# Levelling the playing field: Measuring wellbeing among people with learning disabilities

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# Contents

Summary 4

1. Introduction 6

2. Our approach 9

3. Our findings 10

4. Recommendations 26

5. Conclusion 34

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## About PBE

We use economics to improve lives. Through analytical expertise and our close connection with the social sector, we help charities, funders, firms and policymakers tackle the causes and consequences of low wellbeing. Our analysts, researchers and economists work on a wide range of issues related to low wellbeing, including mental health, education, employment, financial security, poverty, disability, inequality, volunteering and civil society. Working with over 1000 volunteer economists, we have supported over 600 charities since 2009.

## Acknowledgements

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# Summary

**The 1.5 million people with learning disabilities in the UK do not form a single, uniform group but a highly diverse population with wideranging experiences and capabilities. Most of the 1.2 million adults with learning disabilities live with little or no formal support, but some will need additional help at different stages of life to enable independence, wellbeing, and participation in their communities. This support can take many forms, ranging from limited financial and practical help with managing day-to-day tasks such as correspondence and paying bills, through to intensive nursing care. Others access day centres providing opportunities to socialise and connect with others, or benefit from supported living arrangements or homecare.**

This diversity of needs and the personalised nature of provided assistance can make it hard to objectively measure the impact of services supporting people with learning disabilities. In England, almost half of all adult social care activity for people aged 18–64 relates to people whose primary support need is a learning disability. In addition, there are around 1,500 charities with a total expenditure of around £4 billion a year, directly supporting people with learning disabilities. All of this activity generates no shortage of powerful case studies and influential qualitative evidence, but there is no current mechanism for developing an overall picture of how well the needs of people with learning difficulties are being met.

Within the general population, similar challenges around capturing outcomes that are the product of very diverse experiences in a consistent way are increasingly being tackled through the use of standardised wellbeing assessments. Such approaches are not considered appropriate for people with learning disabilities, however. They are often viewed as too complex, impractical, inaccessible for people with more complex communication needs or poorly aligned to what really matters for the lives of people with learning disabilities. This has resulted in a fragmented approach that risks decisions being made without a complete understanding of the impact they will have.

We want to level the playing field for people with learning disabilities by establishing better, more consistent ways of measuring the impact of things that affect their lives. The approach we take must reflect what matters for people with learning disabilities but also meet the evidence needs of policymakers. That means developing solutions that are robust and reliable, but also pragmatic and usable in day-to-day services. Ultimately, we are seeking to find ways to measure and promote the overall quality of life of people with learning disabilities – what we call their wellbeing.

This report is a first step towards that goal. We spoke with organisations that support and advocate for people with learning disabilities, and we engaged with academics and commissioners too. Most importantly, we heard directly from people with learning disabilities themselves. These conversations helped us understand the problems with current wellbeing outcome measurements. They also helped highlight opportunities for improvement.

We have identified a potential way forward, with five key recommendations that we believe would help to make a difference. These outline a pathway from improving measurement in practice through to strengthening the evidence base and enabling more robust long-term analysis:

1. **Develop and test a new set of outcome questions tailored specifically towards the wellbeing domains of people with learning disabilities.**
2. **Establish the evidence base for using a government-approved question as the anchor for wellbeing valuation in economic evaluation.**
3. **Ensure that these tools provide a multi-format delivery with a "guiding tool" to support people with a range of capabilities to respond.**
4. **Formulate stronger guidance for capturing changes in wellbeing over time.**
5. **Create a new longitudinal research study focused specifically on people with learning disabilities.**

We hope that this report prompts action that will deliver practical, tangible improvements in how organisations working with people with learning disabilities can measure and communicate the difference they make. We look forward to collaborating with others to take forward as many of these recommendations as possible. Ultimately, we hope that it can support a more inclusive country where decisions are made with a complete picture of their impact for everyone, regardless of whether they have a disability.

# 1: Introduction

There are around 1.5 million people with learning disabilities in the UK, of which around 1.2 million are adults.[1] It's a highly diverse group, with the term "learning disability" capturing a wide range of people with differing strengths, capabilities and needs for support. Understanding this diversity is central to creating environments, services and communities that enable everyone to thrive.

Support needs within the group are equally diverse. While many people with learning disabilities live with a high degree of independence, around 150,000 adults receive long-term social care support in England.[2] For some individuals, this might mean receiving direct payments of £100-£200 a week that can be used to provide PA support to help with managing finances and correspondence.[3] Others may need assistance within a residential home or supported accommodation, with help required with day-to-day activities such as getting dressed and preparing food. This more intensive care typically comes with far higher costs, ranging from £1,200-£1,900 a week.

Beyond the formal social care system, there are a large number of charities, housing associations, health professionals, employers and others supporting and advocating for people with learning disabilities. Indeed, there are around 1,500 registered charities in England and Wales that state they support people with learning disabilities within their charitable objectives, spending a combined total of around £4 billion a year.[4]

## What is a learning disability?

A learning disability is a reduced intellectual ability.[5] It affects how a person understands information, learns new skills and copes with everyday tasks. It is a lifelong condition, and while its impact varies from person to person, it can influence many aspects of day-to-day living.

Aspects of life might include difficulties with planning or completing household activities, managing money safely, understanding time, problem-solving, communicating needs carefully, or travelling independently.

People with learning disabilities may also need support to process information, adapt to change or make decisions, especially in unfamiliar situations. Depending on the individual's needs, the level of support may range from occasional assistance to intensive, full-time support.

1 How common is learning disability in the UK? Mencap (accessed April 2026)

2 Social care - research and statistics, Mencap (accessed April 2026)

3 New analysis reveals two-thirds of social care commissioning budgets are spent on working age and disabled adults, County Councils Network (11 November 2024)

4 PBE analysis of The Charity Commission data. Not all of this expenditure will have been directly supporting people with learning disabilities.

5 What is a learning disability? Mencap (accessed April 2026)

This complex landscape of differing needs, commissioners and providers can make it hard to measure and understand the impact of the support that is provided to people with learning disabilities.

One important measure we might use relates to life expectancy. People with learning disabilities typically live around 20–23 years fewer than the general population, largely due to health inequalities that could be avoided with the right care at the right time.[6]

However, this is a metric that takes a long time to observe. We therefore need to monitor more timely outcomes that contribute to this goal. More fundamentally, it is important to understand whether people are living well, not just living longer.

Currently, people with learning disabilities experience worse outcomes across a range of areas.[7] They have increased chances of experiencing poorer mental health compared to those without a learning disability. They can face abuse, discrimination, and exclusion, and encounter significant barriers when accessing essential services. Their long-term outcomes are also affected. For example, while 86% of adults with learning disabilities want to work, only 4.8% are employed in England. Other barriers they face range from difficulty in filling out job applications through to the fear that their benefits will be taken away.[8]

While these are all important outcomes to consider, there is considerable interplay between them. Even where outcomes can be measured more quickly than life expectancy, it remains difficult to trace the effect of a programme or intervention through to long-term outcomes for individuals.

Dealing with this complexity is not unique to this area. In other contexts, and for the general population, significant progress has been made by adopting standardised outcome measures. For example, wellbeing – defined as how one feels and functions – has become an important metric for understanding overall quality of life and the impact of interventions.

All too often, however, these standardised outcome measures have not been designed with people with learning disabilities in mind. This risks excluding them from surveys and leaving them invisible in the evidence base that informs policy decisions. This is particularly concerning given the poorer outcomes experienced by this group.

> **"Wellbeing could be like opportunities that someone has in life and in society...having lots of opportunities makes them happier, or having very little opportunities will make someone more unhappy with life."**
> Focus group participant

6 Learning Disabilities Mortality Review (LeDeR) Annual Report 2021/2022, Bristol, North Somerset and South Gloucestershire Clinical Commissioning Group (accessed April 2026)

7 Health and Care of People with Learning Disabilities, Experimental Statistics 2024 to 2025, NHS Digital (4 December 2025)

8 Work and learning disability research, National Development Team for Inclusion (July 2023)

We want to level the playing field for people with learning disabilities by providing better, more consistent ways of measuring the impact of things that affect their lives. Specifically, we believe that better understanding of their wellbeing – as an overall measure of their quality of life – in the same way as we do for the general population, is essential to improving outcomes. Without understanding wellbeing, we risk reducing people only to health outcomes or failing to understand whether people are living well, not just living longer.

This report is a first step towards tackling this dilemma by improving our understanding of what measuring wellbeing with this population could look like. We have taken the time to understand these issues with organisations that support and speak up for people with learning disabilities. We also listened to academics, commissioners and health professionals. Most importantly, we heard directly from people with learning disabilities themselves.

## Navigating this report

We describe our approach in more detail in Section 2.

We present a summary of the key themes that emerged from our engagement with organisations around the sector in Section 3, and we set out our recommendations for next steps in Section 4.

We offer some conclusions in Section 5. We have also included quotes from our lived experience group and support staff throughout the report to reflect their perspectives.

# 2: Our approach

As detailed in figure 1, we sought to map the evidence base around the measurement of the quality of life of people with learning difficulties through four, complimentary, workstreams.

Figure 1: Our approach to exploring wellbeing among people with learning disabilities

In **Workstream 1**, we conducted an evidence review by studying the literature on how wellbeing is currently captured among people with learning disabilities. In **Workstream 2**, we managed a 'call for evidence' to better understand how frontline providers and charities measure wellbeing among this population. In **Workstream 3**, we held interviews with different stakeholders to understand what they would want from a wellbeing measure. And via **Workstream 4**, we met with lived experience groups at different points in the project to explore what wellbeing means to them, hear how they express it in everyday life, and gather their feedback on what any future wellbeing measure could include to ensure their voices are represented.

> "You can see people [with a learning disability] when they're doing well – they're more confident, they communicate more, they interact more with people." Support staff

# 3: Our findings

There were five broad themes that emerged from our discussions. In this section we review each of these in turn.

## Theme 1: There is a lack of consistency in approaches to measuring wellbeing outcomes for people with learning disabilities

A common message across our evidence review was that there is no consistent or shared approach to measuring wellbeing for people with learning disabilities. This has led to wellbeing being captured through a wide mix of methods where the questions vary in language, length, and interpretation.[9] This variation reflects a number of factors: differences in the strengths and capabilities of different groups of people with learning disabilities, differing levels of reliance on quantitative and qualitative evidence within organisations, and who was relied on to gather information about wellbeing.

The types of support provided for people with learning disabilities vary widely across different organisations supporting them, reflecting the skills and capabilities of the people they support. For example, some people with a learning disability might need additional support finding suitable work, while others may need full-time support throughout their life. These different capabilities and support needs affected how organisations approached trying to capture the impact of their services.

Variations in communication capabilities were highlighted as a particular challenge. Many people with learning disabilities do not communicate their feelings through words alone. Instead, wellbeing can appear through behaviour, mood, gestures, routines, or even how a person responds to familiar people and environments. For some, wellbeing is shown in small signs of comfort, enjoyment, or connection; for others it may be recognised through relationships and the observations of people who know them well.

These challenges cause some organisations to be sceptical of using quantitative measures of wellbeing. Instead they chose to rely more heavily on "observational practice", requiring experienced professionals to pay attention to relational cues, patterns over time, and forms of communication that go beyond the traditional self-reported survey.[10] Capturing this information about impact in rich qualitative descriptions is often seen as a more powerful way of understanding the difference that their organisation is making compared to quantitative measures.

9 Christina Nicolaidis. et al., Creating accessible survey instruments for use with autistic adults and people with intellectual disability, Autism in Adulthood (11 March 2020)

10 Joanna Grace et al., Expanding possibilities for inclusive research: Learning from people with profound intellectual and multiple disabilities and decolonising research, Social Sciences (7 January 2024)

Charities also described how many measures of wellbeing depend on staff judgement. Each staff member may interpret concepts like 'engagement', 'confidence', or 'emotional wellbeing' differently. Some record progress as part of support plans, others collect notes or session reflections, while others rely on conversations with families or carers. This creates inconsistencies not only across organisations but within the same service over time. Such inconsistencies make it difficult to evidence impact to funders, to compare outcomes across programmes or to track change over time meaningfully.

Families and carers also play a role in interpreting wellbeing, and their insights are valuable because they are often the ones who notice the subtle shifts in behaviour, routine or mood that others may miss. However, studies have highlighted that proxy reporting alone may not always be reliable and, as a result, can decrease the validity of the findings and raise ethical concerns.[11]

Organisations highlighted that even when wellbeing is being observed carefully, the lack of a standard measure means the information cannot easily be shared, aggregated, or interpreted beyond the specific context it was gathered for.

### Why definitions of wellbeing matter: an example from our 'call for evidence'

Charity A supports parents with learning disabilities and focuses on wellbeing as a measure of how people feel about the support they receive, their confidence, their relationships, and their progress towards goals.

This reflects a definition of wellbeing that is experience-based, emotionally oriented and closely tied to practical life functioning (e.g. being able to attend appointments, follow advice, or build a social network).

Charity B, by contrast, supports adults with profound and multiple learning disabilities (PMLD) in day services. Their definition of wellbeing is much broader, more holistic, and strongly influenced by conceptual frameworks such as Maslow's Hierarchy of Needs and the Care Act of 2014 definition of wellbeing.

Charity B's definition of wellbeing is multi-dimensional and aspirational, emphasising the reaching of one's potential. Charity B cannot rely on self-report at all — instead, wellbeing is understood through behaviour, expression, interaction, and environmental responses.

11 Katherine E McDonald & Dora M Raymaker, Paradigm shifts in disability and health: Toward more ethical public health research. American Journal of Public Health (December 2013)

## Theme 2: Available outcome measures are not always well-aligned to what matters for people with learning disabilities

For years, researchers and policymakers have tried to pin down what makes a 'good life' for the general population. This research has shaped established tools like the Warwick Edinburgh Mental Wellbeing Scale or the ONS's UK Measures of National Wellbeing framework. Likewise, frameworks have been developed that try to capture what good social care provision looks like.[12] While these frameworks capture much that is important for the general population, they may not represent the range of experiences that shape wellbeing for people with learning disabilities.[13]

So, what do people with learning disabilities think are important to them in their day-to-day lives? Research in identifying these aspects have found that environmental factors, choice and independence, activities, valuable social roles, and relationships (including those with staff and family) are particularly important to people with learning disabilities.[14] The Scottish Commission for Learning Disability (SCLD) found several domains, such as relationships with others, self-determination, material wellbeing and being treated with dignity and respect to be strongly related to changes in life satisfaction.[15]

When we asked people with learning disabilities what matters to them, their answers pointed us towards many of the same themes that we see for frameworks developed for the general population. For example, how people feel, their health and their connections to others are common across many wellbeing frameworks. However, there were also some differences - sometimes seemingly small things that might be taken for granted in the general population can impact wellbeing in a big way. There was a strong link between safety and predictability for instance, with changes in routine often causing heightened levels of distress. Also, for some people with learning disabilities, an ability to communicate thoughts and feelings effectively with others cannot be taken for granted, and having the right support in place to do so is likely to be transformational for their quality of life.

Figure 2 provides a tentative initial summary of the kinds of "domains of wellbeing" that were suggested, providing a simple example of how it may appear in the daily life of a person with a learning disability.

12 The Care Act of 2014 sets out a service of wellbeing domains that local authorities must consider when assessing a person's needs and planning care. The domains highlighted in the Care Act of 2014 are designed to ensure that people receive the right support, and they provide a clear framework for judging the quality and effectiveness of care. Alongside the Care Act of 2014, the Adult Social Care Outcomes Framework (ASCOF) sets out nationally monitored indicators that local authorities use to assess how well adult social care is supporting people. The domains highlighted in ASCOF are needed for benchmarking performance, comparing local areas and ensuring that support services are accountable.

13 Evaluating projects for people with learning difficulties: when 'off-the-shelf' can miss the mark, What Works Centre for Wellbeing, (May 15 2019)

14 Lynette Harper et al., Triangulating visual and verbal data to enhance research interviews with people with learning disabilities, Learning Disability Practice (30 January 2025)

15 Mostly a 10, but sometimes a zero: The wellbeing of people with learning disabilities, Scottish Commission for People with Learning Disabilities (SCLD), (May 2021)

## Figure 2: Wellbeing domains identified through conversations with lived experience groups

| Domain | What it means | An example |
| --- | --- | --- |
| 1. Emotional wellbeing | Feeling calm, content, understood and emotionally supported. | A person feels happy and settled because support staff take time to speak to them and give reassurance when plans change. |
| 2. Safety & predictability | Having routines, structure and an environment that feels safe and consistent. | Someone feels calmer travelling because the bus comes at a predictable time, and they have a simple timetable to follow if it's late. |
| 3. Relationships & belonging | Feeling connected, valued and part of a community; having trusted relationships. | A person looks forward to going to their day centre because they have friends there who know them well. |
| 4. Ability to communicate effectively | Being able to express needs, choices and feelings in ways that work for the individual. | Staff use symbols, objects of reference or sign-supported speech so the person can say what they want for lunch. |
| 5. Daily activities, purpose & enjoyment | Taking part in meaningful activities that give a sense of purpose, enjoyment or achievement. | A person feels proud going to work each week, where they contribute, learn new skills and have something to look forward to. |
| 6. Independence & control | Having choices and being able to make decisions about everyday life with the right support. | Someone chooses their own clothes each morning with a visual choice board. |
| 7. Sensory comfort & environment | Feeling physically comfortable; having the right sensory environment (light, noise, textures). | A person relaxes more when allowed to use noise-cancelling headphones in a busy space. |
| 8. Self-expression | Being recognised as an individual; having opportunities to express personality, preferences and strengths. | A person chooses the music for a group activity because it reflects their personality and what they enjoy. |
| 9. Physical health and functioning | Being physically well and supported to stay healthy | A person feels better and more active because they have support to attend medical appointments, eat balanced meals and go for regular walks. |

**"If I've done good at work or helped someone, even something small, that makes me feel better. It's about having that opportunity to have more relationships with people… knowing you're not the only person that feels that way." Focus group participant**

Many charities and support organisations are instinctively already trying to reflect these domains of wellbeing in the services they provide. They build routines, create opportunities for meaningful roles, support communication needs, and nurture trusted relationships. However, they can find it difficult to identify standardised measurement tools that align neatly with what they do.

A number of existing tools are used to measure wellbeing and quality of life, including some that have been adapted for people with learning disabilities. Figure 3 shows that these tools vary in what they capture, with no single approach covering all nine domains identified through our evidence review. Domains such as "Ability to communicate effectively", "Sensory comfort and environment" and "Self-expression" are particularly poorly covered.[16]

16 It is also important to note that there are other tools developed to capture wellbeing that we have not included here, as they have not been adapted for use with people with learning disabilities or are not readily accessible beyond research settings. For example, measures such as the EQ-HWB, or broader frameworks like the Social Progress Index (SPI), offer valuable insights but are not currently designed for practical use in this context.

## Figure 3: Comparison of existing wellbeing tools against domains identified through evidence review and lived experience engagement

| Domain | POS | ASCOT | WEMWBS - ID | EQ-5D-3L | LD-specific QoL tools (e.g., GAS-ID) | Learning Labs (NEF) | Care Act of 2014 | CQC |
|---|---|---|---|---|---|---|---|---|
| 1. Emotional wellbeing | ✓ | (✓) | ✓ | (✓) | ✓ | ✓ | ✓ | ✓ |
| 2. Safety & predictability | (✓) | ✓ | X | X | X | (✓) | ✓ | ✓ |
| 3. Relationships & belonging | ✓ | ✓ | (✓) | X | X | ✓ | ✓ | X |
| 4. Ability to communicate effectively | (✓) | (✓) | X | X | X | (✓) | X | X |
| 5. Daily activities, purpose & enjoyment | ✓ | ✓ | (✓) | X | X | ✓ | X | ✓ |
| 6. Independence & control | ✓ | ✓ | X | X | X | ✓ | ✓ | ✓ |
| 7. Sensory comfort & environment | X | X | X | ✓ | X | X | X | X |
| 8. Identity, autonomy & self-expression | (✓) | (✓) | (✓) | X | X | ✓ | X | X |
| 9. Physical health and functioning | X | (✓) | X | ✓ | X | (✓) | ✓ | (✓) |

Notes: This table compares to what extent existing wellbeing questions cover the domains identified through our evidence review. The meaning of the symbols is as follows:
✓ = Direct coverage: The domain is explicitly measured by the questionnaire;
(✓) = Partial or indirectly covers: The domain is touched on but not fully captured or appears indirectly through other related items and;
X = Not covered: The questionnaire does not include this domain, or anything closely related to it.

Source: PBE review of evidence on measuring wellbeing among people with learning disabilities.

More generally, the different tools being used by charities and others differ in three important ways: (i) purpose; (ii) suitability for people with learning disabilities; and (iii) practicality.

## (i) Purpose

Some tools have been developed specifically to capture wellbeing or quality of life in a very broad sense. For example, the Personal Outcomes Scale (POS) includes questions on emotional wellbeing, relationships, social inclusion and independence, while the Adult Social Care Outcomes Toolkit (ASCOT), widely used by local authorities, focuses on social care-related quality of life, including control, safety, occupation, social participation and dignity. Similarly, the Learning Labs developed by the New Economics Foundation (NEF) take a broad view of wellbeing, covering emotional, social, motivational, intellectual and physical aspects.

Other tools are more narrowly focused. The Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID) focuses specifically on emotional distress for example, while EQ-5D-3L captures health status and therefore provides only a partial view of overall wellbeing.

General wellbeing tools such as the as the Warwick–Edinburgh Mental Wellbeing Scale adapted for people with intellectual disability[17] (WEMWBS-ID) sit somewhere in between the broad and narrow approaches, focusing on emotional wellbeing and functioning.

## (ii) Suitability

Existing wellbeing measurement tools vary in the extent to which they are designed or adapted for people with learning disabilities. Measures such as POS, GAS-ID and WEMWBS-ID have been specifically developed or adapted for the group, with the deliberate aim of more directly reflecting their differences. Others, including ASCOT and ED-5D-3L, were not originally designed with people with learning disabilities in mind. But they are applied in practice, often with adjustments or the use of proxy respondents. Elsewhere, some organisations have developed their own questions aligned to domains set out in the Care Act 2014, while the CQC uses a broader question framework to assess how services support people's wellbeing.

## (iii) Practicality

There are also important differences in practicality. Some tools, such as POS, offer a rich and detailed picture of people's lives but can be lengthy and resource-intensive to rollout. Others, such as ED-5D-3L, are shorter and easier to use but capture a more limited range of outcomes. Similarly, frameworks like Learning Labs and approaches informed by the Care Act or CQC are often flexible but lack standardisation making comparisons across settings more difficult.

Figure 4 provides a summary of the differences recorded in the different tools across these three themes of purpose, suitability, and practicality in real-world settings.

17 People with learning disabilities are also referred to as people with intellectual disabilities.

## Figure 4: Comparison of existing tools based on their purpose, whether they measure wellbeing, their suitability for people with learning disabilities, and their practicality in real-world use

| Tool | What is it best for? | Is it measuring wellbeing? | Is it adapted for people with learning disabilities? | Is it easy to use in practice? |
|---|---|---|---|---|
| POS | Deep understanding of someone's life, but takes time | ✓ Yes – broad quality of life and wellbeing | ✓ Yes – versions for LD (incl. proxy) | ✗ No – long (30–40+ items) |
| ASCOT | Understanding care quality and outcomes | ✓ Yes – social care–related wellbeing | (✓) Partly – not designed for LD but can be used | (✓) Medium – structured but manageable |
| WEMWBS-ID | Tracking emotional wellbeing over time | ✓ Yes – mental wellbeing specifically | ✓ Yes – adapted version exists | ✓ Relatively easy – shorter scale |
| EQ-5D-3L | Health status, not full wellbeing | ✗ No – focuses on health, not wellbeing | ✗ No – not LD-specific | ✓ Very easy – short and standardised |
| LD-specific tools (e.g. GAS-ID) | Tracking personalised goals and progress | (✓) Partly – depends on goal chosen | ✓ Yes – designed for LD | (✓) Medium – depends on setup |
| Learning Labs (NEF) | Group-based reflection and lived experience insights | ✓ Yes – designed around wellbeing concepts | (✓) Adaptable – used flexibly | (✓) Medium – depends on facilitation |
| Care Act (2014) framework | Policy framework, not for direct measurement | ✓ Yes – defines wellbeing broadly | ✗ No – not a measurement tool | ✗ Not practical as a tool |
| CQC framework | Assessing services, not individuals | (✓) Indirect – looks at wellbeing via care quality | ✗ No – inspection-focused | ✗ Not a tool for direct use |

Notes: This table compares existing tools based on their purpose, whether they measure wellbeing, their suitability for people with learning disabilities, and their practicality in real-world use. The meaning of the symbols is as follows:
✓ = Yes: The tool clearly meets the criterion;
(✓) = Partly: The tool meets the criterion to some extent or with limitations;
✗ = No: The tool does not meet the criterion. "Easy to use" reflects considerations such as length, complexity, and the level of support required to administer the tool in practice. The term 'Learning Disability' is abbreviated as LD.

Source: PBE review of evidence on measuring wellbeing among people with learning disabilities.

Taken together then, we find that no single tool fully captures all aspects of wellbeing while also being easy to use and well-suited to people with learning disabilities.

## Theme 3: Existing wellbeing measures are often too complex

Standardised wellbeing measures offer a valuable way of measuring the outcomes for many social interventions. However, concerns were raised by organisations working in the social sector that many of the standard tools were too complex to be used in practice for people with learning disabilities. Often the measurement tools were not designed with their communication styles or cognitive processing in mind. Moreover, answering these questions requires a level of reflection, abstraction, and verbal processing that can be particularly challenging, especially when asked in the moment. The consequence is not only incomplete or unreliable data, but the exclusion of people themselves from how wellbeing is defined, measured, and valued.

There were three specific points raised by the organisations we heard from: (i) the language used in the wording of the question; (ii) the numeric scales used to give responses, and; (iii) the sheer number of questions required for some measures.

### (i) Language

Concerns were raised about the ambiguity or complexity of language used in some of the common wellbeing measures. For example, the ONS life satisfaction question asks "Overall, how satisfied are you with your life nowadays?". Respondents were unsure about whether the word "satisfied" could be misinterpreted, and the lack of a clear anchor for timescales are also likely to make it more difficult for some people with learning disabilities to respond.

As a minimum, organisations needed questions to be available in easy read format. Easy read is a way of presenting information, so it is easier to understand. It uses short sentences, simple words and a clear layout. Information is supported by pictures or symbols to help explain the text. However, even this would not be appropriate for some groups who struggle with reading or who have limited verbal communication. Wellbeing questions relying on self-report were completely unsuitable for people with profound or multiple disabilities, leading organisations to rely instead on observation, sensory cues and personalised interaction rather than questionnaires.

> **"It's also about the word happy... what does that mean? What does it look like? ... If I'm literal, you know, happy is I'm smiling all the time"**
> **Focus group participant**

### (ii) Scoring

The numerical scales used by many survey questions were a concern for the organisations we heard from. For example, the ONS personal wellbeing questions ask respondents to evaluate how satisfied people are with their lives on a 0-10 scale. Responding to this question requires people to complete an abstract thought process that some people with learning disabilities may find difficult.

Organisations told us they had adapted in a range of ways to help "translate" these scales. Some used smiley face emoticons while others used colour coding to help respondents choose an appropriate answer. However, questions were also raised about these common adaptations. Smiley faces could be interpreted very literally - reflecting someone's mood or even facial expression in that particular moment. Likewise, colour scales can mean very different things to different people running the risk that responses are influenced by what particular colours are associated with for that individual, rather than the underlying question.

Members of our lived experience groups highlighted that questions that had a small number of short verbal descriptions of responses, rather than numeric scales or emoticons, were most helpful.

### (iii) Volume

The final concern was raised about some tools related to the sheer number of questions required to be answered. Even where the language of questions has been specifically adapted for people with learning disabilities, the length of the surveys can be a barrier to participation. The POS, for example, has 48 questions coupled with semi-structured interviews of participants.

The time taken for staff to administer the questions, as well as maintaining the interest and focus of respondents over a longer period of time can likewise both create barriers to the use of these tools.

As a result of these challenges, organisations also shared that the people they support are often shielded – sometimes unintentionally – by staff, carers or family members who decide when, how or whether someone can take part in wellbeing discussions. This can happen because supporters worry about overwhelming the person or feel protective. In other cases, time pressures or staff shortages may mean that only certain individuals are put forward for research or feedback activities.

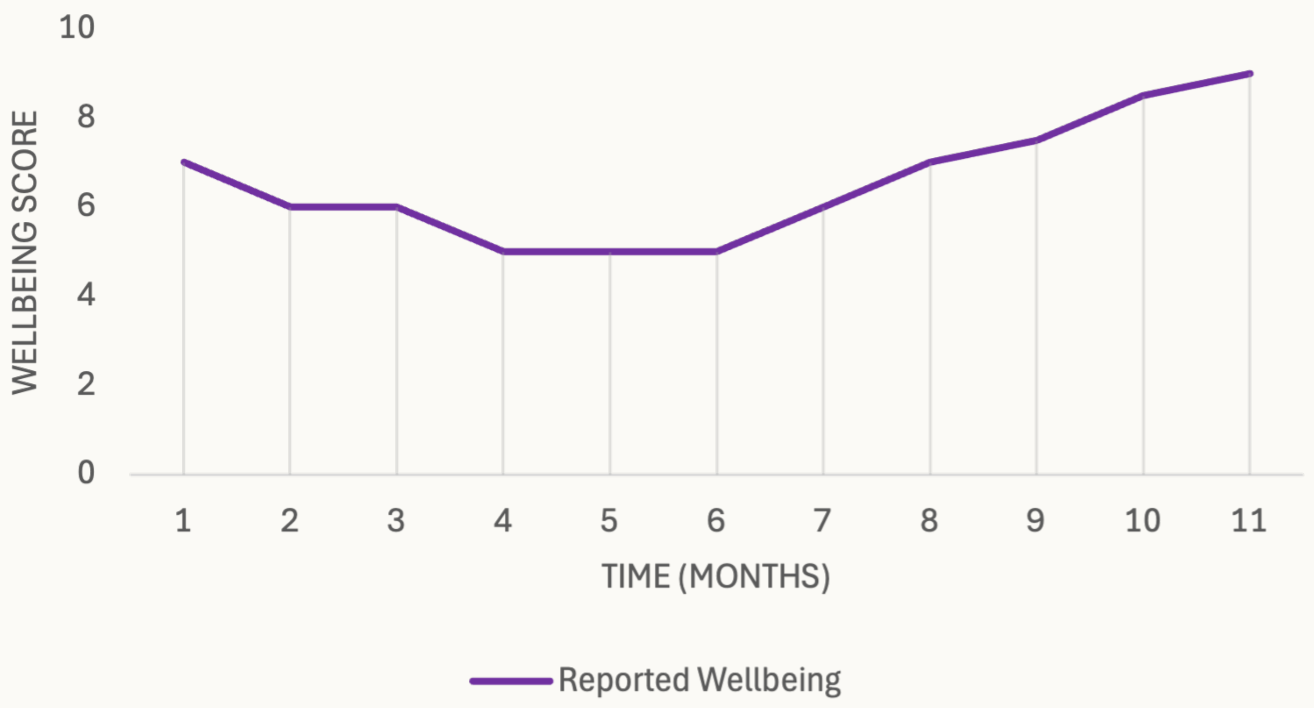
Overall, organisations reported that people with learning disabilities engaged meaningfully only when questions were visual, concrete and emotionally familiar; standard numerical or abstract scales often led to vague or overly positive answers.

## Theme 4: Concerns about comparing changes in wellbeing outcomes over time

Many – but not all – of the organisations we heard from expressed concerns about comparing responses on wellbeing questions over time. They described a pattern we refer to as the "J-curve effect". This is where self-reported wellbeing or quality of life appears to decline at the start of a programme before improving over time. It can make organisations nervous about relying on quantitative measures to capture the impact of their interventions as the measured change will depend on when in the support outcome questions are asked.

We present an illustrative example of how this effect could impact reported scores in figure 5.

## Figure 5: Illustration of J-Curve effect in reported wellbeing among people with learning disabilities




Notes: Time (months) begins at the point when support starts (Month 1) and ends when support concludes (Month 11). The vertical axis shows reported wellbeing, measured using a standard life satisfaction scale (for example, the ONS 0–10 scale).

Source: PBE illustrative example (not based on real data)

This concern is not unique to studies focused on people with learning disabilities. Wellbeing studies often assume people can easily and consistently rate how happy they are but, in reality, our answers are influenced by mood, personality and how we think. This is known as a response shift.[18] This means the same person might give a different answer later, not because life has changed but because their judgement of life has changed. This can also happen when people become more self-aware or begin to reflect more deeply on their experiences, which can initially make them feel worse.[19]

18 Bruce D Rapkin & Carolyn Schwartz, Toward a theoretical model of quality-of-life appraisal: Implications of findings from studies of response shift. Health and Quality of Life Outcomes (15 March 2004)

19 J. A. Lyke, Insight, but not self-reflection, is related to subjective well-being. Personality and Individual Differences, (2009)

While a common concern in wellbeing research, the organisations we spoke with felt this "J-curve" effect may be more pronounced for people with learning disabilities. Some highlighted, for example, that people with learning difficulties are often told how lucky they are to receive support. This can lead to immediate responses to questions about their wellbeing that reflect what has been repeated to them since a young age. Additionally, it was highlighted that some people with learning disabilities may want to give a pleasing response when they are concerned about the feelings of the person asking.

Many respondents also highlighted the role of trust in shaping how people respond to wellbeing questions over time. It was emphasised that, as relationships and trust develop with those involved in a particular programme, communication improves and service users feel that they can be more open and honest about the challenges they are facing. This may also contribute to the "J-curve" effect.

Organisations also discussed options for how this issue could be addressed in practice, acknowledging the need to combine multiple sources of evidence – such as asking questions across different life areas and capturing more qualitative information. For example, the LGA referenced the Better Life survey, where short explanatory videos developed with Speak Up in Rotherham and featuring people with learning disabilities were used to help councils consistently explain survey questions and their purpose.[20]

## Theme 5: Different organisations have different needs from a more standardised approach to measuring wellbeing

People with learning disabilities are often supported by a broad network of individuals and organisations, including family members, paid carers, support workers, social care providers, NHS services, housing associations, and local authorities, all of whom contribute to their day-to-day wellbeing. Having a standardised wellbeing measure could bring more consistency to understanding the impact across these different organisations. This would have particular benefits at a commissioning level, where wellbeing information is drawn together from multiple frameworks and qualitative sources forming an inconsistent and "patchy" picture.

Our stakeholder discussions suggested that a wellbeing measure would indeed be valuable across these settings, helping to assess whether support is improving lives and to improve decision-making. The organisations we spoke to highlighted that they want more information about whether the people they support are thriving, struggling or need urgent support. They also noted their need to collect evidence of their impact to support funding decisions, commission services or assess quality, including regulators such as the Care Quality Commission (CQC).[21]

20 Open Letter to Commissioners of Learning Disability Services (November 2025) - YouTube

21 For organisations that support people with learning disabilities, CQC requirements strongly influence how services collect information, demonstrate outcomes and evidence improvements in wellbeing.

Nevertheless, our conversations also highlighted differing evidence needs across individual organisations and across stakeholder groups. Figure 6 summarises the different discussions, detailing what each group said they would need from a wellbeing measure and the types of tools or approaches that would best support them.

## Figure 6: Stakeholders, their needs, and the wellbeing measurement tool for people with learning disabilities

| Stakeholders | Need | Wellbeing measurement tool | |
|---|---|---|---|
| | | Quantitive | Qualitative |
| Charities and service providers | Charities need a wellbeing tool that is practical to use day-to-day, captures person-led and context-specific wellbeing, and demonstrates impact to funders, regulators and families. They require an approach that supports reflective practice, works across diverse learning disability profiles, aligns with CQC expectations and Care Act domains, and is sensitive to phenomena such as the J-curve effect. | Accessible domain-based scales; standardised measures that can be linked to cost–benefit and WELLBY valuation; questions that show directional change over time. | Narrative logs, session reflections, stories of change, and examples showing how adjustments in support affect wellbeing. |
| Families, carers and support workers | Families and frontline staff observe day-to-day changes that a person may not express directly. They need a tool that helps them record shifts in wellbeing, track “good days” and “hard days,” communicate concerns to social workers or clinicians, and advocate for appropriate support. This is particularly essential for people with profound and multiple learning disabilities (PMLD) who may not be able to self-report in a traditional way. | Behavioural indicators, pattern-tracking questions, proxy-supported scales; accessible domain-based scales | Observational notes, family reflections, insights, and interpretations of sensory or emotional responses |

| Stakeholders | Need | Wellbeing measurement tool | |
|---|---|---|---|
| | | Quantitive | Qualitative |
| Health professionals | Health professionals need a wellbeing tool that goes beyond symptom reduction and helps them understand how a person is doing across different areas of their life. They need something that can capture changes in day-to-day functioning, support person-centred conversations, track progress over time, and complement clinical outcome measures. | Short, domain-based scales that can track change over time alongside clinical measures; simple indicators that reflect functioning and quality of life. | Session reflections, patient narratives, and examples of changes in daily life that help interpret progress beyond symptom scores. |
| Housing associations | Housing associations need a wellbeing tool that helps them understand how housing and the living environment affect tenants' quality of life, particularly for people with learning disabilities. They need something that can capture day-to-day experiences at home, identify risks to sustaining tenancies, support planning with other care providers, and demonstrate impact to regulators and funders. | Accessible domain-based scales focused on housing-related wellbeing (e.g. safety, independence, environment); simple indicators linked to tenancy sustainment and quality of life. | Tenant stories, "good day / hard day" reflections, observational notes on how the home environment supports or hinders wellbeing, and case studies showing changes over time. |
| Lived experience groups | People with learning disabilities need a tool that allows them to express how they feel in ways that genuinely work for them. They told us they want to be understood, influence decisions about their lives, feel heard, and contribute to shaping their own support. The tool must reflect their priorities and allow wellbeing to be shared through words, images, emotions, symbols or behaviour. Their insight emphasises the importance of using LD-specific wellbeing domains that capture what matters in everyday life (e.g., relationships, routine, safety, sensory comfort, communication access). | Accessible domain-based scales; supported self-report questions tailored to different communication needs. | Lived experience narratives; examples of "good days" and "hard days"; symbols, photos or objects to express meaning; and observational notes. |

| Stakeholders | Need | Wellbeing measurement tool | |
|---|---|---|---|
| | | Quantitive | Qualitative |
| Local authorities and commissioners | Local authorities need a wellbeing tool that helps them monitor service quality, meet their duties under the Care Act 2014, and provide evidence for the CQC. Ideally, they require consistent and comparable wellbeing information that can: (a) demonstrate whether services are improving people's lives; (b) identify unmet needs or safeguarding risks; (c) inform commissioning, inspections and contract renewal; and (d) support economic evaluation, including cost–benefit analysis aligned with the HMT Green Book. | Standardised wellbeing indicators that can be linked to cost–benefit and WELLBY valuation; accessible domain-based scales. | Case studies, observational summaries, individual progress narratives that provide contextual understanding of outcomes. |
| Researchers and evaluators | Researchers require an approach that is methodologically robust, capable of detecting change over time, and suitable for comparison across groups or services. They also need data that can support economic valuation, including WELLBY calculations, life satisfaction mapping, and HMT Green Book analysis. | Standardised measures that can be linked to cost–benefit and WELLBY valuation; longitudinal datasets; longitudinal data enabling control-group comparisons. | Contextual information, such as focus group discussions, interviews to interpret quantitative change, and insights into how the tool functions in practice. |
| Trusts and Foundations | Trusts and foundations need a wellbeing tool that helps them understand what difference their funding is making across key areas of people's lives. They need an approach that can capture changes across relevant domains, compare impact across programmes, and demonstrate value for money through cost–benefit analysis. | Domain-based measures that can be aggregated and linked to cost–benefit analysis (e.g. WELLBY valuation); consistent indicators that allow comparison across projects. | Case studies, stories of change, and beneficiary insights that show how and why outcomes have improved. |

Notes: The stakeholders listed in this table are arranged alphabetically for ease of reference and do not indicate any hierarchy or relative importance.

Source: PBE review of evidence on measuring wellbeing among people with learning disabilities

Broadly speaking, the need of various stakeholders for a more standardised quantitative wellbeing measure fell into two broad categories:

- **Understanding the underlying drivers of wellbeing:** This is to help understand how and why the overall quality of life for service users is changing. This would help to prioritise and shape services delivered as well as communicate the difference that the support makes.

- **Value for money assessments:** This would allow organisations to demonstrate the economic impact of their work in ways that funders and governments recognise. This is currently challenging for those working with people that have learning disabilities, with a sense that established approaches are difficult to implement or potentially undervalue changes for people with learning difficulties.

Developing approaches that can meet each of these needs in turn has the potential to ensure that decisions are made with a better understanding of their impact on the lives of people with learning disabilities. Capturing the aspects of wellbeing that matter to people with learning disabilities would be hugely beneficial for local authorities, commissioners and charities alike.

# 4: Recommendations

Given the challenges outlined and the range of different needs across stakeholders, we should not expect to move towards consensus around any one single wellbeing indicator. We can nevertheless develop a framework that allows for the establishment of a more consistent suite of options that can be used in different settings. In doing so however, there are important trade-offs that we must hold in mind: between simplicity and precision, for example, and between building on what already exists and tailoring new approaches specifically to the needs of people with learning disabilities. [22]

Against this backdrop, our recommendations are designed to help organisations, and the broader sector, take practical steps towards developing an approach to impact measurement that can work for all.

### Recommendation 1: Develop and test a set of questions tailored specifically towards the wellbeing domains of people with learning disabilities

Through our evidence review and discussion with the lived experience groups, we have identified a clear interest in understanding how services impact on the key drivers of wellbeing for people with learning disabilities.

In the short-term, there are tools that already exist that capture some of the learning-disability-specific domains of wellbeing identified through our engagement with stakeholders. We would recommend that stakeholders looking for an understanding of how their work impacts on these drivers of wellbeing identify those domains of wellbeing that feel most important for them and choose the tool that most closely aligns.[23] Figure 7 provides a starting place for considering this.

22 Christina Nicolaidis et al., "Creating accessible survey instruments for use with autistic adults and people with intellectual disability: Lessons learned and recommendations." Autism in Adulthood (1 March 2020)

23 Note, we would not recommend that organisations pick individual questions from within each of these surveys as their validity has only been assessed as a whole. It will provide more robust evidence of impact if all the questions from a particular toolkit are used together.

## Figure 7: Coverage of identified wellbeing domains across existing measurement tools

| Domain | Measures that align |
|---|---|
| 1. Emotional wellbeing | POS, WEMWBS-ID, GAS-ID |
| 2. Safety & predictability | ASCOT |
| 3. Relationships & belonging | POS, ASCOT |
| 4. Ability to communicate effectively | No strong fit, best available: POS, ASCOT |
| 5. Daily activities, purpose & enjoyment | POS, ASCOT |
| 6. Independence & control | POS, ASCOT |
| 7. Sensory comfort & environment | EQ-5D-3L |
| 8. Self-expression | No strong fit, best available: POS, ASCOT, WEMWBS-ID |
| 9. Physical health and functioning | EQ-5D-3L, Care Act 2014 |

However, given that no existing tool captures all the domains relevant to people with learning disabilities, we think there is a case for additionally developing and testing a new set of questions that specifically target the domains of interest for people with learning disabilities. In particular, domains related to the ability to communicate effectively, and self-expression are not currently covered effectively within existing tools.

Importantly, any new measures developed need to retain a strong focus, not just on strict analytical precision, but on practical application within typical service environments. This means that they need to be limited to a minimal number of questions and supported by effective guidance (see recommendation 3). They should also complement, rather than replace, the rich qualitative and observational data that organisations already collect, helping to strengthen and triangulate understanding of wellbeing (see recommendation 4).

## Recommendation 2: Establish an evidence basis for using a government-approved question as the anchor for the wellbeing valuation in economic evaluation

For some of the organisations we've spoken with, the primary motive for finding an appropriate wellbeing measurement methodology is its potential for facilitating a subsequent value for money assessment. But this opportunity is not currently open to many organisations working with people with learning disabilities. If the standardised questions used for these kinds of value for money assessments – that rely on abstract questions, numerical scales and reflective thinking – cannot be understood, then data cannot be used.

This leaves us with a challenge: how can we collect wellbeing information in ways that people with learning disabilities can meaningfully engage with, while still producing data that commissioners, funders, governments and researchers can use for comparison and economic evaluation?

A practical answer may lie in using a question that is already built for social care settings and building evidence to align it with established approaches for wellbeing valuation. Wellbeing measures have gained greater policy relevance and attention since HM Treasury published new guidance about their use for analysing the impact of policies.[24] This guidance supported the use of standardised measures, such as the ONS life satisfaction measure, in value for money assessments of government policies. These techniques have offered great opportunities to help demonstrate the value of charity interventions.[25]

We therefore recommend anchoring any new measurement in a question that is already tested in adult social care, government-approved, and designed with accessibility in mind. We believe a strong candidate for this is the Adult Social Care Survey (ASCS) question: "Thinking about all the different things in your life, good and bad, how would you say you feel about your life in general?"

Unlike the ONS life satisfaction question, the ASCS question has been tested specifically in adult social care settings, includes an easyread version, and uses concrete, easy-to-understand response options (such as "really great" to "really terrible"). It is also already familiar to many local authorities and service providers. This aligns well with the reality that many organisations operate within adult social care frameworks and routinely use ASCS based information to assess quality and outcomes.

The challenge is that there is not yet an evidence pathway linking improvements in this outcome to an HM Treasury endorsed economic valuation framework. We believe that new evidence needs to be invested in to support this.

We would suggest conducting a simple mapping exercise to provide a translation between responses to the ASCS question and responses to the ONS life satisfaction question (used in existing HM Treasury guidance). This mapping exercise would follow established approaches.[26]

24 Green Book supplementary guidance: discounting - GOV.UK, HM Treasury (21 April 2013).

25 Sara MacLennan and Jon Franklin, Helping funders to measure what matters, PBE (May 2025)

26 Isaac Parkes, The C-WELLBY: Towards a Universal Measure of Children's Wellbeing for Policy Analysis, Centre for Economic Performance, LSE (15 April 2025)

First, a representative sample of the general population answers both the ASCS question and the ONS life satisfaction question. Second, this then makes it possible to map how the ASCS categories correspond to life satisfaction scores. Finally, these changes can then be translated into an economic value drawing on HM Treasury guidance for valuing life satisfaction improvements.

### Illustrative mapping between ASCS "Life in General" responses and ONS life satisfaction scores

ASCS-style responses → LS score → WELLBY value

For example, a movement from "Really terrible" to "Okay" on the ASCS question could be the equivalent of a 2-point improvement on the ONS 0-10 life satisfaction scale. If sustained for a year, this would be the equivalent of a two WELLBY increase, associated with a monetary benefit of around £32,000 (in 2025 prices) based on HM Treasury guidance.

## Recommendation 3: Ensure that these tools provide a multi-format delivery with a "guiding tool" to support people with a range of capabilities to respond.

A single method of delivering outcome surveys is not inclusive enough to support the wide range of capabilities across different people with learning disabilities. A message that we consistently received and understood from the evidence review was how the wellbeing questions are delivered matters, just as much as what is being asked.

Charities described how delivery method makes a difference to who is willing and able to respond: some who struggle with reading may express themselves clearly using photos or objects; some may need to hear a question in audio format; while some may need the reassurance of a video introduction delivered by a person with learning disabilities. And for people with profound and multiple learning disabilities (PMLD), wellbeing is primarily understood through observation, expressions and/or sensory cues.

Our lived experience groups echoed these findings. Participants emphasised that they need time, choice, and trust-building when responding to surveys about wellbeing. Familiar formats make the real difference and can determine whether the question feels approachable or overwhelming. We also learnt that supporters and carers often play a crucial role in helping to measure wellbeing, but that they too need guidance so they not only know what to ask but how to ask and to avoid leading or rephrasing the question incorrectly.

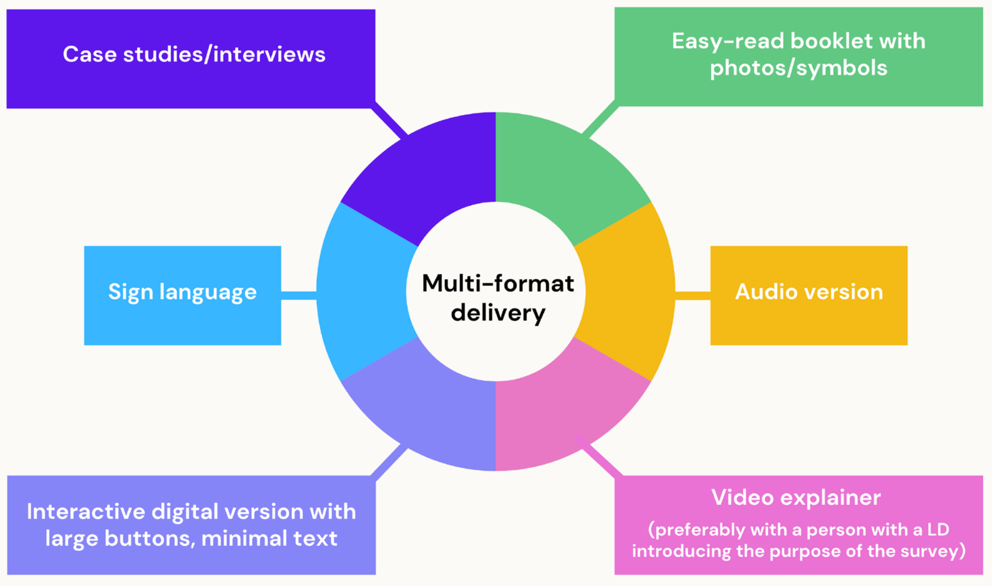
We recommend that wellbeing measures for this population consist of a multi-format delivery – with accessible easy read formats supported by audio and video explainers of questions – supported by a "guiding tool" that helps organisations choose the right model of delivery for each person, depending on their capabilities (see figure 8).

## Figure 8: Three-step approach to delivering wellbeing questions tailored to different needs of the respondents

### Step 1: Determine the level of support needed

| Level | How it works | Method |
|---|---|---|
| Independent | Person reads/hears question and answers on their own | Easy read with photos/symbols |
| Supported | Questions are read, prompted, and explained by a carer, family member or support staff | Supported surveys, potentially with answers entered by carer, family member or support staff |
| Observed | Responses are not given directly but understood through behaviour and reactions, using input from carers or staff who know the person well | Facial expressions, engagement, signs of comfort or distress interpreted by carer, family member or support worker |

### Step 2: Select the most appropriate delivery format




### Step 3: Provide a guiding tool with instructions for supporters and carers on how to administer the surveys

Using surveys that follow a flexible approach may enable people with learning disabilities to express their wellbeing in ways that feel comfortable, familiar and respectful. And at the same time, could protect the credibility needed for the evaluation as the wellbeing questions remain the same, even if the format varies.[27]

27 Katherine E McDonald et al., Facilitating the inclusion of adults with intellectual disability as direct respondents in research: Strategies for fostering trust, respect, accessibility and engagement, Journal of Applied Research in Intellectual Disabilities (January 2022)

## Recommendation 4: Formulate stronger guidance for capturing changes in wellbeing over time

Given the concerns raised about the reliability of comparing outcome measures at two points in time, it is likely to be helpful to establish stronger guidance around how to manage the risks associated with this. This is likely to mean going beyond the "traditional" evaluation approach of gathering a single measure at the start of an intervention and a single measure at the end of the intervention.[28]

We believe there are two components of this: first, gathering more frequent observations using quantitative tools; and secondly, taking a more consistent approach to triangulating different types and sources of evidence.

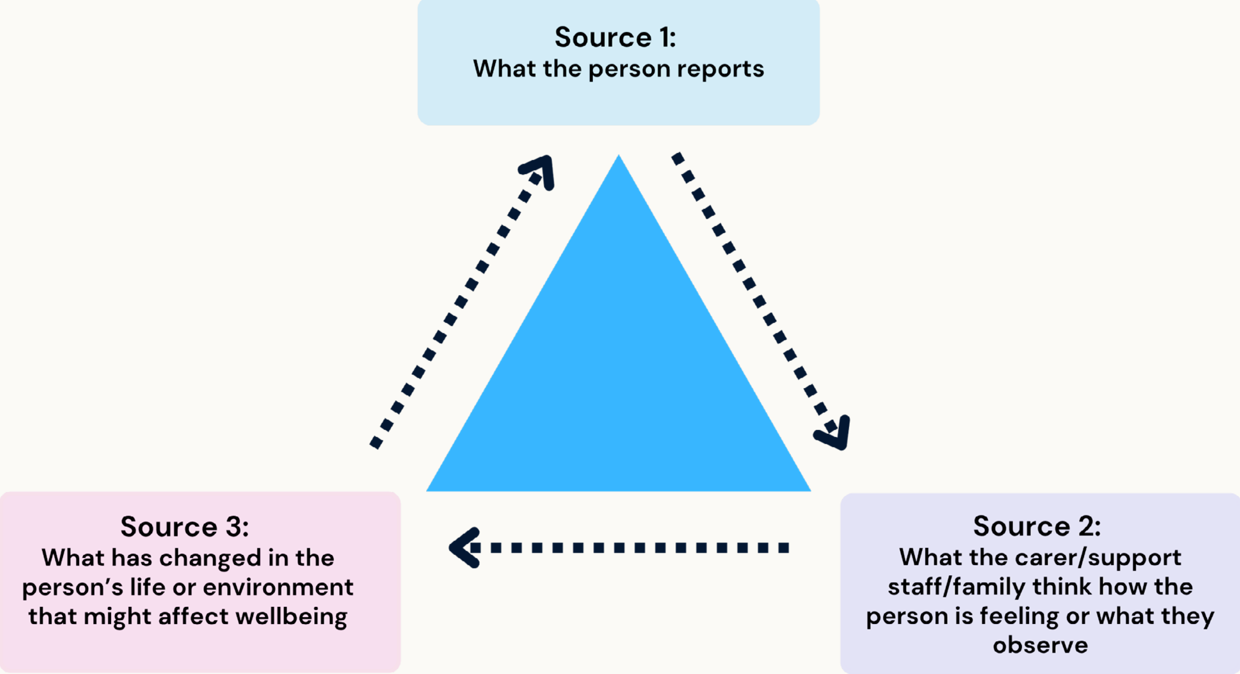
It can be difficult to pin down exactly how often measures need to be taken as it will depend on the nature and context of support being provided. However, it's likely that as well as the traditional before and after measures it would be useful to capture at least one additional interim measure at a point where organisations and their service users feel that "trust" has been established. At this stage, the selection of the exact timing of this will vary from service to service and is probably best left to those that know the intervention best. However, over time it's possible that more evidence can be built up to assess the scale of the J-curve effect, and the contexts in which it seems most important.

We also recommend using triangulation as an approach to interpreting wellbeing scores over time for people with learning disabilities.[29] Figure 9 summarises the approach, with three sources of data being used. First, self-reported wellbeing scores from the service user (wherever possible). Secondly, proxy or observer insight. This means asking a carer or loved one of the service users to provide their assessment of how they are doing. Finally, observational, environmental or contextual data that will inform whether there have been any changes in the individual's life circumstances. Across all three sources, both quantitative and qualitative information can be captured, depending on how tools are designed and applied in practice.

28 In practice, many organisations supporting people with learning disabilities provide ongoing support without a clear start or end point, meaning that wellbeing is often tracked more continuously over time.

29 Triangulating visual and verbal data to enhance research interviews with people with learning disabilities

## Figure 9: Measuring wellbeing using the triangulation approach




A recurring message from stakeholders is that progress cannot just be captured through numbers or scores alone. Instead, wellbeing may need to be understood through multiple approaches that bring together different sources of information and observations with which we can get a reliable picture of change over time.

## Recommendation 5: Create a new longitudinal research study focused specifically on people with learning disabilities

A lot is now known about what drives wellbeing in the general population, but we still lack a similar and comprehensive understanding for people with learning disabilities. A key reason for this is that, alongside the standardised measures of wellbeing developed by the ONS, there are a number of rich longitudinal studies for the general population that have allowed people to disentangle the effects of a host of different factors on wellbeing.

In addition, longitudinal datasets that collect a host of socio-demographic data of people also provide a valuable source of information to compare the outcomes of interventions against. Wellbeing data, collected before and after by providers, can then be matched to similar people in these longitudinal datasets to provide a higher-quality more robust evaluation of the true impact of a policy or intervention.[30] Unfortunately, this is type of longitudinal data does not exist for people with learning disabilities and while some datasets do include individuals with learning disabilities, sample sizes are often too small to support robust analysis.[31]

30 Typically taking organisations from level 2 to level 3 in the Nesta Standards of Evidence framework.

31 For example, existing longitudinal datasets such as Understanding Society include relatively small samples of people with learning disabilities, limiting their use for robust analysis.

We recommend that there is a national effort to gather a representative, longitudinal dataset for people with learning disabilities. Having this evidence will enrich our understanding of the experiences of people with learning disabilities, while also providing comparison groups that help us understand what would have happened in the absence of a particular programme or service, which in some cases may mean remaining in more restrictive or less supportive environments. And importantly, to understand what is the additional impact of the programme or service that they are part of. Year after year, such data can be analysed to support robust evaluations, track long-term outcomes and strengthen the evidence base for interventions that support people with learning disabilities.[32]

## Figure 10: The use of a comparison group and intervention group to strengthen evaluations of interventions

| Intervention group | Comparison group |
|---|---|
| People with similar characteristics supported directly by the provider/service | People with similar characteristics (e.g., age, level of support needed, learning disability profile) taken from a national dataset |
| Receives the intervention/service | Does NOT receive the intervention/service |
| Provider collects baseline wellbeing measure in 2025 | Dataset includes baseline wellbeing measure collected in 2025 |
| Provider collects endline wellbeing measure after service completion in 2026 | Dataset includes follow-up wellbeing measure in 2026 |
| Change in wellbeing reflects the effect of receiving the service | Change in wellbeing reflects what would have happened anyway |

Once wellbeing changes for both groups are compared, we can estimate the additional improvement caused by the service (the impact). This impact can then be converted into monetary benefits using HMT Green Book valuations. For example:

**"Charity A delivered around £X in benefits for every £Y spent"**

32 For example, the #BeeWell programme has created a large-scale wellbeing dataset for young people, opening up new opportunities for analysis and understanding for a previously under-served population.

# 5. Conclusion

**Our evidence review set out to answer a simple question: how can we measure wellbeing among people with learning disabilities? Early on, it became clear that the voices of people with learning disabilities are being narrowed into tools that have not been designed with them in mind. As a result, they have been excluded from the evidence base that shapes decisions about funding, service design and policy – a gap that overlooks a population of people who tend to achieve worse outcomes across a host of areas.[33]**

Across every strand of our evidence review, a similar message emerged: wellbeing for this population is experienced and expressed in ways that existing standardised measures simply may not be capturing. We have found that wellbeing, for some, rests on domains that capture emotions, safety, relationships, communication, day-to-day activities that bring purpose and enjoyment, independence and control, sensory comfort and the environment, and identity, having autonomy and self-expression. While there is a strong overlap with many of the drivers of wellbeing identified for the general population, some of these domains may not be picked up by conventional wellbeing frameworks. In addition, scales that are abstract with numbered ratings are often inaccessible and ineffective for understanding the wellbeing of people with learning disabilities.

This tension between accessibility and rigour of the evidence shapes how frontline providers have approached their own ways of measuring wellbeing. But this, non-standardised and inconsistent approach to measuring wellbeing can make it challenging to communicate impact effectively.

Yet different stakeholders - like providers, commissioners, governments, researchers, NHS mental health staff, funders, housing associations – need reliable data to understand whether support is working. More importantly, there is a risk that the voices of the people with learning disabilities are being ignored when it comes to designing and delivering policies.

Our recommendations suggest some initial steps towards addressing this gap: identifying and using learning disability specific wellbeing domains; anchoring economic impact measurement in an accessible and tested question; using multi-format delivery; interpreting wellbeing through triangulation; and finally, increasing national efforts to collect longitudinal data to deepen our understanding of the experiences of people with learning disabilities. Taken together, these recommendations aim to improve research on wellbeing and economic analysis of this underrepresented population. Importantly, these approaches are intended to complement, rather than replace, the qualitative and observational data already collected by organisations, helping to make measurement more meaningful without adding unnecessary burden.

33 Spotlight on Poverty: People with Learning Disabilities, British Association of Social Workers (22 February 2023)

Most importantly, this evidence review has shown that people with learning disabilities should be made a priority when it comes to the process of defining and measuring their own wellbeing. Our discussions with them have helped us to re-think existing frameworks, methodologies and grounded the recommendations through lived experience.

Ultimately, as one of the organisations we spoke to stated,

> **"We want everybody to feel like they're seen, they're heard and they belong in society".**

Economics to improve lives

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