REPORT OF: THE JOINT HEALTH OVERVIEW AND SCRUTINY COMMITTEE (JHOSC):

Oxfordshire Learning Disability Plan

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Report to:

- Karen Fuller (Director of Adult Social Care).
- Bhavna Taank (Head of Joint Commissioning - Live Well).
- Clair Taylor (My Life My Choice Project Co-ordinator).
- Alex Wheeler (Senior Joint Commissioning Officer).

INTRODUCTION AND OVERVIEW

1. The Joint Health and Overview Scrutiny Committee considered a report on the Oxfordshire learning disability plan for adults during its public meeting on 29 January 2026.

2. The Committee would like to thank Bhavna Taank (Head of Joint Commissioning - Live Well); Clair Taylor (My Life My Choice Project Co-ordinator); and Alex Wheeler (Senior Joint Commissioning Officer).
for attending the meeting and answering questions from the Committee.

3. The topic of adult learning disabilities is of significant interest and concern to the HOSC given that it has a constitutional remit over health and healthcare services as a whole, and this includes the initiatives taken by Oxfordshire County Council and its NHS partners to improve services for adults with learning disabilities. The Committee is also aware of some of the health challenges affiliated with learning disabilities.

4. Upon commissioning the report for this item, some of the insights the Committee sought to receive were as follows:

   - The nature of this plan and its development.

   - The role of coproduction in the development of the plan.

   - Whether the plan will be continually reviewed, and of so are there timescales and intervals for this?

   - The input from lived experience in the plan’s design and planned implementation.

   - The governance surrounding the plan’s implementation and the role of key system partners in developing the plan.

- The role of the voluntary sector in the context of the plan's development and in the provision of services for adults with learning disabilities.

SUMMARY

5. During the 29 January 2026 meeting, the Director of Adult Social Care highlighted the strong foundations of co-production that had shaped the plan and emphasised the positive atmosphere surrounding its development. It was noted that the plan had recently been discussed at Cabinet, where its formal signing and subsequent media coverage had been warmly received, reflecting a strong endorsement of the work undertaken.

6. The My Life My Choice Expert by Experience that was present in the meeting described the empowerment gained through the co-production process and illustrated how lived experience had helped frame the plan's priorities. It was also explained that the plan aligned closely with both local frameworks and wider national policy.

7. The discussion moved into the structure of future reviews, and Officers explained that although the plan had originally been designed for formal reviews at three-, five- and seven-year points, this structure had been amended following feedback gathered through the World Café engagement event. People with learning disabilities had expressed a preference for an earlier review to ensure timely reflection and the ability to respond more dynamically to changing needs.

8. Discussion then shifted to system-wide commitments, particularly in relation to the pact signed between Oxfordshire County Council and My Life My Choice. Officers confirmed that the Council took pride in having signed the pact, which contained practical commitments shaped directly through lived experience. These included promoting access to work, supporting good housing and facilitating independence. Some commitments, such as improving recruitment into social care, were already being advanced through joint work with advocacy groups. However, Officers recognised that wider system commitments, including those shared across health, social care and voluntary organisations, required further development. They highlighted the goal of strengthening integration between health and care and ensuring that commissioning decisions, service planning and housing alignment were conducted transparently and in line with the needs of people with learning disabilities.

9. The early priorities for addressing inequalities were then discussed in detail. Officers explained that the initial focus within the first one to three years would be on the most significant and well-evidenced inequalities disproportionately affecting people with learning disabilities. These included poorer access to healthcare, higher prevalence of co-existing conditions such as epilepsy and sensory impairments, and persistent barriers experienced by people from ethnic minority communities. They emphasised the importance of improving access to and quality of annual health checks, addressing disparities in life expectancy and tackling negative experiences within NHS settings. Subgroups

had already begun examining data relating to dentistry, pain management, health checks and wider health inequalities to establish baseline measures. Officers confirmed that KPIs were being developed and would continue to evolve as new insights and lived-experience contributions emerged.

10. System-wide collaboration was also explored in the discussion, with officers emphasising that the Learning Disability Plan had been developed jointly across health, social care and the voluntary sector. This collaborative approach created valuable opportunities to improve pathways such as annual health checks, early intervention and community support. Officers highlighted the role of joint commissioning teams, which operated across organisational boundaries and allowed for better alignment of priorities and monitoring. The Learning Disability Improvement Board would review progress, enabling system partners and experts by experience to challenge inconsistencies and identify any gaps in delivery. Officers reiterated that consistent improvement, particularly in areas such as epilepsy management or the avoidance of unnecessary hospital admissions, depended on strong, integrated governance, shared data and the sustained use of lived experience to inform decisions.

11. Further emphasis in the discussion was placed on ensuring that adults with learning disabilities felt genuinely empowered when seeking employment, particularly where employment might affect their benefits. Officers explained that empowerment formed a central principle of the plan and that a wide range of existing support, including workplace coaching, advocacy services and detailed benefits advice, helped to ensure people made informed, confident decisions. They described how advocacy organisations offered travel training, peer support and guidance tailored to individual needs, while social care teams regularly assisted with navigating the benefits system as part of transition planning. This approach was designed to ensure people felt supported and informed throughout their employment journey.

KEY POINTS OF OBSERVATION:

12. This section highlights four key observations and points that the Committee has in relation to the Oxfordshire Learning Disability Plan (and adult learning disability services more broadly). These four key points of observation have been used to determine the recommendations being made by the Committee which are outlined below:

Event to share progress and good practice on learning disabilities: The Oxfordshire Learning Disability Plan is explicitly designed as a ten-year framework, underpinned by regular review points, dynamic workplans, and sustained involvement of people with lived experience, families, carers, voluntary organisations and statutory partners. Within this context, an anniversary event is not a symbolic or celebratory gesture alone, but a practical mechanism for accountability, learning, system leadership and cultural change.

The Committee understands that the Oxfordshire Learning Disability Plan was developed through extensive engagement and consultation, including open focus groups, self-advocacy groups, and a World Café–style event that brought together people with learning disabilities, families and professionals in a shared learning environment (as set out in Annex 4 of the report submitted to the Committee for this item). This approach aligns strongly with national expectations that learning disability strategies should be co-produced and should continue to involve people with lived experience throughout delivery, not merely at the design stage. National guidance from NHS England and the Department of Health and Social Care emphasises that sustained engagement is essential to reducing health inequalities and improving outcomes for people with learning disabilities, particularly in relation to prevention, access to services and community-based support[1].

An anniversary event offers a structured opportunity to return to the people who helped shape the Plan and demonstrate how their input has influenced real-world change. Research on public sector accountability suggests that visible, participatory review moments strengthen trust between institutions and communities, particularly where strategies relate to marginalised groups. One particular study on public accountability highlights that accountability is most effective when it is dialogic rather than purely report-based, enabling shared reflection rather than one-way performance reporting[2]. An anniversary event creates precisely such a dialogic space, allowing partners to present progress while also hearing challenge, reflection and lived experience perspectives.

The Committee understands that from a system-leadership perspective, the Oxfordshire Learning Disability Plan is explicitly delivered at “place” level, drawing together Oxfordshire County Council, NHS partners, district councils, voluntary organisations and provider organisations under the oversight of the Learning Disability Improvement Board. Place-based working, as promoted through Integrated Care Systems, relies on shared ownership, mutual learning and alignment across organisations. National evaluations (including from the King’s Fund) of place-based approaches in health and social care have found that learning events and shared reflective spaces are critical to sustaining collaboration over time, particularly in complex systems where no single organisation has full control[3].

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[1] https://www.england.nhs.uk/learning-disabilities

[2] https://academic.oup.com/book/7082

[3] https://www.kingsfund.org.uk/insight-and-analysis/reports/place-based-systems-of-care

An anniversary event can help provide a focal point for this shared ownership. It allows partners to step outside routine governance meetings and consider the cumulative impact of their work across themes such as “Having a Good Life”, “Health and Wellbeing”, “Having a Place to Live” and “Homes not Hospitals”, which are set out in *Annex 1 – Oxfordshire Learning Disability Plan 2025–2035*. Importantly, it also supports the cross-cutting priorities identified in the Plan, including workforce development, transitions, equality and assistive technology, by enabling learning to be shared across thematic boundaries rather than remaining siloed within individual sub-groups.

There is also a strong quality-improvement rationale for such an event. The dynamic workplans in *Annex 2* of the report submitted to the Committee for this item repeatedly emphasise the importance of sharing good practice, learning from what is “good now”, and spreading effective approaches across services. For example, Theme One explicitly identifies the need to “share areas of good practice with others to develop services”. An anniversary event offers a structured mechanism to do this at scale, allowing providers, professionals and experts by experience to showcase initiatives that have improved outcomes, reduced inequalities or enhanced inclusion. Several studies on improvements to health an care services in the United Kingdom consistently show that peer-to-peer learning and storytelling are powerful drivers of change, often more effective than written guidance alone[4].

Examples from other areas of the country reinforce this argument. In Greater Manchester, annual learning disability partnership events have been used to bring together local authorities, NHS organisations, providers and self-advocates to review progress against the Greater Manchester Learning Disability Strategy, share practice on employment, health checks and community inclusion, and set shared priorities for the year ahead[5]. Evaluations of this approach have highlighted improved consistency across localities and stronger relationships between statutory and voluntary sector partners. Similarly, West Yorkshire Integrated Care Board has supported annual learning disability and autism conferences focused on progress against Building the Right Support, enabling local learning to inform system-wide commissioning and service redesign[6].

There is also a clear link between anniversary events and workforce development. The Oxfordshire Learning Disability Plan and the associated Physical Health Strategy for Oxfordshire place significant emphasis on training, reasonable adjustments, and the involvement of

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[4] https://www.health.org.uk/publications/quality-improvement-made-simple
[5] https://www.gmhsc.org.uk/learning-disability-and-autism
[6] https://www.wypartnership.co.uk/our-priorities/learning-disability-and-autism

experts by experience in educating professionals. Academic research shows that narrative-based learning, where staff hear directly from people with lived experience, can significantly improve attitudes, confidence and practice among health and social care professionals[7]. An anniversary event provides a natural platform for such learning, reinforcing the Plan's commitment to co-production and strengths-based approaches.

Finally, the recommendation for an event to share progress and good practice also aligns strongly with the ethical and legal foundations underpinning the Plan. The Care Act 2014 places a duty on local authorities to promote individual wellbeing and to involve people in decisions that affect them[8]. An anniversary event is a tangible expression of this duty, demonstrating that people with learning disabilities are not merely subjects of policy but active partners in shaping and reviewing it. It also supports the Human Rights–based emphasis on participation, dignity and respect that runs throughout the Oxfordshire Learning Disability Plan.

In summary, the recommendation that partners at place consider an anniversary event to share progress and good practice is grounded in the design of the Oxfordshire Learning Disability Plan itself, supported by national policy, reinforced by academic evidence, and validated by practice in other areas of the country. Such an event would strengthen accountability, support continuous improvement, embed co-production, and sustain momentum over the life of a ten-year strategy. For these reasons, it represents a proportionate, practical and strategically sound recommendation from the Oxfordshire Joint Health Overview and Scrutiny Committee.

Recommendation 1: *That partners at place consider an anniversary event to share progress and good practice.*

Importance of outcome measures for the strategy and deliverables: The Committee understands that the Oxfordshire Learning Disability Plan 2025–2035 is explicitly designed as a ten-year strategy, supported by dynamic work plans, thematic sub-groups and oversight by the Learning Disability Improvement Board (as set out in Annex 1 of the report submitted for this item). It spans four substantial thematic areas—Having a Good Life, Health and Wellbeing, Having a Place to Live, and Homes not Hospitals—supported by cross-cutting priorities such as workforce development, transitions and equality. The breadth of this scope makes it essential that outcomes, rather than simply activities, are clearly articulated and monitored. Academic literature on long-term

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[7] https://www.sciencedirect.com/science/article/pii/S1755458620300413

[8] https://www.legislation.gov.uk/ukpga/2014/23/contents

public service strategies consistently emphasises that clarity around outcomes is a prerequisite for accountability, particularly where delivery responsibilities sit across multiple organisations rather than within a single accountable body[9].

The dynamic work plans contained in Annex 2 of the report submitted to the Committee already demonstrate a strong commitment to specifying actions and indicative measures of success, such as improved access to health checks, increased community opportunities, and reductions in inappropriate hospital admissions. However, the Committee rightly seeks to ensure that these are further developed into a coherent outcomes framework that allows progress to be assessed in the round. This aligns with national guidance on outcomes-based commissioning and service evaluation, which stresses the importance of distinguishing between outputs (what has been done) and outcomes (what has changed for people)[10].

Preparing such outcome measures specifically for scrutiny by the Committee in 2027 is also well-judged in temporal terms. The Plan itself anticipates formal review points at years three, five and seven, recognising that a ten-year strategy must remain adaptable to changing needs, system pressures and policy context. A scrutiny review in 2027 therefore coincides with an important early milestone: far enough into implementation for meaningful patterns to emerge, but early enough for learning to inform subsequent phases of delivery. Research into adaptive governance highlights that early formative evaluation points are critical in long-term programmes, as they allow systems to course-correct before approaches become embedded and hard to change[11].

In addition, the Committee is recommending that partners at place level provide a statement on their respective roles and contributions to learning disability services. This is particularly significant in the context of integrated care and place-based working. The Oxfordshire Learning Disability Plan is not owned or delivered by a single organisation; rather, it depends on coordinated action by Oxfordshire County Council, NHS organisations, district councils, voluntary and community sector partners, and commissioned providers. National policy on Integrated Care Systems emphasises that successful place-based delivery requires clarity of roles alongside flexibility, and an honest assessment of interdependencies[12].

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[9] https://academic.oup.com/book/7082

[10] https://www.gov.uk/government/publications/outcomes-based-commissioning

[11] https://www.tandfonline.com/doi/full/10.1080/14719037.2017.1340508

[12] https://www.kingsfund.org.uk/insight-and-analysis/reports/integrated-care-systems-explained

A collective partner statement supports this by making explicit how responsibility is distributed across the system. It also mitigates a common risk in multi-agency strategies, whereby accountability becomes diffuse and progress is difficult to attribute. Academic studies of collaborative governance consistently identify role ambiguity as a barrier to effective collaboration, particularly in complex systems serving people with multiple needs[13]. By requiring partners to articulate their contributions, the recommendation strengthens transparency without undermining the collaborative ethos of the Plan.

Crucially, the as part of its recommendation, the Committee would like such a statement to go beyond formal role descriptions to include reflection on what has supported and hindered collaboration in practice. This element aligns strongly with the learning-oriented approach embedded in the Oxfordshire Learning Disability Plan, which repeatedly emphasises sharing good practice and learning from challenges. Annex 4 of the report submitted to the Committee demonstrates that people with learning disabilities and their families value honesty about where services work well and where they do not. Extending this honesty to system-level collaboration supports a culture of improvement rather than blame.

Evidence from other areas of the country supports the value of such reflective partner statements. In Greater Manchester, periodic system reviews of learning disability and autism programmes have included partner reflections on collaboration, particularly in relation to Building the Right Support and Homes not Hospitals initiatives. These reflections have been used to identify systemic barriers, such as workforce shortages and data-sharing constraints, and to inform subsequent commissioning and service redesign[14]. Similarly, West Yorkshire has used joint system statements to accompany scrutiny and assurance reports, explicitly identifying enablers and barriers to partnership working as part of its learning disability improvement programme[15].

From a scrutiny perspective, this recommendation also strengthens the JHOSC's ability to exercise its statutory role under the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations. Effective scrutiny depends not only on data, but on narrative context that explains why progress has or has not been achieved. Studies of health scrutiny have found that committees are most effective when they are able to scrutinise system behaviour and relationships, rather than focusing solely on performance indicators in isolation[16]. A

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[13] https://onlinelibrary.wiley.com/doi/10.1111/j.1540-6210.2006.00620.x

[14] https://www.gmhsc.org.uk/learning-disability-and-autism/

[15] https://www.wypartnership.co.uk/our-priorities/learning-disability-and-autism

[16] https://www.health.org.uk/publications/reports/effective-health-scrutiny

partner statement on collaboration provides this contextual lens, enabling the JHOSC to make informed, proportionate recommendations.

Finally, the recommendation has a clear ethical dimension. The Care Act 2014 requires local authorities and partners to promote wellbeing and to involve people meaningfully in decisions affecting their lives[17]. Outcome measures grounded in lived experience, combined with honest system-level reflection, can help ensure that the Learning Disability Plan remains focused on real improvements in people's lives rather than just procedural compliance. Preparing these materials for scrutiny in 2027 reinforces the principle that long-term strategies must remain accountable not only to governance bodies, but ultimately to the communities they serve.

Recommendation 2: *For outcome measures to be developed on all due deliverables, and for this to be prepared for scrutiny by the JHOSC in 2027. It is recommended that there is a statement from all partners at place level on their roles and contributions to LD services, and on what has supported and hindered collaboration.*

Improving the quality of annual health reviews: Annual health reviews and checks are a critical mechanism through which the health system seeks to identify unmet needs, prevent avoidable deterioration and address the significant life expectancy gap experienced by people with learning disabilities. National data consistently shows that people with learning disabilities experience markedly poorer physical and mental health outcomes than the general population, with women dying on average 23 years younger and men 20 years younger, largely from preventable or treatable conditions[18]. Within Oxfordshire, the Learning Disability Physical Health Strategy explicitly recognises these inequalities and identifies annual health checks as a core tool for early identification and intervention (as set out in Annex 3 of the report submitted to the Committee).

However, research and inspection evidence demonstrate that the effectiveness of annual reviews depends not simply on completion rates, but on their quality, consistency and person-centredness. Studies of annual health checks for people with learning disabilities have shown that while uptake has improved nationally, variability in quality remains significant, with some reviews becoming overly transactional or clinically narrow, failing to address wider determinants of health, mental wellbeing, or reasonable adjustments[19]. The Committee is recommending that people with Learning Disabilities, paid and unpaid carers, and health staff undertaking annual reviews are empowered to improve the quality of annual reviews. This therefore reflects an understanding that improving

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[17] https://www.mencap.org.uk/advice-and-support/social-care/care-act

[18] https://leder.nhs.uk/images/aflreport2324/action-from-learning-report-22-24/

[19] https://www.kingsfund.org.uk/insight-and-analysis/blogs/annual-health-checks-learning-disability

quality requires empowerment across the whole system, including those receiving reviews, those supporting them, and those delivering them.

The Oxfordshire Learning Disability Plan places strong emphasis on people being treated as experts in their own lives, with their voices shaping care and support. This is reinforced throughout Annex 1 of the report submitted to the Committee, which highlights person-centred and strengths-based approaches as core principles. Empowering people with learning disabilities to influence the quality of their annual reviews aligns directly with these principles. Academic literature on shared decision-making and patient empowerment consistently shows that when individuals are supported to understand the purpose of reviews, prepare for them, and express what matters to them, reviews are more likely to result in meaningful actions and sustained improvements[20].

Paid and unpaid carers also play a pivotal role in the effectiveness of annual reviews. Carers often hold crucial knowledge about changes in behaviour, communication, physical health and emotional wellbeing, particularly for people with profound and multiple learning disabilities. The Oxfordshire Physical Health Strategy acknowledges the importance of carer involvement in identifying deterioration and supporting proactive care planning. Empowering carers to contribute confidently and systematically to annual reviews helps to ensure that reviews capture real-world experiences rather than isolated clinical snapshots. Research on carer involvement demonstrates that structured carer input improves continuity of care and reduces the risk of missed diagnoses or inappropriate treatment[21].

Health staff undertaking annual reviews, particularly in primary care, are also central to improving quality. While annual health checks are a contractual requirement within the GP contract, evidence from the Learning from Lives and Deaths (LeDeR) programme indicates that variability in staff training, confidence and understanding of reasonable adjustments continues to affect the quality of interactions and outcomes[22]. Empowerment in this context is not about increasing burden, but about equipping staff with the tools, training and specialist support needed to undertake reviews well, including adequate time, accessible resources and clarity about follow-up actions. This aligns with the Oxfordshire Plan’s commitment to joint training and co-delivery with Experts by Experience, particularly under Theme Two: Health and Wellbeing.

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[20] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6492310

[21] https://www.sciencedirect.com/science/article/pii/S0149718917303667

[22] https://www.england.nhs.uk/learning-disabilities/improving-health/learning-from-deaths/

Practice from other areas around the country reinforces the value of this tri-partite empowerment approach. In Cornwall, for example, GP practices have worked alongside people with learning disabilities and local advocacy organisations to co-design annual health check templates and preparatory materials, resulting in improved patient satisfaction and more actionable outcomes[23]. Similarly, in Greater Manchester, system partners have supported training programmes that bring together GPs, carers and self-advocates to explore what “good” looks like in an annual review, drawing on lived experience to improve practice and confidence[24].

Academic studies of quality improvement in primary care underline that improvements are most sustainable when they are co-produced with those who use services and those who deliver them. One study in the British Medical Journal described effective healthcare improvement as the “co-production of health”, requiring active partnership between patients, families and professionals rather than unilateral professional control[25]. The JHOSC recommendation reflects this evidence base by explicitly recognising that quality is jointly created and therefore jointly improvable.

This recommendation also has important equity implications. People with learning disabilities may experience communication barriers, diagnostic overshadowing and reduced access to reasonable adjustments during reviews. Empowerment initiatives—such as accessible preparation materials, health passports and supported decision-making—help to mitigate these barriers and support compliance with the Equality Act 2010 and the duty to make reasonable adjustments[26]. The Oxfordshire Learning Disability Plan explicitly commits to improving access and fairness within health services, and empowering participants in annual reviews is a practical expression of this commitment.

In essence, the recommendation that people with learning disabilities, paid and unpaid carers, and health staff undertaking annual reviews are empowered to improve the quality of those reviews is firmly grounded in the nature of the Oxfordshire Learning Disability Plan, is supported by national policy, is reinforced by academic research, and validated by practice elsewhere in the country. It recognises that annual reviews are a critical intervention point in reducing health inequalities, and that their effectiveness depends on genuine partnership, shared knowledge and mutual empowerment. The Oxfordshire JHOSC promotes a model of

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[23] https://www.cornwall.gov.uk/health-and-social-care/learning-disability/
[24] https://www.gmhsc.org.uk/learning-disability-and-autism/
[25] https://qualitysafety.bmj.com/content/25/7/509
[26] https://www.equalityhumanrights.com/en/advice-and-guidance/equality-act-guidance

care that is preventative, person-centred, and capable of delivering sustained improvements over the life of the ten-year Plan.

Recommendation 3: *That people with Learning Disabilities, paid and unpaid carers, and health staff undertaking annual reviews are empowered to improve the quality of annual reviews.*

Further Engagement with People with Learning Disabilities, Autism and Epilepsy, and the Timely Involvement of Voluntary Sector Organisations: The recommendation that there be further engagement with people with learning disabilities, autism and epilepsy, and that relevant voluntary sector organisations—alongside their experts by lived experience—are engaged in a timely way, reflects a core concern of the Committee. This is that preventable harm, avoidable or prolonged hospital admissions, and early deaths continue to arise where systems fail to listen early enough, learn systematically, or act collaboratively across organisational boundaries. Within the context of the Oxfordshire Learning Disability Plan 2025–2035, this recommendation reinforces the centrality of lived experience, early prevention and community-based practice in improving outcomes.

The Oxfordshire Learning Disability Plan is explicit in its commitment to co-production and meaningful involvement of people with lived experience, families, carers and voluntary sector organisations. As set out in Annex 1 of the report submitted to the Committee, the Plan was developed through extensive engagement, including focus groups, self-advocacy groups and a World Café–style event, ensuring that lived experience informed both priorities and design. However, the Plan also recognises—implicitly through its emphasis on dynamic work plans and iterative review—that engagement must be sustained throughout delivery, not confined to strategy development. The JHOSC recommendation rightly highlights the need to extend and deepen this engagement, particularly in relation to people with learning disabilities, autism and epilepsy, whose health risks and care pathways often intersect but are not always addressed in an integrated way.

The significance of epilepsy in this context warrants particular attention. Epilepsy is substantially more prevalent among people with learning disabilities and autistic people than in the general population, and it is a known contributor to premature mortality, including sudden unexpected death in epilepsy (SUDEP). National evidence indicates that people with learning disabilities and epilepsy are at significantly higher risk of avoidable deaths, often linked to gaps in coordination, lack of specialist input, or insufficient understanding of risk factors across services[27]. The Learning Disability Physical Health Strategy for Oxfordshire explicitly

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[27] https://www.nhs.uk/conditions/epilepsy/epilepsy-and-learning-disabilities

references learning from the LeDeR programme, which has repeatedly identified epilepsy and seizure management as areas where better coordination and earlier intervention could have prevented harm[28].

Further engagement with people who have lived experience of learning disability, autism and epilepsy is therefore not simply desirable, but essential to effective prevention. Academic research demonstrates that people and families often hold early warning signs of deterioration—changes in behaviour, seizure patterns, communication or mood—that predate crises or admissions, but that these signals are frequently overlooked in fragmented systems[29]. Structured and ongoing engagement enables systems to capture this experiential knowledge and translate it into safer, more responsive care pathways.

The recommendation also highlights the critical role of voluntary sector organisations, particularly those rooted in lived experience. Organisations such as epilepsy charities, autism advocacy groups and learning disability self-advocacy networks often operate closest to individuals and families, providing peer support, education, early advice and navigation through complex systems. The Oxfordshire Learning Disability Plan already acknowledges the contribution of organisations such as My Life My Choice and Oxfordshire Family Support Network in engagement, advocacy and community development. The JHOSC recommendation builds on this by emphasising the importance of timely engagement, ensuring that voluntary sector expertise informs service design and prevention strategies from the outset rather than retrospectively.

Evidence from across England supports this approach. In Leicestershire and Rutland, systematic involvement of epilepsy charities and learning disability advocacy groups within local "communities of practice" has strengthened professional understanding of epilepsy risk, improved care coordination and contributed to reductions in avoidable admissions[30]. Similarly, in Greater Manchester, voluntary sector-led communities of practice on learning disability, autism and mental health have been used to share learning from serious incidents and LeDeR reviews, enabling frontline professionals to adapt practice and improve early intervention[31].

The concept of communities of practice is particularly relevant to this recommendation. Communities of practice bring together practitioners, people with lived experience and voluntary sector organisations to learn collectively, share tacit knowledge and improve practice over time.

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[28] https://leder.nhs.uk/learning-from-lives-and-deaths/

[29] https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(18)30888-2/fulltext

[30] https://www.nhslrutland.co.uk/learning-disability

[31] https://www.gmhsc.org.uk/learning-disability-and-autism

Academic literature suggests that communities of practice are especially effective in complex fields such as learning disability and epilepsy care, where challenges cut across professional boundaries and clinical guidelines alone are insufficient to drive change[32]. By engaging voluntary sector organisations and experts by lived experience, these communities can ground professional learning in real-world experience and support cultural change alongside technical improvement.

Preventing avoidable and prolonged hospital admissions is a recurring priority within the Oxfordshire Learning Disability Plan, particularly under Theme Four: Homes not Hospitals. The Plan aligns with national policy on Building the Right Support, which emphasises community-based provision, early intervention and shared responsibility across system partners to prevent unnecessary inpatient care[33]. Engagement with people with learning disabilities, autism and epilepsy—and with voluntary sector partners who understand the daily realities of managing risk in the community—is fundamental to making this ambition real. Research on avoidable admissions consistently highlights that breakdowns in communication, lack of continuity and failure to understand individual triggers are key drivers of crisis and admission[34].

The recommendation is also closely linked to the prevention of early deaths. LeDeR reviews have repeatedly demonstrated that many premature deaths among people with learning disabilities were potentially avoidable, with contributory factors including poor coordination, inadequate adjustments, and missed opportunities for escalation or intervention[35]. Engaging voluntary sector organisations with expertise in epilepsy, autism and learning disability enables systems to move beyond retrospective learning towards proactive prevention, embedding lessons into everyday practice through shared learning and peer support.

The Committee notes with concern the latest research on learning disability and epilepsy deaths over a ten year period which finds that people die on average at 56 years (36 for some ethnic minorities), some seven years younger than people with learning disability with any other condition[36]. LeDeR reports have consistently found a lack of appreciation and management of epilepsy risk. People with a learning disability who also have epilepsy account for 40% of all emergency admissions for

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[32] https://onlinelibrary.wiley.com/doi/10.1002/casp.1719

[33] https://www.england.nhs.uk/learning-disabilities/care/building-the-right-support

[34] https://bmjopen.bmj.com/content/9/9/e030456

[35] https://www.england.nhs.uk/learning-disabilities/improving-health/learning-from-deaths

[36] Shanar R, Epilepsy-related premature mortality in adults with intellectual disability in England: a population-based analysis 2026 JNNP 97, issue 4

ambulatory care sensitive conditions for people with a learning disability and are more likely to be placed in out of county settings[37].

This recommendation being made by the Committee is against the backdrop of a previous JHOSC report to Oxfordshire County Council's Cabinet in 2024 and recommendations accepted by Oxfordshire County Council in 2025. Recommendations were accepted across the whole system because of the shared recognition of the vast impact of new national requirements for two specialist clinicians to sign off an epilepsy medication commonly used for treatment of the most dangerous seizure types which was experienced on top of a service which was already very overstretched with long waiting lists. The ICB Impact report predicted a wide range of harms including increased deaths. The South-East region has found rising deaths since the introduction of the new requirements.

The aforementioned JHOSC report to Cabinet and system partners shared learning from the Midlands where an independent regional report into the death of Clive Treacey had identified system wide failures in his care before his sudden death in a residential setting as well as systemic errors in the investigation of his death which was erroneously investigated as cardiac with his epilepsy ignored. Since then, the Midlands review has led to coproduction of new guidance for commissioners and providers of care which incorporates an evidence-based safety checklist piloted in Cornwall since 2016 which has reduced risks and deaths.

In Lincolnshire, advanced clinical practitioners in general practice have used the guidance and person-centred checklist in a proactive review of people with learning disability with epilepsy as part of a reasonable adjustment (as people with epilepsy and learning disability and carers are likely to be unaware and from September 2026 reasonable adjustments will be mandatory) and used this to liaise with the epilepsy nurse specialist for modification of treatment. The Primary Care Network (PCN) has planned a training to support annual reviews across the locality.

From a governance and scrutiny perspective, the recommendation being made by the Committee supports the JHOSC's role in promoting system learning rather than reactive assurance. Timely engagement with voluntary sector partners and lived experience experts helps ensure that strategies and action plans are informed by real risks and practical solutions, reducing the likelihood of repeated failings. It also aligns with the Care Act 2014's emphasis on wellbeing, prevention and participation,

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[37] Jaydeokar S, Out of borough placements for people with learning disabilities 2004

reinforcing the duty to involve individuals and communities in shaping services that affect them[38].

Therefore, the recommendation for further engagement with people with learning disabilities, autism and epilepsy, and for the timely involvement of voluntary sector organisations and experts by lived experience, is both necessary and evidence-based. It responds to well-documented risks around avoidable admissions and early deaths, aligns with the Oxfordshire Learning Disability Plan's principles of co-production and prevention, and reflects national learning from LeDeR, Building the Right Support and integrated care policy. By strengthening communities of practice and embedding lived experience at the heart of prevention, Oxfordshire is better placed to deliver safer, more responsive care and to realise the long-term ambitions of its ten-year Learning Disability Plan.

Recommendation 4: *For there to be further engagement with people with a Learning Disability/autism and epilepsy, and that relevant voluntary sector organisations (with their experts by lived experience) are engaged with in a timely way; with a view to understanding what they can contribute to communities of practice and prevention of avoidable and long admissions to hospital and early deaths.*

Legal Implications

13. Health Scrutiny powers set out in the Health and Social Care Act 2012 and the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 provide:
    - Power to scrutinise health bodies and authorities in the local area
    - Power to require members or officers of local health bodies to provide information and to attend health scrutiny meetings to answer questions
    - Duty of NHS to consult scrutiny on major service changes and provide feedback n consultations.

14. Under s. 22 (1) Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 'A local authority may make reports and recommendations to a responsible person on any matter it has reviewed or scrutinised'.

15. The Health and Social Care Act 2012 and the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 provide that the Committee may require a response from the responsible person to whom it has made the report or recommendation and that person must respond in writing within 28 days of the request.

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[38] https://www.mencap.org.uk/advice-and-support/social-care/care-act).

16. The recommendations outlined in this report were agreed by the following members of the Committee:

Councillor Jane Hanna OBE – (Chair)
District Councillor Dorothy Walker (Deputy Chair)
Councillor Ron Batstone
Councillor Gareth Epps
Councillor Emma Garnett
District Councillor Katharine Keats-Rohan
District Councillor Elizabeth Poskitt
District Councillor Val Shaw
City Councillor Louise Upton
Barbara Shaw

Annex 1 – Scrutiny Response Pro Forma

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