

ACCELERATED MULTIMORBIDITY IN PEOPLE WITH LEARNING DISABILITIES

Public policy to reduce
avoidable illness,
admissions and
premature mortality for
adults with learning
disabilities and multiple
long-term conditions.

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Using evidence from the DECODE project to transform prevention, integrated care and population health management.

THE POLICY OPPORTUNITY

DECODE* shows that multiple long-term conditions** in adults with learning disabilities emerge earlier, cluster in predictable ways and can be identified before significant deterioration. This creates a practical opportunity to redesign NHS care around prevention and anticipatory intervention rather than crisis response.

Why this matters

People with learning disabilities experience profound and persistent health inequalities. More than 85% of adults with learning disabilities live with multiple long-term conditions, with chronic disease often developing decades earlier than in the wider population. Yet NHS pathways remain largely organised around single diseases, specialties and episodic care.

The result is a fundamental mismatch between how services are organised and the realities of accelerated multimorbidity. Symptoms may be overlooked or attributed to the learning disability itself; physical and mental health conditions frequently coexist; and opportunities for earlier intervention can be missed.

What DECODE adds

- Evidence that there are recognisable patterns (clusters & trajectories) of multiple long-term conditions.
- Evidence that long-term conditions commonly associated with later life emerge much earlier.
- Evidence that combinations of long-term conditions are associated with hospital admissions.
- A basis for using population health intelligence to identify risk and support earlier, more personal intervention before significant deterioration.

Core message

The challenge is no longer simply understanding the problem, but translating evidence into action.

***DECODE:** Data-driven, machine learning-aided stratification and management of multiple long-term Conditions in adults with intellectual Disabilities.

****Multiple Long-Term Condition:** is defined as the presence of two or more chronic health conditions (either physical or mental).



A DIFFERENT MODEL OF CARE IS NEEDED

Current approaches improve access, but they do not yet reflect the earlier onset, interaction and trajectory of disease experienced by people with learning disabilities.

DECODE turns the strategic shift into a practical model

The evidence provides a concrete route to support the **NHS 10 Year Health Plan** with preventative, community-based, digitally enabled and personalised care for one of the most disadvantaged populations.

FROM HOSPITAL TO COMMUNITY

- Organise primary care, community, mental health, social care and specialist around the person rather than individual diseases.
- Use neighbourhood and multidisciplinary teams to manage risk earlier and reduce avoidable deterioration and admission.

FROM ANALOGUE TO DIGITAL

- Use linked population data to identify people at greatest disease risk and their disease trajectory.
- Use data driven intelligence to aid clinical decision making.

FROM SICKNESS TO PREVENTION

- Identify disease risks earlier to strengthen Annual Health Checks and intervene before complications and crisis.
- Use the DECODE evidence to move Annual Health Checks and long-term conditions management from periodic screening and reactive review towards anticipatory care.

Underlying Key Principles

Reasonable adjustments, accessible communication, longer consultations and partnership with families and carers must be built into routine care, not added afterwards.

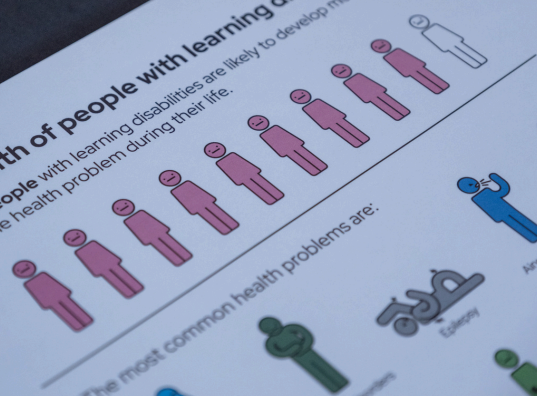
CURRENT MODEL

- Single-disease pathways
- Reactive episodes of care
- Specialty-led care
- Risk recognised after deterioration
- Standardised approaches

MODEL REQUIRED

- Integrated multimorbidity pathways
- Anticipatory prevention
- Person-centred coordination
- Earlier risk identification
- Personalised reasonable adjustments

The health of people with learning disabilities
9 in 10 people with learning disabilities are likely to develop more than one health problem during their life.



Why this matters for implementation

DECODE is not a case for creating a wholly separate service. It is a case for redesigning existing systems so that prevention, neighbourhood care, population health management and integrated pathways reflect the actual disease trajectories of people with learning disabilities.

IMPLICATIONS FOR POLICY & PRACTICE

01 **Make multiple long-term conditions in people with learning disabilities a focus in all Joint Strategic Needs Assessments**

Lead: Integrated Care Boards, Local Health Authority and Wellbeing Boards

Use linked healthcare data and population health management to identify adults with learning disabilities at greatest risk of multiple long-term conditions, and set out strategic approaches to tackle the challenge. Recognise accelerated multimorbidity explicitly in commissioning strategies, integrated care plans and strategic planning for long-term conditions.

02 **Enhance the Learning Disability Annual Health Check**

Lead: NHS England

Incorporate earlier, evidence-based risk assessment for cardiovascular disease, chronic kidney disease, diabetes, swallowing disorders, aspiration risk and other common conditions identified through DECODE. Support this with clinical guidance, decision support and clear referral pathways.

03 **Integrate the needs of people with learning disabilities and multiple long-term conditions into every long-term condition pathway**

Lead: NHS England, Royal Colleges and Integrated Care Boards

Commission integrated pathways spanning primary care, community services, specialist services, mental health and social care. Pathways should explicitly recognise earlier disease onset, reasonable adjustments and partnership with families and carers.

04 **Embed population health management, predictive analytics and better data**

Lead: Integrated Care Boards

Use linked healthcare data to identify adults with learning disabilities at greatest risk of deterioration and coordinate earlier intervention through multidisciplinary neighbourhood teams. Improve use of learning disability registers, ethnicity and wider determinants data; use linked datasets to monitor outcomes and variation; and test any predictive tool for equity across ethnic and socioeconomic groups before deployment.

05 **Build a workforce equipped for proactive, personalised care**

Lead: NHS England, professional regulators and education providers

Develop national guidance and workforce programmes to improve recognition of atypical presentation, reduce diagnostic overshadowing, strengthen communication and shared decision-making, support reasonable adjustments and integrate physical and mental healthcare. Recognise families and carers as essential partners in early recognition and care planning.

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The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Find out more, please visit:

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decode-project.org



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