

### 1. How are services addressing physical health management of adults with learning disability?

#### 1.1. Identification and diagnosis

Public Health England (PHE) estimates that 7,413 people 2.17% of the population have an LD of which 4,848 are aged 18 and above. But there are currently 1,359 people (0.4% of the population) with LD in Tower Hamlets that are registered on GP registers. The NHS England Operating Plan target is 1,593 and this is a mandatory target.

Local Authorities across London are in a similar situation to Tower Hamlets, despite the improvement and increases to the Tower Hamlets Learning Disability GP register size by 200+ in the last year, the borough population still underrepresents the estimated prevalence with a gap of approximately 234 individuals over the age of 14.



Based on the presentation from joint commissioners, this is a gap in the 14- 17 age group. There are a number of reasons for this: there are many families and young people who are registered with a GP outside of the borough; registration of learning disability is voluntary for people under the age of 18; and it's important to note that diagnosis can change as people get older.

As far as possible, identification of 'potential' learning disabled individuals has been done, but there is no clear process to formalise this in order for earlier, appropriate transition planning to start. This is a key gap in the SEND action plan. Further work to align SEND, Children and Adult Services is required to improve representation of people with an LD and performance in this area. A collective response and agreement in regard to process and pathways is needed across the partnership.

A transitions taskforce inclusive of children's and adults social care teams as well as paediatricians and education services should ensure identification and diagnosis can be made earlier and ensure clear pathways are put in place whereby appropriate transition to adult's services are planned earlier.

## December 2020 Progress Update

Efforts to continue identifying individuals with a learning disability continue as the GP register sizes counts 1,435 individuals at present, an increase of just under 300 individuals within 18 months with increases in both adults and children populations.

A strategy to address the under-representation of children and young people, addressing recommendation 1, was agreed by the SEND Board in September 2020. This proposal outlined a series of actions to be undertaken to ensure identification was improved. Actions include the development of an identification process of young people with a learning disability to enable coding on the GP learning disability register. This work is being taken forward by the 'Preparing for Adulthood Transitions Group' improving the alignment and further enhancing the collaboration between Adult and Children's Services for transitions.

**Recommendation 1 (from 10 March):** Joint working between SEND, Children's and health services should aim to address the under representation of 14 -17-year olds on the learning disability primary care registers. This will ensure more effective coverage of primary care health checks for this group.

**Recommendation 2 (from 10 March):** The issue of effective transition planning is addressed through the new LD strategy and joined up with the Children and Families Strategy and CAMHS Transformation Plan.

Based on statistical diagnosis, it was also suggested at the challenge session that many adults with mild learning disabilities or learning difficulties do not need learning disability interventions because health services can meet their needs effectively. This could free up resources to support people with more complex needs.

However, service experience also indicates that often without proper intervention in place earlier in a persons' life, it could result in developing dependency of LD services and requirement of intensive intervention in later life. This presents a strong argument to identify and diagnose people with LD and work with health provision to ensure that LD needs are being met effectively.

### **1.2. Mortality review**

The Learning Disability Mortality Review (LeDeR) started in 2016. Since then, 30 individuals with a learning disability have died and 26 of those have had a review completed. In comparison to other local authorities Tower Hamlets has carried out more reviews which shows a commitment to learning and improving services.

The sub-committee felt that the recommendations from LeDeR is evidence-based and reflects learning from Safeguarding Adults Reviews (SARs) that involve people with a learning disability who have died in Tower Hamlets. The sub-committee felt that services including primary care can take more actions to embed the learning from SARs and apply this learning into practice. Services must give reasonable consideration to how these issues are resolved in order to improve outcomes and patient experience.



## **December 2020 – Learning from Covid-19 Deaths**

Tower Hamlets continues to support the LeDeR programme. Unfortunately, in 2020, 14 individuals have so far died. Of these 14, seven individuals died with confirmed Covid-19, five since December 2020.

Since the beginning of the Covid-19 pandemic, two individuals died in Quarter 1 of 2020; one man and a woman who were both from a white ethnic background and over 80 years old. Learning from the reviews of these deaths in Tower Hamlets, and 30+ other Covid-19 deaths across NEL, highlights the importance of using appropriate infection control procedures and usage of PPE across accommodation settings which accounted for 75% of where the individuals who died lived.

The 'NEL Rapid Review Analysis' highlighted good practice including how the majority of individuals made use of a hospital passport and even coordinate my care, ensuring that key details about the person and their needs could be communicated to the clinical team. The report further remarks that for individuals on an End-of-life pathway, care continued to be coordinated well with regular check-up's conducted during the pandemic. Where individuals were suspected to have covid-19, they were recorded as having had personal plans in place to manage their self-isolation and provided with 1-1 support.

Following the initial outbreak of the Covid-19 pandemic in the UK, the learning disability population and services appeared to have managed well with no new Covid-19 deaths until the more recent escalation of the virus in December 2020. Since the start of December 2020, five individuals have died with confirmed Covid-19, and while the reviews of these cases have not been completed, initial understanding of the individual situations would indicate a shift from the initial deaths in April. Of the five, all of them were not accessing services and live in family homes suggesting that services have robust procedures in place to reduce the spread and management of Covid-19 in services. All five were male and while the two individuals from a white ethnic background were aged 45 and 69, the three individuals from an Asian ethnic background were all under 26 years old showing a large disparity.

These recent deaths do however highlight concerns around possible lack of understanding and awareness of the risks posed by Covid-19 to individuals with a learning disability by family members as well as the appropriate usage of PPE during in-reach support.

### December 2020 Progress Update

The LeDeR programme has strengthened links with the Safeguarding Adults Review processes to ensure that the actions and recommendations from those cases have taken forward and addressed.

The North-East London 'first 100 deaths' report highlighted key learning and recommendations to take forward. A number of these are being addressed through existing projects including the improvements to Primary Care training and the annual health check process. A by-product of this work has been improvements in the transitions process of identifying children and young people with a learning disability. The Hospital Passport project brings together improvements in care co-ordination

alongside improved digital tools and access while incorporating them with end-of-life care through utilising Coordinate my Care. This work and the LeDeR programme is overseen by the Tower Hamlets Learning Disability Partnership Board Health Sub-Group and ensures engagement from all key partners.

There is still a need to increase the local pool of reviewers, further acknowledged from recommendation 5 below. This continues to be challenging for certain providers, especially during high staff-turnover periods but Tower Hamlets remains in a good position and the programme continues to perform well.

### **1.3. Health condition of people with an LD**

The sub-committee feels there is good work being done to raise awareness of learning disabilities across health structures and adults with an LD are encouraged to carry their LD hospital passports which will help staff in hospital settings make reasonable adjustments to support safe and effective care for people whilst also improving the patient experience. The introduction of electronic health passports will make it much simpler for people with LD to access services across the system. The number of people with a Health Action Plan (HAP) increased from 38% at March 2017 to 96% in March 2019.

However, there is a genuine concern that LD support is not understood by health practitioners and staff in hospitals and are not always able to make reasonable adjustments to people with an LD and often prioritise their primary health needs. There are also indications from Learning Disability Mortality Reviews (LeDeR) to suggest staff would benefit from training on Mental Capacity assessments.

**Recommendation 3 (from 10 March):** Joint commissioners for Learning Disability services and Safeguarding Adults Teams must ensure that SARs recommendations are actioned and monitored and facilitate how learning of SARs is applied and embedded into service/action plans.

**Recommendation 4:** Raising awareness of LD and Mental Capacity Assessments amongst health practitioners and staff is a positive initiative, but it needs to be better coordinated. A training programme implemented in all health settings would improve LD patient experience.

Analysis of GP registered data according to (JSNA LD factsheet 2016) by conditions shows an inequality (relatively higher prevalence) in health conditions of people with LD compared to general Tower Hamlets population. There are notable differences in health conditions such as diabetes, asthma, stroke, and mental health. LD patients have twice the rate of cancer prevalence and morbidly obese case rates are considerably higher.

According to LD data recorded by the Community Learning Disability Service (JSNA LD Factsheet 2016) adults with LD prevalence is higher amongst the Asian population, particularly the Bangladeshi community, and affects male and female relatively equally in the borough. This differs to GP registers which indicate that of those with an LD the split is more 60% for male and 40% for female which seems to be more in line with national estimates. The sub-committee was positive there are specific work

programmes in place to support LD clients manage the above-mentioned health conditions and are seeing some improvement on how health conditions such as asthma and diabetes are being managed. The sub-committee encourage service provision to continue making more tailored support arrangements to ensure health issues are appropriately managed.

The LD work programme has a lack of trained reviewers (related to LeDeR) with majority based in the Community Learning Disability Service.

There is a need for more trained reviewers' and funding for this would need to be further discussed.

### December 2020 Progress Update

In partnership with the North East-London Learning Disability and Autism programme, training and awareness sessions have been offered throughout the year on key areas relating to learning disability such as annual health checks, care and treatment reviews and positive behaviour support. These have been open to all health and social care staff in Tower Hamlets and have been well received. Learning disabilities link nurses within the Tower Hamlets Community Learning Disabilities Service and the Clinical Lead for Learning Disabilities for Tower Hamlets CCG have joined many of the GP networks at awareness raising and training event focused on the health needs and inequalities experienced by people with learning disabilities, particularly in the context of Covid-19. These sessions have also been linked with the NHS England Learning Disabilities Quality Improvement, Quality Outcomes Framework 2020/21.

Further training and improvement work is planned through the Learning Disability Quality Checker and Empowering Voices services (see below) which aims to provide insight from service users in regard to how services can improve their offer and accessibility.

Linked to a local incentive scheme to develop electronic health passports the over seen by the Alliance Board funding a project has been initiated to pilot the use of the Coordinate my Care (CMC) for this purpose. CMC was developed for individuals requiring end of life care an complex health needs and is an electronic health care plan that can be access by GPs, out of hours, GP services, 111, the London Ambulance Service and Accident and Emergency services. Work is in progress with the Coordinate my Care developer to develop he platform to make it more accessible for individuals with learning disabilities and promote its utilization as a health passport. Although at early stages it is hoped that the completion of CMC plans for people with learning disabilities in Tower Hamlets could be built into standard practice as part of Annual Health Check, initial assessments and annual reviews completed by CLDS.

In addition to pursuing longer term goals of electronic health passports, within the context of the Covid pandemic, significant work was undertaken by multiple partners including CLDS, the CCG and GP surgeries to raise awareness of hospital passports and brief Covid hospital passports and ensure that those individuals with the most complex health needs have at least one of these in place to support situations in which they may have required urgent hospital admission, without their usual carer network in place.

**Recommendation 5 (from 10 March):** To pursue providers such as Barts Health to offer a pool of reviewers to support the LeDeR programme.

The sub-committee is interested in further understanding how we support those people who show signs of LD but do not meet the initial CLDS threshold through assessment. This also relates to the partnership arrangements and strength of relationships between social care and health partners to ensure people with LD at all levels are supported the best way possible to avoid later dependency on services. Due to lack of time the sub-committee would like to include this as an important issue to be picked up by LD commissioners as part of ongoing strategic planning work.

**Recommendation 6 (from 8 Feb 2021):** Utilise online platforms and develop (electronic) health passports for people with learning disabilities in Tower Hamlets and build into standard practice as part of Annual Health Check, initial assessments and annual reviews completed by CLDS.

**Recommendation 7 (from 8 Feb 2021):** Ensure those with complex health needs have a (electronic) hospital health passport in place.

#### **1.4. Coproduction and user involvement**

The sub-committee was pleased that two service users, Richard Fullerton and Andros Attoungatre from Create day services were able to attend the challenge session in March 2020. Their presence signified the importance of effective co-production and service user involvement to shape service design and delivery of appropriate LD services. The sub-committee highlighted that it is important that service user engagement is integral in determining what is important for them in the development of future planning and strategies. The sub-committee encourages commissioners to hear the views of parents and carers, in particular to assess whether they feel engaged in the way support is organised for people with LD.

The commissioning team explained that there are plans to develop a programme of coproduction between health and care services and adults with a long-term disability by expanding scope of 'Empowering Voices service'. This will improve and co-produce more initiatives and project with people with a learning disability. The Quality Checker Service will also enable people with lived experience to quality assess services for accessibility and ability to meet the needs of these people.

It was noted that there is scope for CLDS to strengthen their links with Healthwatch Tower Hamlets an independent charity with a main statutory function to obtain views of local people about their needs and experience of local social care and health services.

#### **December 2020 Progress Update**

Despite the challenges of Covid-19, Empowering Voices and the Quality Checker services have already provided positive action in the borough. Empowering Voices have co-produced with a theatre company a new training offer for Primary Care, the service has taken a pivotal role in evaluating a series of learning disability procurement tender submissions and continues to hold virtual events for individuals to come

together and discuss any issues or concerns affecting the learning disability population.

Links have also been made with Tower Hamlets Healthwatch to ensure that views and opinions can be obtained and sought easily to further inform of improvements in the borough. The Quality Checker Service is scheduling their first set of service quality checks in January 2021 and will continue to provide support for services to become more accessible and offer adjustments and improvements to how services can become friendly and suitable environments for people with a learning disability.

### **1.5. Annual Health checks**

Annual health check figures for adults with an LD over the last three years indicate that uptake is improving and is exceeding NHS England annual targets of 75%. With an increasing learning disability population, Primary Care is required to conduct more and more annual health checks to continue to meet this target.

With the upcoming introduction of the 'Autism-specific Health Check' this could challenge primary care in delivering health checks for over 2,000 individuals with a diagnosis of autism.

#### December 2020 Progress Update

Primary Care has adapted during 2020 to ensure learning disability annual health checks can still be received. This has mainly been achieved through the identification and prioritisation of 'at-risk' individuals and providing a virtual offer to those not requiring to come into a practice.

There is some variability in terms of completion rates of annual health checks across Networks and surgeries for the year to date, CLDS link nurses are offering support to Networks and surgeries who appear to have lower numbers of checks completed to date. As in previous years the highest proportion of annual health checks are due to be completed in the final quarter of the year.

**Recommendation 8 (from 10 March):** Healthwatch and LD commissioners/LD services should work together more closely to obtain views of LD service users and enhance the repository of information which can help service improvement and monitoring.

There is extensive evidence to suggest that by providing 'learning disability friendly environments', it can help services implement reasonable adjustments and improve outcomes for people with LD. There is a commitment from adult social care to increase community provision, but the committee was not clear if there is partner commitment to increase 'LD friendly environments' particularly as some inpatient services are being decommissioned in favour of more community provision.

**Recommendation 9 (From 8 Feb 2021):** Given the variability of annual health check completion rates across network areas, more targeted support should be offered to networks where rates are low.

## 1.6. Health screening

Cancer is a leading cause of morbidity and mortality and a major contributor to health inequalities nationally and locally. Many cancers are considered preventable. Screening is the process of identifying people who appear healthy but may be at increased risk of a disease or condition.

The general uptake of Cancer (3 conditions) and obesity screening in Tower Hamlets is improving year on year, but performance is below national projections in majority of the areas. However, uptake remains a challenge for the learning disability population nationally.

	Tower Hamlets Learning Disability rate 2019	Tower Hamlets Learning Disability rate (2021 March)	England General Population Average 2019
Obesity Rate (18+)	38%	38%	10%
Bowel Cancer Screening Rate	22%	26%	60.5%
Breast Cancer Screening Rate	22%	21%	71%
Cervical Smear Test Rate	39%	33%	70.5%

### December 2020 Progress Update

The pandemic initially led to sharp decreases in the use of cancer screening tests across the UK. Screening programmes have since resumed, but the resulting delays for some people mean that it is really important that adults with a learning disability are encouraged and supported to access these programmes.

Two new initiatives are in progress to improve the uptake of both the Breast and Bowel Cancer Screening working with the Homerton Hospital and Royal Free Hospital screening teams. Plans aim to improve awareness of the screening process with families, carers, and users themselves through small meetings and discussions as well as offering opportunities for users to attend and become familiar with the screening equipment and staff teams.

## **Other health and wellbeing impacts arising from the Covid-19 pandemic – December 2020**

A number of health and care services have been impacted by closures or reduced capacities and increased waiting times. While services adapt to offer online and virtual appointments, this can be challenging for some individuals who experience digital poverty, may be unable to interact or even access online appointments, or may not wish to attend in person due to the risk of catching the virus in the community or on public transport.

*S “I have received good information from my GP, but I have only had one phone call in December from social services to check on me”*

### Physiotherapy

Prior to the pandemic, the CLDS physiotherapy team provided a number of services to the learning disability population. A number of interventions would regularly take place in specialised environments; hydrotherapy, rebound therapy, postural management, mobility rehabilitation, and also provide support through joint working with other health and social care services, voluntary sector providers.

Due to the ongoing impact of the pandemic and the effects of the lockdown, there has been a huge impact on the learning disability population. Mainstream services often draw up the expertise and knowledge of the CLDS to support challenging patients, however due to the pandemic this support has had to reduce often leaving individuals without adequate or sufficient support needed. Interventions such as hydrotherapy and rebound therapy have been placed on hold and joint working with social care services has stopped due to their closures. Active work inside patient homes has also reduced due to the high risk associated with the vulnerable population.

At present there are approximately 103 individuals on the waiting list with expected increase in referrals due to individuals' loss of function and mobility due to lockdown and a reduction in advice and guidance. The physiotherapy team has seen a 15% increase in referrals to the service and focus on functional abilities at home.

The physiotherapy team have adapted their delivery model in line with the C19 risks and lockdown restrictions. New referrals are triaged virtually and advice/guidance packs distributed out to help initial activity levels. Virtual assessments are taking place and an online physiotherapy exercise sessions have been developed, accessible for six weeks. A large number of the joint discipline work is being conducted virtually and improvements are being made with preventative pathways such as the transition physiotherapy team working closely with the paediatric team.

### Speech and Language support

Speech and Language support is another area which has been impacted by the pandemic. The lockdown restrictions has imposed barriers to completing communication assessments resulting in a delay in allocations and support being provided. As a full and appropriate communication assessments relies on a total communication approach including body language and facial expressions, the restrictions and requirements around PPE and safety precautions i.e wearing a face mask , has increase the difficulty in completing an assessment correctly. As a large

number of the learning disability population is unable to access telehealth, 25% of current cohort can access the tool, and virtual appointments this makes this aspect of the assessment harder and subsequently more time consuming.

With the closures of a number of other services including day centre activities and schools, the opportunity for the population to practice their communication with peers and staff has reduced therefore impacting on the individual's ability to develop communication and social skills.

### Day services

In response to the government lockdowns, a number of social care services closed including the numerous learning disability day services, resulting in a large number of individual's not receiving their usual support and accessing their daily activities in the community. The Covid-19 pandemic saw all day centres close in March 2020, and means that support has had to be provided in a different way. For adults with a learning disability who normally attend day centres and services, this will have impacted on people's daily structure, routine and social opportunities. Feedback is that there has also been a significant impact on the family carers of people with learning disabilities who have had limited opportunities to access care for their family members and the respite that this provides from their caring role leading to the increase possibility of carer fatigue, stress and burnout. Each of these factors in turn is likely to have influenced the well-being of people with learning disabilities.

Since this time, support has been provided to people in a very different way. Regular phonecalls, home visits are taking place where needed, and services are increasingly using digital technology to provide support and activities to people. In addition, in recognition of the potential increased strain being felt by carers as a result of their family members being home more often, accommodation-based respite is now being offered where possible and where needed, subject to the availability of Covid-19 testing. We are continuing to offer 'carer relief' home-based respite, and the Carers Emergency Service to provide urgent support to carers; and since December 2020 we have started providing respite and carer relief free of charge.

### Social isolation

*B "I get lonely."*

*S "The third lockdown is better than the first one. I really miss face-to-face contact"*

Changes to services and restrictions on gatherings further impacted the social isolation of this population as individual's remained at home, either by themselves or in family homes where families felt increased pressures having to care for these individuals with less support.

Social isolation of this population is likely exacerbated through the digital exclusion facing a number of individuals. As support and services move towards providing digital intervention and options, this can disproportionately affect the learning disability population due to increased likelihood of poverty and knowledge around digital access.

While the Empowering Voices Service and other day activities services have offered virtual sessions and in-reach support, the lack of prior infrastructure, understanding



and skills development for the learning disability population to access digital resources also restricted their ability to access these services. The limitations also impacts on individual's ability to socialise during the pandemic. Compared with the general population who made use of a number of digital tools to connect with their communities and families, people with a learning disability will often not have the equipment such as smart phones/computers to access such methods of communication.

In order to rectify this, the Empowering Voices Service procured digital technology to distribute to users to enable their continued interaction and access, and plans going forward to develop a learning disability social media and training/skills development programme is in scope.

S "I feel scared sometimes as I have a noisy neighbour, but the council has helped me feel more safe and that makes me feel as though my voice is respected"

### *Mental health and complex behaviour*

G "*I have good days and bad days; I don't get lonely because of the support I have from my carer*"

It is still too early to have a robust evidence base to draw on to determine the impact of the pandemic on the mental health and presence of complex behaviour amongst individuals with learning disabilities. There is a general suggestion that across the general population there has been an increase in reported feelings of depression, anxiety, worry, and loneliness<sup>6</sup>. With individuals with pre-existing depression, anxiety and obsessive compulsive disorders experiencing a detrimental impact upon their mental health in the context of the pandemic.

We know that individuals with learning disabilities and autism experience higher rates of mental health difficulties compared to the general population with prevalence rates of mental health difficulties reported to range between 25% and 40% amongst this population, compared to around 15% in the general population. Therefore it is not surprising that people with learning disabilities will have been more adversely impacted in terms of the mental health. Further to this we know that people with learning disabilities are more likely to have grown-up in and have been living in poverty and have more limited means to escape from poverty. Therefore in the current context of the Covid pandemic it is likely that many would have had limited access to resources, services or activities which may have supported their well-being in the context of a global pandemic.

With the onset of the pandemic many people with learning disabilities have experienced significant adversity and change to their previous lifestyles. This is in part due to the fact that many individuals with learning disabilities have co-morbid physical health issues which have meant that they have either formally been asked to shield or informally have made the decision to shield. Sadly, reviews of deaths during the course of the pandemic have shown that people with learning disabilities are up to 6 times more likely to die from Covid than members of the general population. Therefore even those individuals that are physically well, they and their families and carers have

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<sup>6</sup> [https://doi.org/10.1016/S2215-0366\(20\)30491-0](https://doi.org/10.1016/S2215-0366(20)30491-0)

experienced high levels of anxiety about accessing the community due to the risk of infection.

In addition to the need to shield and anxiety about the health implications of Covid having a significant impact upon the lifestyles of people with learning disabilities, their lifestyles have also been impacted by the closure of many services offering day opportunities. This has had a direct impact upon their occupation, daily structure, and social opportunities. Furthermore, there has been a significant impact on the family carers of people with learning disabilities who have had limited opportunities to access care for their family members and the respite that this provides from their caring role leading to the increase possibility of carer fatigue, stress and burnout. Each of these factors in turn is likely to have influenced the well-being of people with learning disabilities.

In terms of referrals to psychological therapies within the Tower Hamlets Community Learning Disabilities service, audit of referrals indicates from April 2020 there has been an overall increase in referrals for psychological interventions, which include referrals for behaviour that challenges and mental health difficulties, with the number of referrals for 2020 those for 2019 by beginning of December. These figures should also be seen in the context of there being an initial slowing of referrals at the start of the pandemic. Furthermore, the proportion of referrals being made whilst individuals are acutely unwell and/or behaviour is posing a risk to themselves, their carers or there is a risk of placement breakdown appears to be significantly higher.

Referrals to the psychiatry team within the Tower Hamlets Community Learning Disabilities service significantly increased during 2020 with the pandemic having both a precipitating and perpetuating factor in regards to the increasing number of mental health crises.

These increases in mental health crisis can also be seen through the number of admissions which occurred during the last few months. Over ten individuals have been admitted due to breakdowns in placements due to behaviour or deterioration of their mental health, a much larger number than is usually seen throughout the year.

During the pandemic, there was also an increased reliance on the use of medication for the management of mental health difficulties and behaviours which challenge. As the availability of social interventions and face-to-face 1:1 specialist health clinical input has decreased, so the necessity to seek to improve mental wellbeing through the use of psychotropic medication has increased.

The long-term aim, in line with the national S Stopping over medication of people with a learning disability, autism or both (STOMP) policy, remains to reduce the over-use of psychotropic medication within the learning disability population. Prior to the coronavirus-19 pandemic in March, the STOMP programme was progressing well and Primary Care had reviewed and reduced medication. To take stock of the increases following the pandemic outbreak however, we are currently auditing the prescribing practices within CLDS and within the primary care networks. It is intended that this data will be used to support future quality improvement work within this area.

Overall it appears that the pandemic has had a significant detrimental impact upon the mental health of many people with learning disabilities. This impact is not just limited

to this population, but also their carer's in terms of the additional burden of support without usual day opportunities and respite available.

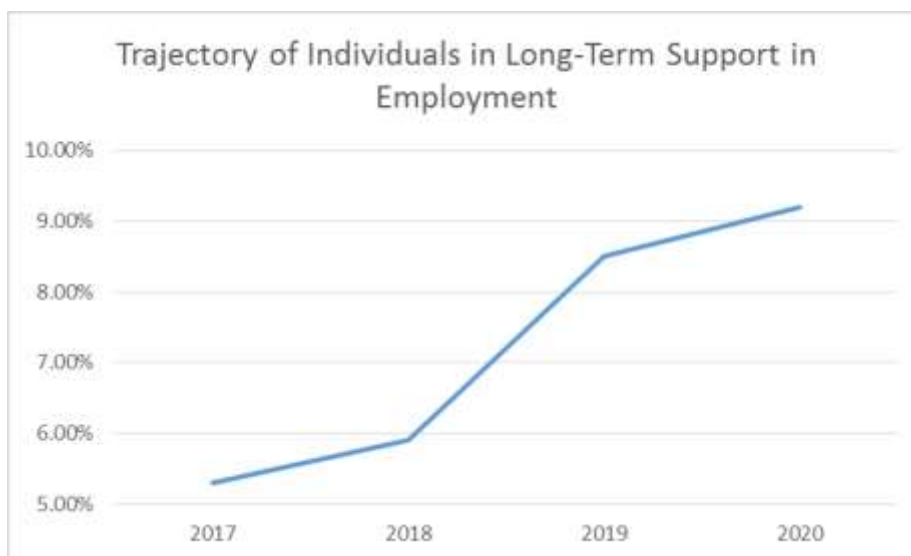
There are also longer terms concerns about the health and well-being of people with learning disabilities following the Covid pandemic. Including the impact of the significant changes that people have experienced, loss and bereavement, anxiety, loss of skills which are still seen as we move forward into 2021.

## 2. How are adults with a learning disability supported into paid employment?

Despite better education support for people with LD and protections in the Equality Act there is still a large divide between the rate of employment of disabled people and that of the wider population across the country.

There are 1.5 million people with an LD living in the UK, but only 6% are in paid employment. Yet evidence and research shows that many people with LD want to work and build careers.

The percentage of people with LD (in long term social care) who have secured paid employment in Tower Hamlets during 2019/20 is 9.2% (quarter 3) which is a 3.3 % age point increase from 2017. Tower Hamlets has a target to support 55 individuals with a learning disability into employment each year so that by October 2020 there is 11% of the learning disability population receiving long-term social care support in employment.



An employment support service and an employment skills and development service are commissioned to deliver these targets, both through the Tower Project. In order to support the delivery of these outcomes, the Think Work First approach was introduced which places an employment and vocational profile as part of the social care assessment, so that referrals and links to services for employment and skills are made from the onset.

In March 2020 the subcommittee heard that Tower Project had developed links with WorkPath, Tower Hamlets' Employment Centre, LD adult day services, healthcare providers including East London Foundations Trust (ELFT) and Barts Health as well as private sector businesses (e.g. Stratford Theatre Royal, Intercontinental Hotel Group, The Town Hall Hotel, Tower Hamlets Homes and West Ham Football Club).

The sub-committee heard, whilst Tower Project has worked successfully to broker jobs within the hospitality sector, it has been more challenging to engage other organisations.

The sub-committee feel that Tower Hamlets Council can lead by example in this area. Organisation need to review and set ambitious local targets that are much more aspirational considering we have a growing population.

#### December 2020 – Impact of the Covid-19 pandemic

As the national general population faced employment challenges and negative impact stemming from the pandemic, so did the Tower Hamlets learning disability population.

While some individuals were able to continue working during the pandemic and retain the job, despite being furloughed, others were not as lucky. Even before the pandemic hit in early March, 13 job offers to people with a learning disability were not honoured due to rising uncertainty brought on by the imposing pandemic and 12 others having their job starts disrupted. Six individuals did start a new job during the pandemic which shows the dedication and hard-working sentiment of both the individual's and the employment service supporting them, however this number is far fewer than was expected.

The job market has also been hit dramatically. The hospitality industry accounts for a large proportion of employment opportunities for the learning disability population and due to the pandemic these employers are no longer in a position to offer recruitment at any level.

While the employment impact may seem separate, it has consequences and impacts on other daily living aspects of the learning disability population. Benefits, money-management and emergencies have increased and are a key feature in responding to support for service users now who have lost their job as a direct result of the pandemic. Service users and their parent/carers have been supported with benefit advice as local services were either locked-down or overwhelmed with support requests during lock down from the general public. Support has also been provided around money management and debt advice to ensure crisis prevention and avoid homelessness.

#### December 2020 Progress Update

Despite these challenges, work has progressed to alter how employment is obtained and how people with a learning disability can be supported into employment. New initiatives and programmes have been developed to continue upskilling the population as well as developing new systems to advertise employment prospects.

*T “I would like to work in a café”*

Prior to the pandemic, 82 people were being supported in work with 126 service users on roll (16 people were above the contract capacity). The Employment service achieved 9.2% by February 2020 with the expectation of achieving 10.9% before the pandemic.

At the beginning of 2020, Tower Project JET, who deliver both the employment support and skills programmes, had 20 jobs brokered across a number of organisations. However, employers including LBTH, GLL and Ideas Store were unable to honour 13 job offers for early March 2020 due to the uncertainty around the pandemic. Despite the challenges posed, six individuals were supported to start a job since March 2020 which shows the determination of the population and services to ensure the learning disability population has full access to achieving their employment aspirations and parity with the general population’s employment prospects.

*G “I would like to be a Makaton trainer”*

Due to changes in service operation following the pandemic, providers began working remotely to great effect with Employment Advisers supporting employers to ensure 14 individuals could remain in work during lock-down and further supporting the furlough of 61 individuals to avoid job loss. The Employment service designed two remote programmes to support people with learning disabilities to improve their employability and independent living skills whilst at home. The Hotel @ Home programme was delivered to 67 individuals between March and July. This programme gained national recognition from Matrix Quality Assurance Assessors who held up the programme as an example of good practice.

*M “I would like to be cleaner”*

Additional programmes which can be delivered remotely have also began – ‘Employment First Supported Internship’, ‘Let’s Work @ Home’ and ‘Books Beyond Words’. These programmes aim to provide training and skills development remotely but plans are being developed to begin face-to-face support when able.

In partnership with ‘Codiers for Covid’, the employment skills provider is developing London’s first Learning Disability recruitment site with the aim of increasing awareness of job vacancies and enable the provider to broker further opportunities.

Commitment to offer employment for this population has improved with the Employment Service securing partnership with Compass Group. Barts Health remain focused on their internal ‘Project Search’ employment initiative. As the hospitality sector has been impacted disproportionately from the pandemic, the service has leveraged additional support from Big Lottery and ESF to support the creation of paid ILM jobs.

The committee felt the need for further projects to be developed with partners, such as green projects or estate-based projects that might develop skills. The committee urged for a review of the Better Care Fund to establish partnerships around joint projects to allow for greater up-skilling of people with LD.

**Recommendation 10 (from 10 March):** Tower Hamlets Council should lead by example and create more paid job opportunities for people with LD and set aspirational targets.

The health and care sector should be another area to pursue locally in Tower Hamlets. The sub-committee felt that health and care partners need encouragement to do more to employ adults with a learning disability. A good place to target potential employers in this sector will be the Health and Wellbeing Board (HWBB) which is a statutory board responsible for improving health and wellbeing in the borough and reducing health inequalities. The board is made up of key partner agencies operating in the health and care landscape. It was noted in the challenge session that board members are committed to recruiting people with an LD within their own organisations. It was also noted that work will commence in quarter 4 to develop a charter with member organisations to achieve this commitment.

It was discussed that many employers have preconceptions about what job a person with LD could do. For example, they may assume jobs need to have repetition or low responsibility, instead of understanding and matching individual talents. Services need to support potential employers to become confident recruiters and supporting people with LD in the workplace. Health and care services should also help organisations develop a truly inclusive culture and support employers tackle barriers to inclusion.

**Recommendation 11 (from 10 March):** To ensure charter to get commitment from member organisations to employ more adults with a learning disability incorporates concept of supporting each other to develop a truly inclusive culture in their respective organisations.

**Recommendation 12 (from 10 March):** To ensure the supported employment programme set ambitious recruitment targets that are based on national benchmarking figures and LD population growth.

**Recommendation 13 (from 10 March):** To ensure the supported employment programme is mindful of job retention and incorporates career development as part of suitable offer to people with an LD. Employers should support persons with LD to better understand the rights in the workplace i.e. help join trade unions.

Improvements in learning disability diagnosis and identification will also increase the potential for people to access employment support services and providing greater clarity on the actual proportion of adults with a learning disability who are in employment will support further improvements to learning disability population employability statistics.

**Recommendation 14 (from– 8 Feb 2021):** The HWBB, Partnership Executive Group and health organisations should create more job opportunities for adults with learning disabilities.

The pandemic has affected a number of job sectors which has affected the creation of new job opportunities for the LD population.

**Recommendation 15 (from – 8 Feb 2021):** In the absence of new LD job placements, a review of green projects and other targeted projects within estates or community settings should be considered as a potential way to increase LD job placements and volunteering opportunities.

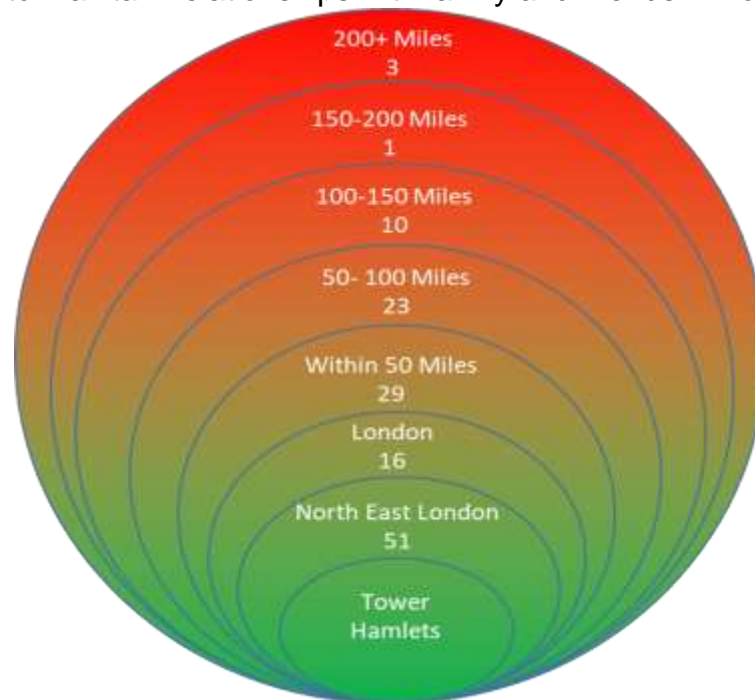
### 3. How are adults with learning disability supported to live locally?

Transforming Care Programme - Building the Right Support, 2015 is a national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition.

According to its vision people should be offered a choice of housing, including small-scale supported living arrangements. Choice about housing should be offered early in any planning processes (e.g. in transition pathways from childhood, or in hospital discharge planning) and should be based on individual need and be an important component of a person's person-centred care and support plan. Where people live, who they live with, the location, the community and the built environment need to be understood from the individual perspective and at the outset of planning.

Everyone should be offered settled accommodation. This should include exploring home ownership or ensuring security of tenure. According to the JSNA LD Factsheet 2016, Tower Hamlets has a high proportion of people living with family/friends. A high proportion of people in Care Home and housing provided by Councils and Registered Providers. However, Tower Hamlets provides significantly lower levels of supported living accommodation than neighbouring boroughs such as Newham, Waltham Forest and City & Hackney.

The sub-committee was informed in the challenge session that there were 133 people living outside of Tower Hamlets some to be closer to family and friends, but many want to return to the borough to be closer to family and their community. The figures also suggest that 37 adults with LD live more than 50 miles away of which at least 4 are more than 150 miles away from Tower Hamlets. This presents a massive challenge for LD patients to maintain relationships with family and friends in Tower Hamlets.





A four-year programme to reduce the number of out-of-borough placements and making better use of existing accommodation options locally to bring individuals back into the borough is underway. This will improve the quality and outcomes whilst improving value for money by supporting people to be independent.

The new programme aims to reduce out-of-borough placements and bring at least 59 individuals back into the borough. This will increase the overall number of people with a learning disability living in Tower Hamlets resulting in an increase to the GP register which could have an impact on increasing targets of health actions plans and screening figures.

To date, only nine people have been placed back in the borough and the sub-committee were not entirely clear how the current Tower Hamlets Accommodation Plan for people with LD (2016-19) is supporting these issues and gaps of the provision of suitable accommodation in the borough.

#### December 2020 Progress Update

*S “The council have been great and very helpful, I am supported by a company called Mears who have been to my house through lockdown and fixed everything that needed fixing. They make me feel safe in my home. It helps me to live independently in my home.”*

The Supporting Independence programme has oversight against meeting the targets of individual’s moving back into borough and achieving the ambitious savings targets associated with this programme of work; actual savings achieved for 20/21 financial year amount to approximately £450,000 despite the impact of the pandemic, this programme continues to operate and improve both the council’s budgetary position and the accommodation options for the learning disability population.

Addressing recommendations 16 and 17, a number of capital schemes are being developed utilising new LBTH properties and refurbishing existing building to enable usage of current void spaces. Plans have been developed for the redevelopment of the 1<sup>st</sup> floor of Sewardstone Road to provide for four individuals returning from out of area including a two-bedroomed wheelchair accessible flat. The new housing development on Norman Grove will include a new shared-living option for up to eight young adults with wheelchair accessible rooms.

An approved provider Framework has been commissioned to further expand local accommodation services, particularly for those people with complex needs who are most at risk of being placed out of area. 10 individuals have been identified as a priority for services to be commissioned via the Framework over the next 12 months.

*G “My boiler broke down, and with the support from my carer I contacted the council and they came to fix it on the same day. I thought that was really good.”*

### Sub-committee comments (8 Feb 2021):

There appears to be lack of information available about the general experiences of people who are living in accommodation outside of the borough. The responsibility of ensuring quality of care may fall on the local authority where the placement is but the sub-committee feels that in light of the pandemic there ought to be better risk assessment of all vulnerable people including those we place outside of Tower Hamlets. This is particularly important to ensure the most vulnerable and isolated people are coping well in this pandemic, lockdown and are receiving the support and care they need.

The sub-committee noted the importance of increasing supported accommodation capacity in Tower Hamlets and suggested that more joint working with Housing Providers is essential.

**Recommendation 16 (from 10 March):** The Tower Hamlets Accommodation Plan for people with LD should set ambitious targets for the development of local accommodation opportunities for people with a learning disability. This should address the historic lack of options across all types of provision within the borough.

**Recommendation 17 (from 8 February):** To secure funding and resources to support development of new supported accommodation schemes.

**Recommendation 18 (from 10 March):** The last LD JSNA Factsheet was updated in 2016. In light of Covid-19 and the impact it has had on LD services it is recommended that the factsheet is updated.

**Recommendation 19 (from 10 March):** Any future adults' learning disability strategic/action plans should have a key set of performance measures to be published and reported to the sub-committee every six months.

**Recommendation 20 (new – 8 Feb 2021):** To work with Housing Providers and Housing Options and consider ways to increase supported accommodation capacity through capital programme /HRA funding. The committee asked that the capital programme or HRA funding be considered for additional provision of housing and noted that the cohort were often a stable source of housing revenue.

#### **4. Final thoughts**

The update related to impact of Covid-19 is well-received amidst the challenges presented by the pandemic.

The sub-committee recognises that there is a significant financial burden on commissioners of health and social care in Tower Hamlets. With the added crisis of the pandemic, there is expected to be a legacy of further pressures across the health and social care system for some time to come.

With this in mind the sub-committee is concerned that the need to make savings across the local health and social care system will drive down quality and, in some cases, services will cease even though they are often life-lines for vulnerable people.

The sub-committee is particularly concerned about the impact of service disruption during the pandemic – including day centres and health checks and screenings – and the impact this has had and will have on the LD population. It is understood that the March 2021 Cabinet decision to close three day centres will not negatively impact adults with learning disability.

The Better Care Fund is well placed to support further integration of health and social care, particularly for people with a learning disability. By utilising money that exists within both the health and social care system the BCF enables us to pool resource between local authority and health (Clinical Commissioning Group) budgets to enable joint spending on shared priorities.

A review of Better Care Fund spending is currently underway with the intention to expand the amount of money pooled in future years and learning disability services should be a key consideration of this work. Better Care Fund could be utilised to fund new projects that might benefit people with Learning Disability.

Whilst it is recognised that there are a number of priority delivery areas across the learning disability programme, any strategic developments will need to specifically address the recommendations outlined within this report. The sub-committee would also expect strategic developments in this area to be evidence based.

It is proposed by the sub-committee that recommendations in this report are carefully considered and developed into an action plan. It is reasonable that recommendations in this report is incorporated into future strategic developments and learning disability work programmes to avoid duplication and maintaining a level of accountability across the system. In this instance, the sub-committee will expect the actions are being delivered in a timely way.

The sub-committee foresees the action plan will sit with the Health and Wellbeing Board while the Learning Disability Partnership Board will take responsibility for its delivery. It is also proposed by the sub-committee that an update on the action plan is scheduled in six to twelve months after the action plan goes live.

## **5. Service User Testimonials**

These testimonials are taken from a video call with service users from the empowering voices group on the 12/01/2021. We covered topics Covid 19 lockdown, primary and social care, accommodation, health, wellbeing, employment, safety and respect.

### **Covid 19 lockdown**

GS: 'I have good days and bad days; I don't get lonely because of the support I have from my carer'

SW: 'the 3rd lockdown is better than the first one, I really miss face to face contact'

BT: 'I get lonely'

TR: 'I have missed people'

MB: 'it's been ok'

### **Support from primary and social care**

SU: 'I have received good information from my GP, but I have only had one phone call in December from social services to check on me'

MB: 'I have been told to stay at home'

SW: 'I get updates on my phone telling me to stay at home and I get good information from my GP and the NHS website. No one from social service has called me since the first lockdown. It has been lonely and scary. I think it's disgusting that no one has been in contact with me. I feel left out. I feel that disabled people have been left out'

GS: 'My GP is excellent; she has been in regular contact with me reminding me to take my medication and stay at home, she knows me well. Social services have given me no support, I feel that they don't care enough. It is bad that no one from social service has contacted me'

### **Accommodation**

SW: 'the council have been great and very helpful, I am supported by a company called Mears who have been to my house through lockdown and fixed everything that needed fixing. They make me feel safe in my home. It helps me to live independently in my home.'

GS: 'My boiler broke down, and with the support from my carer I contacted the council and they came to fix it on the same day. I thought that was really good'

BT: 'living with my sister makes me happy and safe'

### **Health and wellbeing**

Group: 'we feel well supported by the organisations we used to attend, we regularly attend online activities set out by them and like to see our friend faces. The activities are fun but we miss being together and sometimes this make us sad'

GS: 'I have good days and bad days; I don't get lonely because of the support I have from my carer'

SW: 'the 3rd lockdown is better than the first one, I really miss face to face contact'

BT: 'I get lonely'

TR: 'I have missed people'

MB: 'it's been ok'

### **Employment**

SU: 'I would like to be a till operator'

SW: 'I would like to help people with learning disabilities, I would like to be and advocate'

GS: 'I would like to be a Makaton trainer'

MB: 'I would like to be a cleaner'

BT: 'I would like to be a cook'

TR: 'I would like to work in a café'

### **Safe and respected**

SU: 'I feel safe in my home'

TR: 'I feel safe and respected'

GS: 'I do everything in my power to keep safe and not have accidents I feel respect from my carers'

SW: 'I feel scared sometimes as I have a noisy neighbour, but the council has help me feel more safe and that makes me feel as though my voice is respected'