



Using scrutiny to drive outcomes: Improving quality of life for people with learning disabilities in Scotland

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Foreword



The Scottish Government wants to improve the lives of people with learning disabilities.

This report is one of a series commissioned by the Scottish Commission for Learning Disability on behalf of the Scottish Government to understand how we can achieve that change.

Scotland's learning disability strategy, *The keys to life*, seeks to improve the quality of life for people with learning disabilities so that they live longer healthier lives, participate fully in all aspects of society and prosper as individuals.

Health and social care provision plays a significant role in the lives of people with learning disabilities. At its best, it can help to ensure that people have greater choice and control over their lives, the opportunity to live as independently as possible and the chance to be active citizens. When it fails however it can achieve the opposite.

Effective scrutiny of service provision is therefore vital, whether through inspection, audit or investigation. This requires an appreciation of the lived experiences of people with learning disabilities and ways in which policy is seeking to transform those experiences. By the same token people with learning disabilities need to be able to understand the means by which the services they receive are being scrutinised.

However effective scrutiny is not simply about improving the quality of care on a day to day basis, critically important though that is. It is also about driving better outcomes so that the quality of services people receive has a real impact on their lives over the long term.

This report was commissioned to help us think about ways in which we can ensure that scrutiny of services does that. It draws on the experiences and perspectives of those involved in undertaking scrutiny, agencies who deliver services and, crucially, people with learning disabilities themselves.

We hope it will provide a platform for dialogue between those groups which will strengthen the connection between scrutiny and improvement which supports the delivery of the Scottish Government's ambitions for people with learning disabilities.

Chris Creegan

Chief Executive, SCLD

A handwritten signature in black ink that reads "Chris Creegan".

Key Messages

A human rights approach to improving quality of life

The planning and delivery of public services in Scotland is rooted in a human rights approach which aims to tackle inequalities and secure a better quality of life for everyone. The Scottish Government has made a commitment to effective scrutiny of public services as part of this approach and this has developed over the last decade, especially in health and social care where the emphasis is around improving health and access to services. People with lived experience of learning disabilities value the support they get from services, but say they want more control over their life choices.

The keys to life, Scotland's learning disability strategy, supports this ambition. There are many examples of organisations that plan, deliver and scrutinise health and social care services working with people with learning disabilities to improve outcomes from services. Developing a framework for identifying and sharing best practice across the range of scrutiny mechanisms can support future progress.

The importance of good data and insight

Access to good data and insight is essential to be able to understand the health and social needs of people with learning disabilities. In order to identify any correlation between learning disability and other health factors, and to be able to measure progress in improving health and other outcomes from services, robust data must be available at a national level. Clarity about the 'data markers' that exist for learning disability can help improve analysis and scrutiny so that services can demonstrate how they are responding to people's needs, tackling inequalities and improving quality of life.

Effective community leadership

Councillors' scrutiny role is a largely untapped resource that can add value to local and national assurance of progress on improving the quality of life for people with learning disabilities. A place based, whole system approach that brings together commissioners, providers, scrutiny bodies and people with lived experience of learning disabilities can help take a life course approach to improving quality of life.

Recommendations

Based on the key messages, the following actions are recommended to strengthen the impact of scrutiny of health and social care services:

- develop a set of clear ‘people focused’ indicators so there is a more consistent approach to how organisations measure and demonstrate progress towards delivering the ambitions of people with learning disabilities. This will help Scottish Government, scrutiny bodies and people with learning disabilities to judge whether services are improving the quality of life for people with learning disabilities
- develop a consistent approach to scrutiny of health and social care services that involves all scrutiny bodies incorporating learning disability specific measures in their work, together with a clear approach to measuring and demonstrating the progress being made by health and social care partnerships in local leadership for issues which affect people with learning disabilities. This will help create a whole system approach to improving the quality of life for people with learning disabilities
- develop a consistent approach to the capture and analysis of data for learning disabilities. This will help services to understand the health and other needs of people with learning disabilities, to understand any correlations between learning disability and other health factors and to measure and demonstrate progress in improving health and outcomes from services for people with learning disabilities
- develop a programme of practical guidance and support to strengthen the impact of scrutiny of learning disability issues with a wide range of stakeholders (including people with learning disabilities and voluntary, community and social enterprise organisations). This will help to showcase good practice, to share and test the outputs from this project and to agree actions for the future in the context of a human rights approach to improving the lives of people with learning disabilities
- develop a programme of practical guidance and support to strengthen local community leadership and local scrutiny of progress on issues relevant to learning disability. This will help bring together councillors, health and social care partnerships, commissioners, providers, scrutiny bodies and people with learning disabilities to develop characteristics of good scrutiny, which will help develop a whole system and life course approach to improving quality of life.

About CfPS

CfPS is the leading national body promoting and supporting excellence in governance and scrutiny. CfPS believes that embedding the principles of transparency, accountability and involvement into organisational culture and processes leads to better decisions and improved outcomes. CfPS works throughout the UK, providing specialist training and consultancy to individuals and organisations looking to improve their governance and scrutiny skills, culture and processes.

About SCLD

SCLD is an independent charitable organisation. It is the lead strategic partner with the Scottish Government in the delivery of Scotland's learning disability strategy The keys to life. SCLD commissioned CfPS on behalf of the Scottish Government to understand the landscape of scrutiny of health and social care for people with learning disabilities in Scotland and how it can be used to drive outcomes.

Note about language

Throughout this report, we use the term 'learning disability'. We recognise that some people prefer the term 'learning difficulty' and this is the term used by People First (Scotland), the national self-advocacy organisation.

Scotland's ambition for people with learning disabilities

Scotland has a 10-year strategy to improve the quality of life for people with learning disabilities. The keys to life was published by the Scottish Government in 2013 and is based on a commitment to human rights for people with learning disabilities. The poor health and early mortality of people with learning disabilities is a major challenge for policy makers and service providers. Understanding and tackling the health inequalities experienced by people with learning disabilities are priorities for action.

In 2015 the Scottish Government and the Convention of Scottish Local Authorities (COSLA) published an Implementation Framework for The keys to life. The Framework has four strategic outcomes, aligned to the United Nations Convention on the Rights of People with Disabilities (UNCRPD), as reflected in Scotland's National Action Plan for Human Rights and the recently published draft national delivery plan for the UNCRPD.

Methodology

This report is based on face to face and telephone interviews, along with desk research, about the scrutiny landscape for health and social care services in Scotland. Early desk research identified key delivery partners across Scotland, from which we selected a sample of organisations to speak to. It was important that organisational input was captured from across sectors and key organisations were identified from the health and social care sector, the voluntary, community and social enterprise sector and the scrutiny sector. Given the breadth of engagement and the timescale of the work, we were only able to speak to a small number of organisations within each of these sectors. Organisations were selected for one or more of the following:

- geographical coverage
- population representation
- role and remit of organisation
- role in scrutiny processes.

Our key messages and recommendations are based on the insight gained during these interviews. A key element of this work was the input of people with learning disabilities themselves about their understanding and experiences of scrutiny processes in Scotland. We were able to test our understanding of the issues with people with lived experience of learning disabilities. Our overarching conclusion from engagement is that scrutiny of health and social care services for people with learning disabilities in Scotland could be strengthened to improve the consistency and effectiveness of assurance of progress towards meeting Scotland's ambitions for a better quality of life.

Who we spoke to

We interviewed people who work for scrutiny and oversight bodies, who have a responsibility for overseeing performance and ensuring accountability, local authorities, health boards and voluntary, community and social enterprise sector organisations. We were also able to talk to people with lived experience of learning disabilities who are part of The keys to life Expert Group.

Local authorities

- Edinburgh
- East Renfrewshire
- Inverclyde
- Glasgow
- Borders

Health boards

- NHS Highland
- NHS Borders
- NHS Lothian

Voluntary, Community and Social Enterprise sector

- Inclusion Scotland
- Health and Social Care Alliance
- Capability Scotland
- PAMIS
- Values into Action Scotland

Scrutiny and oversight bodies

- Healthcare Improvement Scotland
- Care Inspectorate
- Mental Welfare Commission
- Scottish Human Rights Commission
- Audit Scotland

A commitment to effective, proportionate scrutiny

'The right questions at the right time'

Member of The keys to life Expert Group

The Scottish Government has rationalised and strengthened the approach to scrutiny of public services over the last decade, building on the human rights approach to delivery of public services. The 2007 'Crerar Review' was commissioned to tackle the issues of complexity within scrutiny in Scotland and sought to establish how scrutiny could be improved through a more proportionate and effective approach.

The review concluded that five principles should govern the application and use of external scrutiny – independence; public focus; proportionality; transparency; and accountability. The review also recognised the important inter-relationship between external scrutiny carried out on behalf of taxpayers and people who use services and internal assurance and self-assessment carried out by organisations as part of good governance.

Building on the review's findings, the Public Services Reform (Scotland) Act 2010 established two new scrutiny bodies for healthcare and social care – Healthcare Improvement Scotland and the Care Inspectorate. Healthcare Improvement Scotland is the national body for the improvement and scrutiny of all registered independent healthcare services and the NHS in Scotland. The Care Inspectorate is the national body for the improvement and scrutiny of local authority social work services and registered care services. Following on from the Crerar Review, the Scottish Government recognised the public scrutiny role of the Mental Welfare Commission for Scotland.

What do we mean by scrutiny?

Scrutiny happens in different ways – for example, through involving people in decisions about planning and delivering services, through citizen-led scrutiny, through internal review and challenge and through external scrutiny and investigation. During our interviews, people's descriptions of what scrutiny meant to them and their organisation varied. This reflects CfPS's experience that scrutiny exists in many forms, both formal and informal, internal and external to organisations.

Examples of descriptions of scrutiny mentioned by interviewees:**Internal facing:**

- part of governance – link between objectives, standards, quality and reality
- formal monitoring and independent external review
- a ‘critical friend’
- asking challenging questions that lead to better thinking, better decisions, better outcomes
- looking at things closely, ensure we are doing what we say
- not just about compliance but about assurance of outcomes
- evaluating against a benchmark
- sense check against intentions and measures

External facing:

- helps challenge organisations to hear the user voice
- should put people in the driving seat of choice and control
- helps to focus on people and how to join up services around them
- involve people, enable them articulate their views
- empower people and build capacity
- focus on improvement, promoting good practice and standards
- ‘shining a light’
- public assurance and public protection that can lead to redress when things go wrong

Implementing The keys to life

'Making mainstream services friendly to people with learning disabilities'

Local authority interviewee

The keys to life Implementation Framework and Priorities (2015-17) sets out four strategic outcomes for improving the quality of life for people with learning disabilities:

- A healthy life
- Choice and control
- Independence
- Active citizenship

There are mixed views about the extent to which these outcomes are influencing practice around planning, delivery and scrutiny of health and social care services for people with learning disabilities. Some local authorities and health boards can describe how these outcomes are changing the way their organisations do business. One voluntary, community and social enterprise sector organisation said they recognised these outcomes being expressed in commissioning plans.

Others said the impact of these outcomes was less clear and that guidance about organisational expectations, and a framework for measuring and reporting progress could help embed practice.

Regardless of the approach being taken to implement The keys to life specifically, more needs to be done to make sure that people with learning disabilities are included in mainstream services and scrutiny processes and to make sure there isn't a 'tick box' approach at strategic level that is disconnected from reality at an operational level.

Some voluntary, community and social enterprise sector organisations said that even with the key messages from The keys to life in place, there was still more to be done to embed a human rights approach to health and social care with equity of treatment and positive outcomes for people with learning disabilities at its heart, in line with the social model of disability. This view was re-inforced by people with lived experience of learning disabilities who value the support they receive from services, but who want more control over their life choices and interactions with services which enable this. In terms of scrutiny activity, this means building on good practice where people with learning disabilities are included at a strategic and planning level, for example peer review.

Making progress towards achieving the strategic outcomes could benefit from a package of cross-sector support for strategic leaders, together with training, development and supervision support for frontline staff so that they can better recognise and meet the needs of people with learning disabilities. Some voluntary, community and social enterprise sector organisations mentioned the opportunities to learn from other policy frameworks, for example 'Getting it Right for Every Child' which was supported with guidance and shared learning about implementation.

The Implementation Framework goes some way towards setting out a practical approach, but expected outcomes and measures remain unclear nonetheless.

Effective planning and delivery of services would benefit from a clearer narrative about 'outcomes for people', along with ways of measuring and demonstrating whether those outcomes were being achieved.

The importance of data

Data about the health and care needs of people with learning disabilities and the extent to which good outcomes are being achieved was regarded by many people as important. The Scottish Learning Disabilities Observatory was described by some as a key resource to provide statistical insight about issues relevant to learning disability. Clarity about the 'data markers' that exist for learning disability could help primary care, acute care and mental health services to monitor health and co-relational health issues. For example any co-relation between learning disability and dementia or diabetes. What is important is that services can demonstrate how they capture and analyse data about the needs and experiences of people with learning disabilities and how this drives greater inclusion of people with learning disabilities in to mainstream services. A key element of this is education and training to ensure excellent outcomes from those services together with increased independence, choice and control.

Health and Social Care Partnerships and Integrated Boards

Many of those we spoke to across sectors talked about the integration of health and social care that is currently taking place through the development of health and social care partnerships and integrated boards as implemented from 1st April 2016. People recognised the potential for partnerships and boards to drive effective integrated working across health and social care through collaborative joint commissioning or shared services, focusing on how to best use the totality of healthcare and social care resources in an area to deliver better outcomes for all. They also recognised the challenge of bringing together organisations and processes with multiple and conflicting objectives.

However, some people in the voluntary, community and social enterprise sector thought the current focus on structures and processes associated with integration risked distracting professionals from improving frontline services in the short to medium term. Some people mentioned that health services and local government have different cultures and they were concerned that a 'medical model' rather than a 'social model' might dominate the work of health and social care partnerships. Assurance that Commissioning Plans of integrated health and social care partnerships are effectively capturing the right strategic outcomes and operational indicators will be important.

Impact on scrutiny of services

Healthcare services for people with learning disabilities have been subject to scrutiny by Healthcare Improvement Scotland (HIS) in the past, but the recent focus has been on joint inspections of services for older people and children's services. HIS has no present plans for services for people with learning disabilities to specifically feature in their scrutiny work, although there is a willingness to develop a partnership approach to this

in the future. In the meantime, there may be scope to build learning disabilities into the current HIS improvement support programme 'Living Well in Communities' that aims to support people to spend more time living at home or in a homely setting. The challenge is to build on previous practice in healthcare scrutiny of including people with learning disabilities in scrutiny activity.

The Mental Welfare Commission (MWC) has recently completed a review of learning disability hospital accommodation as part of their national themed visits programme.

The resulting report, 'No Through Road: People with Learning Disabilities in Hospital' (published in February 2016) looked at the following issues:

- Quality of life
- Environment
- Rights and restrictions
- Health needs
- Participation and involvement.

MWC has also started publishing the outcomes of its local visits to places where people with learning disabilities receive services. The Commission also publishes the outcomes of investigations it carries out as part of its case work when people make a complaint about mental health services and some of these relate to people with learning disabilities.

The use of scrutiny to drive outcomes for people with learning disabilities appear to have strongly influenced the work of the Care Inspectorate. For example, the Inspectorate raised the awareness of care service providers for people with learning disabilities about The keys to life and sent printed copies of the strategy. During year 2, providers of care services and care at home services were included in an Inspection Focus Area on The keys to life and were asked about their awareness of the strategy. Amongst 186 care homes surveyed in 2014/15, 90% reported being aware of The keys to life and 65% had, at that point, already started to plan how they would implement the strategy. The Inspectorate's Triennial Review for 2011 to 2014 references its examination of the extent to which care services supporting adults with a learning disability were using The keys to life to influence their practice, and the impact this was having on people's experiences.

Involving people

'What matters to them, not what's the matter with them'

Health Board interviewee

Everyone we spoke to across the sectors described how people with learning disabilities were involved in the way their organisations were run, took decisions or carried out their work. Not all the organisations we spoke to have a specific learning disabilities focus but the principles of involvement and influence were still key. An overarching principle was that scrutiny was about user voices and supporting people to have influence and that visible participation and involvement of people is important.

There are lots of different ways in which people are involved. Organisations often involve people who use services on boards or other types of strategic planning groups, either through personal involvement or through representation.

Families and carers are often also involved at strategic level. What people with learning disabilities say is important, but organisations sometimes find it hard to capture their views, especially when communication can be complex. Investing in ways to capture seldom heard voices is important and families, carers and peer advocacy through user-led or voluntary, community and social enterprise sector organisations can help overcome barriers.

Several organisations had user groups that focus on improving services for people with learning disabilities and we heard examples of involvement that had influenced strategies and changes to services. We also heard about the work of the Scottish Health Council to support health boards to meet the 'participation standard' and heard examples about how people were involved in scrutiny of services.

We heard from one voluntary, community and social enterprise sector organisation that employs people with learning disabilities as 'quality checkers', because they believe anything being done about the lives of people with learning disabilities should only happen with people with learning disabilities being fully involved.

Examples of involvement

The following examples were mentioned by interviewees:

- workshops to develop a community plan for learning disabilities services
- capturing views through 'Talking Points'
- 'Tell it like it is' – a library of personal stories for people providing services
- young people with learning disabilities on transition issues
- people who use services and carers helping to change residential services
- personal outcomes training (raising people's aspirations and expectations of services)
- people involved in inspections and visits (people with lived experience, patient and public partners, inspection volunteers)
- people involved in recruiting staff
- people with lived experience employed as 'quality checkers' or as involvement and engagement leaders
- using the REACH standards – a set of 11 standards as launched by Paradigm which detail the expectations people with learning disabilities have from supported living
- using national learning disabilities week as a focus for developing alternative social opportunities, for example a football team, as well as raising awareness of access to mainstream services
- mystery shopper exercise through health diaries of people with lived experience
- citizens' panels linked to local action plans
- service users making their own videos to show and share their personal experiences

Hearing and understanding the voices of people who use services is important in developing excellent governance and embedding a positive organisational culture. Ensuring that these voices are heard is also a key element in the scrutiny of services, crucial to making a difference to the outcomes achieved. We heard how relational approaches to involvement that centre on co-operation and co-production are important to move beyond token inclusion. Approaches that help to bring professionals together with people with learning disabilities as equal partners are important. However, this needs investment in capacity building to support professionals and people who use services to take part, articulate and understand each other's views.

Voluntary, community and social enterprise sector organisations mentioned that the quality of participation is important, not just levels of activity. Participation should increasingly be based around people's life experience, not just their experience of needing care, to build active citizenship. It is also especially important to recognise that people can have different perspectives beyond learning disability, for example if they are lesbian, gay, bisexual and transgender. Demonstrating an effective approach to equalities issues and inclusion is important.

Assuring progress

All the people we spoke to described how their organisations assured the progress they were making towards achieving their aims and objectives. While some organisations had a learning disability focus to assurance, most assurance processes were not specific to The keys to life.

Nonetheless, those organisations felt confident that they could provide evidence of outcomes for people with learning disabilities.

Assurance processes take many forms and have different names. Many organisations have people with lived experience of learning disability or advocacy organisations represented on advisory boards or other groups with similar functions, for example working groups that provide evaluations of outcomes from actions or an implementation or improvement board. In some organisations, assurance happens through regular management meetings that review performance relating to issues which affect people with learning disabilities. One organisation reported a dedicated quality assurance team looking at how The keys to life is being integrated in to their work. Peer review and shared learning were also mentioned as ways to test performance and learn from practice.

Example of assurance

This example is from a local authority

Local The keys to life action plans were launched in June 2013 covering 1 to 5 years. During year 1 provider groups and service user groups were consulted to establish their priorities about how to address the 52 recommendations. In year 2 the action plans were reviewed by local citizens' panels that included people with learning disabilities and action plans were consolidated against the four strategic outcomes of the Implementation Framework.

A 'flagging process', reflecting 'Strategic outcome 1: A healthy life', means that services are aware someone has a learning disability, so that a liaison nurse can meet them to give the right support. Measures used to check progress are numbers of people reporting concerns about their care, hearing people's experiences and feedback that their "journey" has improved. This is planned to be extended through collating patient stories that will feed into a clinical governance and quality board.

Reflecting 'Strategic outcome 2: choice & control', a 'Keep Safe' initiative has been launched in two towns. If someone with learning disabilities feels upset or vulnerable, they can look for a window sticker which indicates a place where someone has been trained to give help and support. Impact is being measured through the numbers of people using this service.

Three projects in the last 12 months focused on moving people with learning disabilities out of care homes and into supported living, including those with complex needs. Success is being measured through people's stories captured on DVD and improved health and well-being indicators, for example people in their own tenancy. 21 people moved into supported living last year. These projects will be reported to a Partnership Board, including stories and videos, along with an assessment of what has been learnt from the journey.

Self-reporting by individuals was described using 'Talking Mats' or 'Talking Points' to find out what has improved for people or through hearing stories of people's experiences. At least one organisation had commissioned independent assessments to measure the difference they were making. One organisation mentioned the opportunity presented by complaints about services to yield good insight that can lead to improvement.

Inevitably, assurance systems often involved transactional indicators (numbers of activities, for example the numbers of people having health checks, numbers in employment, numbers with self-directed support or numbers of people responding to consultations) that were monitored through internal audit or formal contract management arrangements. Often, these also only focused on financial performance rather than outcomes for people. As well as transactional indicators relating to people who use services, we heard about internal transactional indicators, such as measuring

staff sickness, injuries and retention to inform workforce planning. One voluntary, community and social enterprise organisation mentioned using a formal quality system (BS9001).

Most organisations across sectors recognised that while transactional indicators were useful in assuring progress, good insight about what the numbers mean and what they say about the outcomes being achieved for people is important. This emphasis on using data and insight as evidence to reflect and change practice was illustrated by one local authority, which reported using methodology developed by the Virginia Mason Institute in Seattle to help organisations create value from their services, as defined from the patient's perspective. Other local authorities and health boards mentioned other quality of life type indicators measured at individual level, such as ability to engage in community-based activity, keeping well, staying out of hospital after 12 months.

The impact of learning disability scrutiny

'Changing everything as a result of listening to people with learning disabilities'

Local authority interviewee

Several local authorities and health boards reflected on an increasing involvement of people with learning disabilities in planning, delivering and monitoring services. One local authority said it was 'changing everything as a result of listening to people with learning disabilities'. But not every organisation we spoke to is measuring learning disability specific outcomes, although some such outcomes did feature within overall performance indicators.

Others mentioned using 'lean' methodology to look at specific indicators and ways of working, for example personal experiences of the 'referral to assessment' pathway and workshops that had been held based on patient stories. Others mentioned ways to empower people with learning disabilities to feel more confident in managing their own health, for example through a DVD with actors with learning disabilities, or to empower staff to feel more confident in supporting people with learning disabilities.

Voluntary, community and social enterprise organisations were more likely to say that there is still more to be done to develop a human rights approach to supporting people with learning disabilities that is not just about providing traditional medical and social care services, for example support for jobs, relationships and homes. Some commissioning and provider organisations reported a greater focus on the choices of individuals, for example through self-directed support. One organisation said it used principles advocated by the self-advocacy group People First (Scotland). In some places, staff roles were being changed to become more person centred. One health board described how frequent attendance at accident and emergency was used as an indicator of other support needs, for example designating places of safety for people with learning disabilities.

People across sectors said that one thing that can help increase the impact of scrutiny of learning disability issues and the achievement of better outcomes for people with learning disabilities would be some practical examples, through published narratives and case studies (for example more detailed research about some of the practice mentioned in this report).

External scrutiny

People's experience of external scrutiny in relation to learning disability was very mixed. Comments ranged from 'nobody asks about The keys to life' to 'inspection is user focused and systematic, they ask about The keys to life recommendations and subsequent action'. Different types of external scrutiny were identified – local scrutiny, either through the involvement of people with learning disabilities, their families, carers and advocates or through local commissioning and delivery partners; national scrutiny, either through inspection of health, social care and mental health services or through the Scottish Government and Scottish Parliament, for example through the Justice Committee and the Health and Sport Committee. There was very little mention of scrutiny of the issues affecting people with learning disabilities by local councillors. Where scrutiny by councillors was mentioned, this was about scrutiny of financial performance and safeguarding. These are both important topics for scrutiny, but it was surprising that the value of council scrutiny wasn't more widely recognised and experienced.

People's experience of external scrutiny through inspection was also mixed. Some mentioned the lack of a dedicated national body to scrutinise learning disability issues or a lack of learning disability themes within existing inspections. Others pointed out recent inspections that had a learning disability element. Generally, there appears to be a perception that learning disability issues are largely missing from existing scrutiny regimes, although The keys to life does feature in the work of the Care Inspectorate and the Mental Welfare Commission. Based on the insight gathered through the interviews, scrutiny can be strengthened to ensure that primary, acute and person-centred care can be easily accessed and services are flexible and responsive.

There were some mentions of the NHS Scotland HEAT targets (measure of NHS Scotland performance in key areas which are now incorporated in to local delivery plan standards). These were suggested as a useful way of improving services for everyone but others commented that one of the issues with measuring success for learning disability services is that health and social care targets are not set specifically for people with learning disabilities and that this can have the effect of widening inequalities. Although improvement in health services and health outcomes for the general population might be a proxy for improvements in the health and services for people with learning disabilities, this cannot be guaranteed given people's lived experience of inequalities. Data was mentioned as an issue here, especially the need for clarity about the 'markers' in health and social care records that could provide better insight about how people with learning disabilities interact with health and care services. Building on experience in England, one local authority is working with a university to define a set of 'markers' to enable measurement of whether people with learning disabilities are getting equitable access.

The extent to which scrutiny bodies provide an improvement function is not always clear. Some people described inspections as sometimes 'risk averse' which prevented innovation, others thought there is a greater role for improvement science and process improvement methodology. As part of their assurance processes, it was common for scrutiny bodies to get feedback from providers about the impact of inspections and to share learning.

The keys to life Expert Group

'I have rights – they should be recognised'

Member of The keys to life Expert Group

We talked about scrutiny of health and social care and the outcomes of the interviews and desk research with people with lived experience of learning disabilities who are members of The keys to life Expert Group. We wanted to hear their views about what we had heard in the interviews, what they think services should be doing and the things scrutiny bodies should be asking about.

Choice and control were important themes in the discussion. Politicians and people who run services need to understand the lived experience of individuals and the support they need, respecting their right to live their lives without anxiety, worry or distress. Communicating information in ways that are easy to understand is crucial so that people with learning disabilities can make choices about how to live their lives and so that services can provide the flexible support that people need. This is particularly important when budgets for health and social care services are under pressure, and when people are anxious about how cuts to services might affect them.

People with learning disabilities value the support they receive from services and we heard some examples of services that made a difference – for example health passports and a 'community hub' where people can meet and get advice if they are ill or bereaved. Whilst these kinds of community services are helpful and valued, people emphasised the importance of independence – services don't always have the flexibility to fit around people's everyday lives. We also heard that some services don't always work for everyone, for example the 'queue jumper' initiative to support people with learning disabilities access accident and emergency services isn't always understood by frontline staff.

People think that scrutiny is important and we heard examples of people being involved in inspections carried out by Healthcare Improvement Scotland and the Care Inspectorate. It is also important for services to assess themselves and for services and scrutiny bodies to include people with lived experience. It was suggested that people with lived experience should be employed to carry out scrutiny activities.

Scrutiny should be about asking questions to establish whether the right elements of a service exist, but also asking if the way services are implemented is any good. Good scrutiny questions were identified as 'the right questions at the right time':

- Is it easy for people to say what they need? Are they listened to?
- Do people have others who understand them, to help them speak up?
- What support do people need and how much time do they need to do things?
- Do you get on with the people who support you? Does your support turn up on time? is there enough time to provide the support?
- Are you happy with your support? How easy is it to change things?

Developing scrutiny, increasing impact

'Solve problems, bring people together, outcomes not targets'

Voluntary, community and social enterprise sector interviewee

People recognised that change rarely happens in a vacuum and that setting out national aspirations for people with learning disabilities to experience better health and better services is a good thing. But a consistent message from the interviews is that achieving national aspirations would benefit from further narrative about the outcomes expected and how progress can be better measured and reported, along with a programme of improvement support.

People recognised that expected outcomes need to be clear and should be meaningful and achievable and that reporting measures should be capable of demonstrating year on year progress, for example perhaps over a three-year period. Increasing the impact of scrutiny and of services will mean moving from a 'compliance' culture to a culture that focuses on outcomes for people and builds on the already stated human rights approach.

Outcomes for people - a human rights approach

The Scottish Government aspires to improve the life choices and quality of life of people with learning disabilities. This is about people with learning disabilities being included in every aspect of community life as equal citizens and about the voice of every person with learning disabilities being heard and respected. This doesn't just apply in health and care, but also equality in other aspects of life such as opportunities for people with learning disabilities to develop their skills and talents.

Most people with learning disabilities make decisions affecting their lives every day and it is important that individuals are supported in making their own decisions and deciding for themselves how support and services should be organised to meet their needs. It is also crucial that those people lacking the capacity to make certain decisions for themselves receive adequate support when decisions are made in their best interests.

A service-led approach to supporting people with learning disabilities can sometimes compromise individuals' rights to make choices about how to live their lives. Often, concerns about risk management are in the interests of services, but not necessarily in the interests of the person they are attempting to support. Safeguarding is important, but people with learning disabilities should be at the centre of all discussions, be enabled to self-direct their support where able and supported in ways which are clearly in their best interests where they are unable to do so for themselves.

The Scottish Government has said that The keys to life is one of the ways it will work towards the goals of the UN Convention on Rights of Disabled People. The Convention is based on the principles of respect for dignity; non-discrimination; participation and inclusion; respect for difference; equality of opportunity; accessibility; equality between men and women; and respect for children.

People were keen to avoid further transactional targets. Although they can be important indicators, experience suggests these are rarely the best way to achieve cultural change because there is a risk they generate bureaucracy and a focus on process that can be a barrier to change. A key function of scrutiny is to make sure that people who plan and deliver services have high aspirations for outcomes for people who use services and challenge the status quo if things are not working or people are not experiencing better outcomes. One voluntary, community and social enterprise organisation said that better scrutiny would show the extent to which people are being brought together to solve problems, with the focus on outcomes rather than targets, something which is especially important now that health and social care budgets are under pressure.

Scrutiny should not concentrate only on services as they are delivered – this is important, but scrutiny also needs to check whether there is a consistent, clear narrative that links together policy, commissioning, procurement and practice as part of good governance. Questions that can help gather insight about this might be:

- What are the challenges we face?
- Why do these matter?
- What can we do to reduce barriers?
- Do we need to think differently about finance or the way we use buildings?
- Are there new skills we need, either professionally or in communities?

It could be useful to develop some case studies of this type of strategic scrutiny to demonstrate what might be achieved.

One interviewee described feedback from service users as the strongest form of scrutiny but that organisations often took more notice of different types of scrutiny, such as inspection reports which tended to have a higher profile. Many services find that the best insight comes from involving people, hearing their voices and responding. When people who use services tell services what they think, they expect results. This doesn't mean giving people everything they ask for, but it does mean that professionals need to be comfortable working with third sector partners and with people who use services. This helps to build knowledge, skills and trust. Trust is important because people sometimes worry that if they speak out they might not get the right treatment or care in the future. There are examples of where collaborative relationships between professionals and people with learning disabilities work well, but voluntary, community and social enterprise sector organisations say there is still some way to go to overcome barriers to make this a universal reality.

Building on the models of user-led scrutiny that emerged from the interviews (for example, quality checkers, patient and public partners, inspection volunteers and citizens' panels) can help bring about a culture of collaboration. Moving towards this approach to involvement and scrutiny would require investment in capacity building for professionals, organisations and people who use services to make this most effective. In terms of staff development around learning disabilities, there could be a role for NHS Education Scotland.

Quality Checkers – involving people with lived experience of learning disabilities

We heard an example of a voluntary, community and social enterprise sector organisation employing Quality Checkers to carry out scrutiny activity. Quality Checkers are people with lived experience of learning disabilities who can check how well services support people with learning disabilities, using standards for services that people who use services would choose for themselves.

We heard very little about local scrutiny by councillors. Experience from other parts of the UK, especially England, suggests that councillors and council scrutiny can play an important role in bringing people together to find solutions to challenges. This often involves re-thinking representational models, so that participative democracy becomes a strong pillar alongside representational democracy. Scrutiny in a political environment can be challenging, but these challenges can often be overcome by keeping the wellbeing of citizens or people who use services at the centre. This is a potential area for further research and support.

There is a need for greater consistency across inspections of health and social care services to make sure that they are fit for purpose for people with learning disabilities. HIS needs to be clearer about how the experience of people with learning disabilities is being assessed in their work across primary and secondary care services. Inspection bodies should build on the recent experience of joint scrutiny of services for older people's and children's services and develop a joint approach to inspection of services for people with learning disabilities. As well as inspecting specialised provision, inspection should also challenge all health and care services about how they are working towards better experiences for people with learning disabilities. This is a way of building up a picture about what good services look like and what service users want and should be part of the new Health and Social Care National Care Standards.

There needs to be a stronger connection between inspection, scrutiny and improvement. An 'account manager' approach was identified by a scrutiny body as important so that inspection bodies maintain good longer-term insight into how organisations learn from inspections over time. Inspection can sometimes be perceived as prescriptive and different approaches can be taken in different circumstances. Peer review of learning disability services was mentioned by a scrutiny body as an effective way to learn about practice and share learning, and this is an aspect that some people felt was being lost across the public sector.

Local Area Co-ordinators were suggested by a voluntary, community and social enterprise sector organisation as a network through which learning about what works can be shared, recognising that scrutiny can be a 'carrot' as well as a 'stick' - about celebrating good practice rather than 'naming and shaming'.

The lack of any learning disability outcomes in the National Performance Framework was mentioned as a risk to fulfilling the ambitions for improved outcomes and it was suggested that there should be a national 'quality of life' indicator for people with learning disabilities. Data quality was also mentioned as a risk, as we were told the current data does not have a consistent learning disability marker.

Thinking about the wider determinants of health and the inequalities experienced by people with learning disabilities, there could be a role for NHS Scotland Public Health to integrate learning disability outcomes into the new public health strategy for Scotland. A key factor is not just the collection of data, but demonstrating how data is used as evidence to effect change. This helps ensure there is a connection between strategic planning and operational performance.

Health and social care partnerships were regarded as an opportunity to develop integrated approaches to improving quality of life for people with learning disabilities, but are relatively new and need time to bed down. On the other hand, focusing too long on structural change and processes might risk inaction on key outcomes. It is not clear how health and social care partnerships are being scrutinised, but linked to the suggestion of a national indicator for learning disabilities was a suggestion that health and social care partnerships should be given responsibility for learning disability outcomes locally.

Finally, Scotland has a strong commitment to human rights and has included the strategic aims of The keys to life in its delivery plan as one of the ways it will meet the obligations of the UN Convention on the Rights of Persons with Disabilities. Involvement, assurance and scrutiny mechanisms provide a real opportunity to develop a rights based health and care pathway for people with learning disabilities in support of this ambition.

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