Q1) What does your organisation want to see included in the 10-Year Health Plan and why?

The health inequalities faced by people with learning disabilities are stark and preventable. People with learning disabilities die significantly younger than non-disabled people—at least 20 years earlier. Those from ethnic minority backgrounds are particularly affected, with an average life expectancy of just 34 years compared to 62 years for white people with learning disabilities.

In 2022, 42% of people with learning disabilities who died experienced an 'avoidable' death.

However, progress has been made in reducing preventable deaths and early mortality, presenting an opportunity to accelerate efforts so that people with learning disabilities receive equitable healthcare and the chance to live their *Good Life*.

Strategic Actions to Address Health Inequalities

The following actions will help reduce these inequalities:

- **Improving Health Services**: Ensure effective, reasonably adjusted health services that improve health outcomes and raise life expectancy for people with learning disabilities. This includes:
    - Supporting investment in better preventative care, such as access to GPs, dentists, opticians, health checks, and specific programs like Postural Care to support body shape protection.
    - Prioritising people with learning disabilities on hospital waiting lists, reducing delays that can lead to worse health outcomes and early death.
    - Promoting the use of multiple formats for NHS communications—whether printed or online—such as large print, braille, easy-read, and audio versions.
    - Reforming the Continuing Health Care (CHC) funding system to better support younger disabled people who wish to live fulfilling lives, including access to work, holidays, and family life.
    - Committing to culturally competent, well-funded training and specialist support in every area, with ongoing monitoring to assess improvements.

- **Focusing on Rights and Inclusion**: Promote the rights and inclusion of all people with learning disabilities, especially those from minority ethnic communities and with high support needs. This will include:
    - Ending the inappropriate use of Do not Resuscitate Cardiopulmonary Resuscitation (DNACPR) across all health services.
    - Ensuring disability equality is at the heart of all government missions, with people with learning disabilities included in plans related to housing, employment, social care, and transport.
    - Committing to a cross-government strategy that empowers people with learning disabilities and ensures their inclusion in all policies.
    - Ensuring strategic funding is available to support self-advocacy and the inclusion of disabled people's voices in national and local health policy and service development.
- **Social Care Reform**: Reform social care to align with NHS changes, ensuring services meet the rights of people with learning disabilities and their families, while also providing fair pay for social care workers. This will include:
    - Ending the rationing of care, which leaves many people with unmet needs, increasing pressure on health services and criminal justice systems. There are approximately 970,000 adults with a learning disability in England, but only 150,000 receive social care support—a decrease over the last 15 years.
    - Ensuring people receiving social care and their families are included in social care policy, design, and delivery, focusing on person-centred and culturally competent approaches.
    - Supporting the Social Care Future movement, which envisions a society where everyone can live in a place they call home, with the people and things they love, in supportive communities. The movement advocates for funding as an investment in people's lives.
    - Providing a pay increase for frontline care workers, funded by the government, as part of the Employment Rights Bill.

Q2) What does your organisation see as the biggest challenges and enablers to move more care from hospitals to communities?

More than 12 years after government action began, people with learning disabilities and autistic individuals continue to be inappropriately admitted to mental health hospitals, subjected to seclusion or segregation, and in some cases, held long after their treatment has ended. To enable effective community support and prevent unnecessary hospital admissions, a cross-government and system-wide approach is essential. This should involve coordinated, concurrent actions, as outlined in the *Joint Briefing - Community Support for People with Learning Disabilities and Autistic People.*

The shift from hospital to community-based care requires addressing several key challenges:

- **Financial Disincentives**: The current financial structure often disincentivises investing in community services. This needs to change to ensure that appropriate services are available in the community when needed, not just in times of crisis.
- **Specialist Community Services**: There must be greater investment in specialist community services, which should be available not only in times of crisis but as an ongoing, preventative measure. This will involve a change in the roles and responsibilities of regulators, commissioners, providers, and professionals.

Opportunities for Disabled Children's Support

There is also an opportunity to ensure that disabled children receive person-centred support, underpinned by a commitment to family life and delivered through an integrated, inter-agency approach. This approach should support schools and families, helping children remain at home. Families need flexible short breaks, including overnight care, without arbitrary limits, to maintain care in the home environment.

Reforming Continuing Health Care (CHC)

Reforming CHC is essential to ensure people receive specialist healthcare in the home. The reforms should aim to:

1. **Simplify the System**: Make CHC easier to navigate, especially for families, by ensuring a clear pathway from children's CHC to adult

care. This will allow young disabled people to transition smoothly into adult services and live a fulfilling life.

2. **Streamline Processes**: Reduce the significant transaction costs currently spent on eligibility assessments, appeals, and monitoring. These resources could be better spent on providing actual care and support, bridging the gap between Adult Social Care and CHC for eligible individuals.
3. **Expand Understanding of CHC**: Extend the system's understanding beyond older people in residential care. CHC teams need experience in supporting younger disabled individuals who want to lead full lives. Additionally, there must be greater awareness of social care responsibilities under CHC.
4. **Support for Community Health Staff**: Ensure that community health staff, such as district nurses and physiotherapists, have the capacity to provide training for support workers. This training will equip them to safely deliver delegated health tasks, such as PEG feeding, enemas, and contracture prevention, without compromising the safety of disabled individuals at home.

Role of Learning Disability Nurses

The 2023 LeDeR report revealed that systems and processes were the most commonly reported issues in care. It found that 42% of deaths reviewed were preventable, a welcome decrease from 50% in 2022. While this is positive progress, more work remains to be done. One significant factor in reducing the risk of NHS failures for people with learning disabilities is the role of learning disability nurses.

Learning Disability Liaison nurses play a crucial role in supporting individuals with learning disabilities by helping them navigate complex systems and processes. They provide valuable advice and support to primary care providers, care teams, families, and individuals. Increasing the number of learning disability nurses—partly through investment in nursing training—can strengthen community services and improve hospital care, including facilitating smoother transitions and positive discharges.

Q3) What does your organisation see as the biggest challenges and enablers to making better use of technology in health and care?

A key challenge in health and care for people with learning disabilities is the lack of personalised reasonable adjustments, which has been identified as a factor in preventable deaths or near misses. Implementing personalised reasonable adjustment flags is crucial in ensuring that people with learning disabilities receive equitable health care. The *Reasonable Adjustment Digital Flag* is an important tool to drive this change, and committing to its full rollout across both social care and health services would be an effective use of technology.

Additionally, there are opportunities to digitise important documents such as hospital passports, health action plans, social care records, and Education, Health, and Care Plans (EHCPs). However, these tools should only be effective if they are owned and controlled by the individuals with learning disabilities, where possible. Empowering individuals to manage and access these documents themselves ensures their autonomy and improves their care experience.

Another challenge is the digital exclusion faced by many people with learning disabilities. While the pandemic led to an increase in the use of digital tools among this population, the evidence suggests that it has not translated into improved skills for accessing services online or using digital health platforms. Many people with learning disabilities face specific barriers to using technology independently.

To address this, it is essential to maintain options for face-to-face or phone interactions with all services. Not all individuals can fully engage with digital platforms, and offering alternative methods of communication ensures inclusivity.

Lastly, many people with learning disabilities require additional time to understand, process, and consider decisions. Technology often accelerates processes and decision-making, which may not work for everyone. It is important that there is enough time for individuals to comprehend information and, where needed, to use technology with appropriate support.

There is an opportunity to use technology to improve the quality of data on ethnicity to then improve understanding and quality of services. People with learning disabilities from Black Asian and Minority Ethnic backgrounds experience greater health inequalities.

Q4) What does your organisation see as the biggest challenges and enablers to spotting illnesses earlier and tackling the causes of ill health?

The A Fair and Supportive Society report demonstrates people with learning disabilities are more likely to live in poor housing environments, be in poverty and be bullied or discriminated against. The action needed to remedy these disadvantages and premature mortality is identified as addressing the social determinants of health requiring cross government action.

Learning Disability England worked closely with people with learning disabilities, family members, and paid supporters over nine months to develop priority actions aimed at promoting better health.

Based on this collaboration, the following areas were identified as key opportunities to improve health outcomes:

1. Eating Well

- **Access to Affordable, Good Food**: Ensuring everyone, including those with dysphagia, has access to nutritious, affordable food.
- **Accessible Information and Support**: Providing easy-to-understand information and assistance on healthy eating.
- **Support for Weight Loss or Diet Changes**: Offering accessible services to help individuals achieve their dietary goals.
- **Choice in Shared Settings**: Ensuring real choice in the food provided in shared support settings.

2. Exercise

- **Affordable Access to Gyms**: Ensuring gym costs are adapted to include the support costs for people with learning disabilities.
- **Information and Support for Exercise**: Providing accessible resources and guidance on various exercise options.
- **Trained Social Care Support**: Ensuring social care staff are confident and trained to discuss exercise and health with individuals.
- **Access to Local Parks and Open Spaces**: Promoting access to outdoor spaces for physical activity.

3. Being Connected

- **Affordable Local Social Opportunities**: Creating affordable places where people can meet others in their community.
- **Transport and Support for Social Activities**: Ensuring individuals have the necessary support or transport to access social events.
- **Valuing Friendships and Family**: Encouraging social care services to recognise and support the importance of friendships and family.

4. Equitable Access to Services

- **Mental Health Services**: Ensuring mental health services are accessible to everyone, including people with learning disabilities.
- **Access to Health Services**: Making sure dental and optician appointments are accessible to people with learning disabilities.
- **Reasonably Adjusted Booking Systems**: Implementing systems that are user-friendly and adaptable, making it easier to manage health appointments.
- **Preventing Individuals from Getting Lost in the System**: Ensuring that people do not fall through the cracks due to complex waiting lists or systems.
- **Positive Attitudes in Healthcare**: Eliminating diagnostic overshadowing and fostering positive attitudes toward people with learning disabilities.
- **Listening to Families and Support Workers**: Ensuring families and support workers are heard when raising concerns about someone's health.

5. Body Shape Protection (Postural Care)

Body shape protection, also known as postural care, is essential for improving health outcomes and reducing the need for surgery or premature death, especially for adults with profound and multiple learning disabilities. Early intervention, as recommended by NICE guidance, can significantly improve long-term health.

6. Help people with learning disabilities get the jobs they want supported by a system that recognises contributions not forcing poverty.

Working with people with learning disabilities and their supporters to remove the barriers to employment and to share what is possible

Co-produce the benefits system that recognises everyone's right to an adequate standard of living and values individual's contribution not penalising disability.

7. Make sure people with learning disabilities have the same access to housing options as their nondisabled peers through cross government working.

Level up social housing so people with learning disabilities, alongside others have access to safe and secure accommodation.

Make sure there are Support to Live options by:

Supporting national and local annual targets to build supported housing for people with learning disabilities and autistic people and publish the number and type of schemes funded.

Supporting reform of the rules for rent setting for housing associations in relation to Supported Housing and public subsidy. This could allow grant funding to support the development of housing needed for many people with learning disabilities and autistic people to have appropriate housing.

Q5) Please use this box to share specific policy ideas for change. Please include how you would prioritise these and what timeframe you would expect to see this delivered in, for example:

• Quick to do, that is in the next year or so

1. **Create a Clear CHC Guide for Families**: Develop a comprehensive guide for both adults and young people transitioning to adult life under Continuing Health Care (CHC). This should include:
    - What to expect during the CHC process.
    - Key information families need to know.
    - Ideally, a dedicated navigator to help coordinate the process and offer ongoing support.
2. **Maintain NHS Learning Disability Improvement Standards Beyond 2024-2025**: Ensure that the existing NHS Learning Disability Improvement Standards and processes continue to be implemented beyond 2024-2025. This will provide consistency and drive long-term improvements in care for people with learning disabilities.

3. **Enhanced Service for Annual Health Checks**: Ensure that there is an enhanced service for Annual Health Checks for both young people and adults with learning disabilities. This would include clearer guidelines, appropriate resources, and access to relevant specialists.
4. **Increase Awareness of the Learning Disability Register**: Run an awareness campaign to educate people with learning disabilities, their families, and primary care staff on the benefits of joining the Learning Disability Register. Clarify the registration process and emphasize how it can help prevent ill health and improve care. Pay particular attention to the inclusion of people with learning disabilities from minority ethnic groups.
5. **Clarify Cross-Government Responsibilities**: Ensure clear and actionable guidelines for cross-government collaboration on issues that affect people with learning disabilities, improving coordination and integration of their rights in all aspects that affect health and wellbeing.
6. **Implement the Accessible Information Standard**: Fully implement the Accessible Information Standard across all health and care services. This would ensure that people with learning disabilities receive health information in formats that are accessible to them, such as easy read, large print, or audio.

In the Middle (Next 2 to 5 Years)

1. **Build on NHS Learning Disability Improvement Standards**: Expand upon the existing NHS Learning Disability Improvement Standards to further embed rights-based quality measures and accountability in all NHS services. These services must be fully inclusive of people with learning disabilities and their families, ensuring that they receive high-quality, equitable care.
2. **Enhance Annual Health Checks with Quality and Outcome Measures**:
   In addition to providing an enhanced service for Annual Health Checks, implement quality and outcome measures to evaluate the effectiveness of these checks. This will ensure that health checks are not only more comprehensive but also lead to tangible improvements in health outcomes for people with learning disabilities.

3. **Add ethnicity data to the mandated data collected as part of The NHS Health and Social Care of People with Learning Disabilities dataset, to enable regular and ongoing analyses.**

   Ensure all health staff correctly record ethnicity data, equipping them with tools and accessible information to explain the purpose to people and their families.

Long-Term Change (More Than 5 Years)

1. **Embed Inclusion of People with Learning Disabilities in All NHS Strategies**:
   Make sure that people with learning disabilities are included in all NHS strategies, particularly in areas that are major causes of death (e.g., cancers, respiratory issues, cardiovascular disease). This will involve ensuring equitable access to diagnosis, treatment, and ongoing care for people with learning disabilities, addressing health disparities in these critical areas.

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