

UNIVERSITY of STRATHCLYDE
**FRASER OF ALLANDER
INSTITUTE**

Scotland's invisible people: Support and opportunities for adults with learning disabilities

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Disclaimer

The analysis in this report has been conducted by the Fraser of Allander Institute (FAI) at the University of Strathclyde. The FAI is a leading academic research centre focused on the Scottish economy.

The analysis and writing-up of the results was undertaken independently by the FAI. The FAI is committed to informing and encouraging public debate through the provision of the highest quality analytical advice and analysis. We are therefore happy to respond to requests for factual advice and analysis. Any technical errors or omissions are those of the FAI.

Executive summary

The Fraser of Allander Institute is embarking on a year-long project looking at outcomes for working age people with learning disabilities in Scotland. In doing so, we will examine areas where the public sector, employers and civil society could help make their lives better. We are also seeking to highlight good examples of where people have had the support required to make their own way to lead a fulfilling life.

This is a project that deserves time and reflection. There is a lot for us to learn, a lot of services and organisations to understand, and a lot of people to engage with. This first report is just one piece of the jigsaw that we are seeking to put together over the next year.

In this report, we focus on getting some of the facts together and we also report on some of the issues that have been raised with us by people with learning disabilities, as well as some of the views of the wider public. We also take a look at the high-level ambition put forward by the Scottish Government in recent years, and how this has permeated across government economic strategies and into funding decisions.

Overall, this has been a sobering report to write. Undoubtedly, there have improvements relative to twenty years ago when long-term hospitalisation for people with learning disabilities was commonplace. But this does not mean enough progress has been made. Whilst it is clear that in pockets of government there is a good understanding of what is required and a great many charities and organisations helping to make voices heard, we have found that there is often a lack of visibility of people with learning disabilities in mainstream policy development.

This is despite the Scottish Government's inclusive growth and wellbeing ambitions. Improving economic outcomes for people with disabilities is often talked about by policy makers, but delivery is – at best – patchy. Far too often a 'one-size-fits-all' solution is assumed with little in the way of recognition about what this means for people with learning disabilities or the range of conditions and issues that this includes, nor is there robust data collected to help.

This is why we have titled this report 'Scotland's Invisible People'. Not only are they not visible in public debate, but the support they receive has receded in recent years and this has largely happened under the radar. COVID-19 has meant that much of the service infrastructure that was relied on has been taken away, and there are grave (and valid) concerns that their human rights are being curtailed.

Our survey of public attitudes also showed that many people know someone that has a learning disability and in fact some estimates put the figure of people with learning disabilities at close to 175,000 – greater than the population of Dundee. This is not a niche issue, and it is time people with learning disabilities received the attention they deserve. We hope this report, and our subsequent work on this will help to ensure that this happens.

Introduction

People with learning disabilities have much to offer Scotland. They are a large and diverse group of people that come from all walks of life. As children, they sit within an education system that endeavours to recognise their needs and provides support to themselves and their families. However, the transition to adulthood and life thereafter is often not straightforward.

As with anyone in our society, sometimes we need help as adults to reach our full potential and people with learning disabilities are no different. Whether it is advice and support to get a new job, or medical help when we are unwell, support is there when we need it.

When there are additional barriers to circumvent, there should be help here too, whether it is ramps for those who cannot use stairs, support workers that come in to help with daily life, or accessible communication for those who need a bit of extra help to understand information clearly.

And yet, people with learning disabilities can feel left behind. Whilst there are examples of people being treated with dignity and respect and being able to live the life they want, there are others who feel constrained in the choices they have with their human rights ignored. Their frustration extends to government, but also to businesses and employers too, as well as wider society.

A focus on support and opportunities

Over the next year, we aim to shine a light on how adults with learning disabilities are supported to achieve their potential. We recognise that people with learning disabilities will likely need some support from society, but that they also have a lot to offer once given the opportunity. This will not be news to anyone who knows a person with a learning disability, yet to others in society this group of people are sometimes invisible, with their challenges misunderstood and potential untapped.

Our programme of work seeks to build upon, and collaborate with, the many brilliant organisations and people in Scotland who already work on this issue. This programme is also part of the Institute's long history of examining the societal and economic implications of public life in Scotland. This subject is only too relevant in our current policy environment. With the Scottish Government's drive towards an inclusive wellbeing economy, their approach to supporting people with learning disabilities can be seen as a bellwether of how serious their intent is.

What to expect in our first report

The Scottish Government's approach with regards to this theme of inclusion is where we start our programme of work and is the theme of this, our first report. This report also provides some key facts and figures as well as bringing in the voices of a group of experts with learning disabilities who explain what their priorities are for this and the next government. We have also included a discussion on public attitudes based on new research carried out for this project.

We cannot cover all the many issues we would like to in one report. Future reports (and lots of other activities) will spread the net wider and look at many of the other components of life that can be especially challenging for people with learning disabilities – for example their work, their home, and their financial security – as well as trying to ascertain the impact of COVID-19 on people's lives.

Throughout our work we will be engaging with as many people as we can to learn and reflect on expertise beyond our own. If you want to be one of those people, we will always be happy to hear from you. Our contact information is included at the end of this report.

Learning disabilities - an explainer

Learning disabilities refer to a varied group of conditions that affect a diverse group of people. Definitions can vary making it difficult for people to feel confident they have the right understanding. For this programme of work, we are using the definition that was agreed by the *The keys to life* Expert Group that is convened by the Scottish Commission for People with Learning Disabilities (SCLD), as set out in Box 1.

Box 1: What is a learning disability?

A learning disability is significant and lifelong. It starts before adulthood and affects the person's development. This means that a person with a learning disability will likely need help to understand information, learn skills and have a fulfilling life. Some people with a learning disability also have healthcare needs and require support to communicate.

Source: *The keys to life*, Scottish Government

Even this definition may not feel adequate to all people with learning disabilities, and many may not be keen on having a label applied to them as an individual. It is important, right from the outset, to understand that people who are under the label of learning disability are not homogenous. They are different people and will face different issues depending on their condition and indeed other factors such as where they live.

Learning 'disabilities' are not the same as learning 'difficulties' such as dyslexia. It is also the case that whilst some people with learning disabilities will be on the autism spectrum, it is not assumed that having autism means you have a learning disability.

Some people with learning disabilities may have very complex needs, some less complex. The levels of support required will vary considerably depending on the person. Some may also behave in ways that are perceived as challenging (which means that their behaviour challenges services and support providers, rather than implying that the person is themselves challenging).¹

Whilst recognising the unique circumstances that people face, there are some common themes that we can explore. The work that we are doing focuses on the barriers that people with learning disabilities face, and what is being done to take those barriers away in Scotland.

This follows the rationale of the social model of disability, which acknowledges that people are disabled by barriers in society, not by their impairments or difference.

This moves us away from only talking about the 'clinical' aspects of people's experiences, but also wider enablers of a good quality of life, for example being able to participate in the labour market, ability to choose where to live and having the opportunity for yourself and your family to be able to lead a financially secure life. This is something that we all have the right to expect.²

¹ See the Scottish Government's website for more information on definitions used in Scotland <https://www.gov.scot/publications/coming-home-complex-care-needs-out-area-placements-report-2018/pages/6/>

² See Scope for more information on the social model of disability <https://www.scope.org.uk/about-us/social-model-of-disability/>

Adults with learning disabilities in Scotland at a glance



23,584

Official statistics show that there are **23,584** adults with a learning disability known to Local Authorities in Scotland.



175,000

Some estimates put the true figure closer to **175,000**, which is greater than the population of Dundee.



20 years

People with learning disabilities have a life expectancy **20 years** lower than the general population. Many illnesses are preventable.



7%

The employment rate for adults with a learning disability is estimated to be **7%**. Many more can and want to work, which brings benefits to the individual and employers.

Of those in work, the employment types are:

41% Open employment

26% Non-open employment

1% Self employed

32% Employment type unknown



62%

62% of people with learning disabilities live in mainstream accommodation. A further 15% live in supported housing, with the remainder either not recorded or living in an adult care home.



42%

Of those recorded, **42%** of people with learning disabilities live with a family carer. More than three quarters of those are parents.

Source: Scottish Commission for People with Learning Disabilities and Scottish Learning Disabilities Observatory

What support and opportunities are available now?

Over the last twenty years, governments across the UK have put forward strategies to try to improve outcomes for people with learning disabilities. This includes the devolved government in Scotland. There is also an active third sector in Scotland that strives to ensure the voices and needs of people with learning disabilities are listened to. We have been struck by the knowledge, compassion and commitment of people working towards better outcomes for people with learning disabilities.

However, as the data shows, it is unfortunately still the case that working age adults in Scotland with learning disabilities face a range of difficulties and that barriers often prevent them reaching a good or adequate standard of living.

As set out in the introduction, there are many component parts that need to pull together to enable greater inclusion of adults with learning disabilities in society. We are new to researching this area, and we know we need to take the time to understand as many of these parts as we can in our work over the next year. The concluding section of this report offers some insights into this.

Our first report focuses on some of the issues that we know well as a research institute - the overall strategy and approach to economic policy of the Scottish Government. The government's strategic direction of course has a role in both providing leadership as well as shaping policy that can impact on people's lives. This feels like a good place for our programme of work to start.

Applicable frameworks

Scotland is obliged to ensure that people have rights under international commitments relating to the disabled community, to which the UK is a signatory and to which Scotland seeks to adhere.

In particular, the *UN Convention on the Rights of Persons with Disabilities* underlines the rights of people with disabilities.

The Convention follows decades of work by the United Nations to change attitudes and approaches to persons with disabilities. It challenges the idea of viewing persons with disabilities as “objects” of charity, medical treatment and social protection towards viewing persons with disabilities as “subjects” with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society.

The Convention is intended as a human rights instrument with an explicit, social development dimension.

There are eight guiding principles that underlie the Convention and each one of its specific articles:

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.
- Non-discrimination.
- Full and effective participation and inclusion in society.
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.
- Equality of opportunity.
- Accessibility.
- Equality between men and women.
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

The other extremely relevant *UN Framework* is the *UN 2030 Agenda for Sustainable Development* that includes the *Sustainable Development Goals (SDGs)*. Disability is referenced in multiple parts of the SDGs, specifically in the parts related to education, growth and employment, inequality, accessibility of human settlements, as well as data collection and the monitoring of the SDGs.

Scotland has an outcomes-based approach to policy making with the National Performance Framework (NPF) at its core. The most recent NPF refresh in 2017 made explicit reference to the SDGs and linked outcomes to goals to show how Scotland was translating the UN Framework into national policy. The NPF's 'Purpose' is:

"To focus on creating a more successful country with opportunities for all of Scotland to flourish through increased wellbeing, and sustainable and inclusive economic growth."

This provides the context in which we can understand the government's intentions. Clearly, the lives of people with learning disabilities are part of this vision that Scotland holds.

Yet, we have spoken to many people in Scotland with learning disabilities and their families, and there is often a gap between ambition and reality. It is important to try and understand why that is the case.

Later on in this chapter, we will look at strategies focused on people with learning disabilities and how wider government strategies include people with learning disabilities, but first we start with looking at the basic question – how does the government know what the issues are?

Approach to collecting data and evidence

On page 3, we summarised some of the known facts for working age adults with learning disabilities. However, despite the importance of this group of people, accurate data is scarce.

The members of the Expert Group, convened by the Scottish Commission for People with Learning Disabilities have lived experience of living with learning disabilities. They help the government understand the practicalities of issues on the ground and ensure that the people that are impacted by government policy have a voice in the policy making process. This is a great tool to have to build effective action.

However, in order to fully understand policy need, it is important to know the scale of the issues faced. For this, representative surveys of the population are used in policy making to understand how many people are affected and why.

Unfortunately, there are not even agreed figures on how many adults in Scotland have learning disabilities. Whilst there are plans to include a question on this in the next Census, there are many other surveys which could be providing data on a more regular basis. These surveys already identify people with disabilities or long-term limiting health conditions and could be extended to capture the population with learning disabilities.

The lack of robust data available for people with learning disabilities is difficult to reconcile with government ambitions to improve their lives and it makes effective-evidence based policy making almost impossible. It also makes it hard to gauge whether things are improving overall, or getting worse, over time. And in times like the challenges our economy faces from COVID-19, there is little up-to-date information on how people with learning disabilities are being impacted by the virus or the economic downturn.

We understand that there are reasons why surveys may struggle to capture information in relation to minority groups, such as people with learning disabilities. But this is not a valid reason given the scale and importance of this - often vulnerable - group in our society. Steps could be taken, perhaps over a number of years or over a range of different surveys, to collect data on learning disabilities that is robust enough to report upon. There is precedent for this as there is disaggregation of other protected characteristics (for example religion, ethnicity) currently captured using the Scottish Survey Core Questions which aggregate responses from multiple surveys.

People with learning disabilities face different challenges to those with physical disabilities. If disability statistics are not disaggregated it can mean that, all too easily, people with learning disabilities are invisible to people looking at cross cutting themes, such as poverty, employability or training.

Improved disaggregation of disability statistics that seeks to identify people with learning disabilities would help both with the visibility of the issues facing this group of people, and improve the ability of policy makers to design appropriate solutions.

Strategies and action plans specifically on learning disabilities

Despite a lack of robust evidence on people with learning disabilities, the Scottish Government (and the Executive previously) have since devolution produced two reviews on learning disabilities.

The first was within the first session of the new Scottish Parliament, under the Labour-Liberal Democrat coalition government:

The same as you? (2000)

Seen as a watershed moment for the sector, [*The same as you?*](#) heralded a wave of optimism. This was the first strategic review of services for people with learning disabilities following devolution and the first major policy initiative in Scotland for 20 years. It followed a rights-based approach that is used to this day.

The next review came over a decade later, produced by the SNP government:

The keys to life (2013)

[*The keys to life*](#) aimed to build on *The same as you?* with a much more ambitious and wide ranging strategy. The strategic priorities are aligned with *A Fairer Scotland for Disabled People*, focusing on healthy and independent living, active citizenship and choice and control.

The keys to life remains the guiding framework to this day. In 2015 and 2019 the priorities were revisited:

The keys to life implementation framework (2019)

The latest [*implementation framework*](#) sets out the next priorities for delivering *The keys to life*. Whilst recommendations for action are made, there are no clear and measurable targets or performance indicators against which the success of the strategy can be judged.

As the most recent published statement from the Scottish Government, we have provided a further summary for reference in Box 2.

Many of the issues reported in *The same as you?* have been highlighted again, suggesting some of the achievements that were hoped for have not been realised 20 years on.

Box 2: The keys to life: Implementation framework and priorities 2019 - 2021

Our vision

Our vision for people with learning disabilities is shaped by the Scottish Government's ambition for all citizens and by everything we have heard from people with learning disabilities. Everyone – including people with learning disabilities - should be able to contribute to a fairer Scotland where we tackle inequalities and people are supported to flourish and succeed. People with learning disabilities should be treated with dignity, respect and understanding. They should be able to play a full part in their communities and live independent lives free from bullying, fear and harassment.



Scottish
Government
gov.scot

Strategic ambitions: A Fairer Scotland for Disabled People

Our priorities for delivery in the next phase of *The keys to life* will continue to be guided by our four rights-based strategic outcomes. They are closely aligned to the strategic ambitions in Scotland's disability delivery plan, *A Fairer Scotland for Disabled People*.

- *Support services that promote independent living, meet needs and work together to enable a life of choices, opportunities and participation.* Health and social care support services are designed to meet - and do meet - the individual needs and outcomes of disabled people.
- *Decent incomes and fairer working lives.* Making sure disabled people can enjoy full participation with an adequate income to participate in learning, in education, voluntary work or paid employment and retirement.
- *Places that are accessible to everyone.* Housing and transport and the wider environment are fully accessible to enable disabled people to participate as full and equal citizens.
- *Protected rights.* The rights of disabled people are fully protected and they receive fair treatment from justice systems at all times.
- *Active participation.* Disabled people can participate as active citizens in all aspects of daily and public life in Scotland.

Strategic ambitions: The keys to life

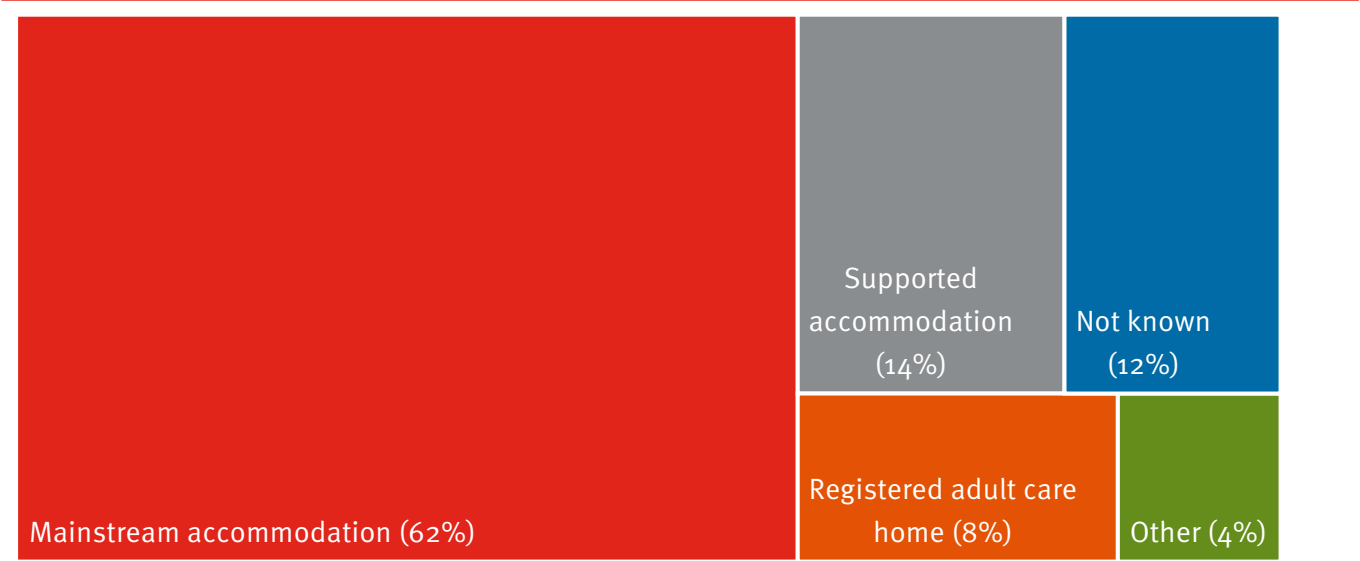
- *A Healthy Life.* People with learning disabilities enjoy the highest attainable standard of living, health and family life.
- *Choice and Control.* People with learning disabilities are treated with dignity and respect, and are protected from neglect, exploitation and abuse.
- *Independence.* People with learning disabilities are able to live independently in the community with equal access to all aspects of society.
- *Active Citizenship.* People with learning disabilities are able to participate in all aspects of community and society.

What has been achieved?

A lot has changed over the last 20 years and many achievements have improved the lives of people with learning disabilities, particularly young people. In compiling this scene-setting report, we have come across many success stories and examples of best practice.

Perhaps the most tangible change is that many more people with learning disabilities now live in the community (see Chart 1), with long hospital stays and institutionalised care once having been the default approach.

Chart 1: Accommodation type amongst adults with a learning disability known to Local Authorities



Source: Scottish Commission for People with Learning Disabilities

Person-centred care and self-directed support have become the preferred model of delivery for care and support services, which have tried to put the individual at the heart of decisions made about them.

Whilst community care and self-directed support represent positive changes for many people, these good intentions need to be backed up with sufficient resources. From what we have learnt so far, this certainly has not always been the case.

In terms of inclusion in policy making, a cultural shift within government has given people with learning disabilities a voice. Networks and forums have been established and organisations like the Scottish Commission for People with Learning Disabilities and People First now play an active role in helping to try to develop evidence-based policy that supports people with learning disabilities.

This has culminated in a much more ambitious government approach for people with learning disabilities. What was once focused on the quality of care services received has now branched out to include many aspects of life, from health and wellbeing to human rights and parenting.

We now know more about people with learning disabilities. Statistics on the learning disability population, provided by most Local Authorities, are now reported on an annual basis which is a step forward, although as already discussed, there is still a long way to go before we have adequate statistics covering people with learning disabilities.

Other research has been taken forward to help understand various aspects of people with learning

disabilities' lives. The Scottish Learning Disabilities Observatory is a good example of a research organisation focused entirely on people with learning disabilities. Their research on health-related issues has provided evidence that enables policy makers and healthcare practitioners to make better informed choices.

Our early findings suggest that all of this progress has rightly raised the ambitions and expectations of people with learning disabilities and that young people are the main beneficiaries of this. The majority of those now leaving school are the first generation to experience an upbringing where institutionalised care is a thing of the past. The challenge now is to remove barriers so that they can actively participate in the communities in which they live and enjoy a fulfilling and as independent as possible life.

Where has progress been too slow?

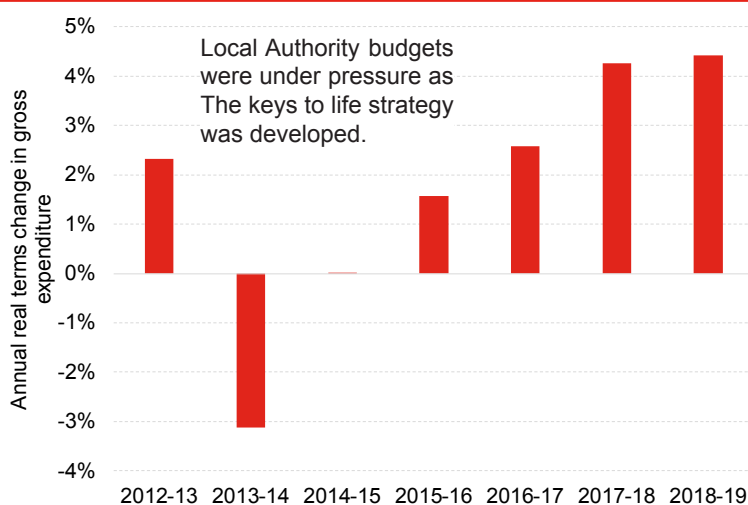
Society has more work to do to bring down barriers that people with learning disabilities face and to reach the ambition that has been set out. This requires a holistic approach, involving many areas of the public sector, and as is often the case with cross-cutting issues on equalities, effective policy making that achieves this remains elusive. Improving outcomes on learning disabilities needs different parts and layers of government to work together to understand what is required.

For example, access to quality local housing and health services is patchy. Support for families and carers is often overlooked. And many people with a learning disability can and want to work, yet face barriers to employment that prevent them doing so. Estimates of the rate of unemployment for people with learning disabilities have not changed in decades, and are far lower than the rate for the wider disabled population. On top of this, support in less policy-oriented aspects of life, such as parenting and intimate relationships appears not to have met the ambitions of *The keys to life*.

Crucially, policy development needs to be joined up with decisions on budgets – a seemingly even greater challenge for the Scottish Government given that local government are key delivery partners.

In Chart 2 we look at local government expenditure since 2011/12 on learning disabilities in local government. The majority of this spend is on care provision, both in residential settings and in the community and is an indicator of the priority being given to people with learning disabilities.

Chart 2: Real terms change in gross expenditure attributed to working age adults with learning disabilities by Local Authorities in Scotland



Source: Scottish Government

The total amount available to spend by local government is determined by the allocation given to local government by the Scottish Government during budget decisions. Therefore, changes in funding at the local level reflect both local and national decisions on where to prioritise spend. Of course, Scottish Government spend is also in turn influenced by UK Government expenditure and how much money comes to Scotland through the Barnett Formula.

Whilst we are unable to identify all spend on people with learning disabilities, we can see how much money is spent by local government on service delivery. In 2018/19, around £850 million was spent in this area which is around 20% of the total gross expenditure on social work by councils. Some of this is statutory spend, whilst other parts represent discretionary spend that goes beyond minimum requirements but, as we will hear later, can make a massive difference to people's quality of life.

Over the last ten years we have seen periods where expenditure has fallen and risen. The publication of *The keys to life* in 2013 coincides with a period of a fall in expenditure on learning disabilities by local government as they faced cuts in the general revenue grant from Scottish Government. At this time the Scottish Government were facing falls in their budget due to a cut in the block grant from Westminster.

Whilst the budget pressures stem from decisions taken by the Westminster Government, it is important to remember that the Scottish Government had a choice in where to prioritise expenditure. Local Government budgets saw, overall, a steep cut especially when relative to other budget areas, for example the NHS. Local Authorities also have choices (albeit often more limited due to statutory responsibilities) on where to prioritise spending.

It should be noted that spend on care for adults with learning disabilities has been relatively protected due to the fact that a large part of the care provided is statutory. The decreases in spending would have fallen on discretionary support services that help people to participate in society and live as independently as possible - key strategic ambitions of *The keys to life*. This raises questions on whether policy ambition was at all joined up with the budget reality.

The move to integrate health and social care services from 2016 onwards had the potential to lead to more efficient service delivery, as well as improving care. The process of integration is still ongoing, but it has been widely felt that to date the pace of integration and the associated benefits have been too slow to be realised ([Scottish Government, 2019](#)).

The last couple of outturn reported years have seen growth in gross expenditure, yet that may have changed this financial year. From what we understand, discretionary expenditure for 2020/21 may have been significantly reduced as councils have withdrawn some of their non-statutory support packages to divert resources elsewhere during the COVID-19 pandemic.³

Overall, it is difficult not to conclude that financial support for adults with learning disabilities has not consistently met the ambition set out in *The keys to life* in 2013.

Learning disabilities in cross government economic strategies

The keys to life demonstrated ambitions that spread well beyond the day to day care of people with learning disabilities and into many other aspects of public policy. So how are the ambitions set out in *The keys to life* reflected across government?

³ https://www.sclcd.org.uk/wp-content/uploads/2020/06/The-Equality-and-Human-Rights-Implications-of-the-COVID-19-emergency-SCLD-Submission_designed.pdf

We have looked at reviews that relate to economic development that have been published since *The keys to life* in 2013 to see how visible people with learning disabilities are in these strategies.

In this first report, we have concentrated mainly on economic strategies, and our findings here may not reflect practice on other cross-cutting issues and other government strategies. However, given the centrality of inclusive growth and a wellbeing economy in the government's Purpose this is an important area to focus on.

We reviewed a number of key documents including [Scotland's Economic Strategy](#) (2015), [Scotland's Labour Market Strategy](#) (2016) and the [Enterprise and Skills Board's Strategic Plan](#) (2018). Whilst most (but not all) cite the need to overcome barriers related to disability, none mention people with learning disabilities specifically. Indeed, there was no disaggregation of any discussion of different disabilities or the range and severity of conditions that different people faced.

There are of course reports focused directly on disability that do this. A [Fairer Scotland for Disabled People](#) (2016), for example, had reference to people with learning disabilities. The update and [progress report](#) in 2020 also committed to a review of Supported Employment provision in Scotland. This shows that, in some parts of government, it is recognised that disabled people are not a homogenous group and do have distinct needs depending on their disability and its severity.

Yet this understanding has not permeated through to other parts of government. In other words, this understanding is not mainstream.

This is most recently exemplified in the Scottish Government's [response](#) to the Advisory Group on Economic Recovery (AGER). Even though the government went explicitly beyond the Advisory Group's recommendations on the recognition of equalities and human rights in their response, there was no mention of people with a learning disability (which is one less mention than was in [the original AGER report](#)).

Disability was referenced, for which the continuation of Fair Start Scotland was cited as the relevant action being taken. Whilst no doubt helpful for some people, existing Scottish Government reports and SCLD's submission to the AGER had recommended that action beyond the provision currently provided within Fair Start Scotland was required for many people with learning disabilities.

So why are people with learning disabilities often invisible in high level strategy documents on our economy, especially when inclusivity is an explicit aim?

This is part of a wider issue with respect to adequate assessments of equalities in policy making in Scotland, but it does appear to be particularly acute for people with learning disabilities. One likely cause of this is the lack of robust data as already noted. Indeed, improving this data was a recommendation made by the AGER, but not followed up on in the government's response.

Better understanding of the disabled population, including the particular issues for those with learning disabilities, is not solely an issue for the Scottish Government to do better on. We also reviewed the election manifestos from the 2016 Scottish Election, and found that out of the five main parties only the Scottish Green Party made any reference to people with learning disabilities, and that was in relation to the justice system. Whilst all parties talked about disabilities in general with respect to employment, there was no differentiation between different types of disabilities.

With the next election in May 2021, this provides an opportunity for all parties to address this.

What do people with learning disabilities and the wider public think?

The keys to life Expert Group

We were keen to ensure that we spoke to the real experts on learning disabilities early on in this programme of work to find out their priorities. *The keys to life* Expert Group represent themselves and are experts in their own experience of living with a learning disability.

We talked to some of the members of the Expert Group, supported by SCLD, about what they think the government's priorities should be. Some of the members had been involved in advising the government during the development of *The keys to life* in 2013 and one member had also been involved in *The same as you?* strategy in 2000.

For those that had been involved for a long time, there was a feeling that some progress had been made, although it was hard to pin down what specifically had improved, and an overall feeling that there was a lot more still to do. Although it was felt that the government was trying, they were not quite getting there. There remains a strong feeling of discrimination by employers and by the general public who do not fully understand what learning disabilities are or how to work and support colleagues with a learning disability.

There were also examples of where it was felt that things have got worse over the last ten years due a reduction in financial support that is being offered to people with learning disabilities for day-to-day activities, for example with bills, applications and general 'life admin'. One person described this support with finances as essential to keeping a the roof over their head.

Support that was previously free is now charged for, the services are often overwhelmed, and it is hard to know where else to go to get other support required. It was felt that the wages paid to people providing social care are inadequate and this leads to poor service and inconsistencies in service provision that are difficult to deal with.

It was felt that there should be easy to access (not only digital) and simpler systems for people with learning disabilities in place so it was not necessary to access multiple services with lots of confusion about what support is available, and what is not. One person described the process of trying to get help to upgrade their, currently unaffordable, heating system and despite believing they were eligible for help, had hit a brick wall. Suitable housing came up as an area where more help was needed as well as better information on what people were entitled to – for example on council tax reduction.

Access to paid employment was a key issue for most of the people we spoke to. A lot of the people we spoke to were involved in voluntary work, one was currently employed and others had previously worked. All described finding paid employment as difficult. The application process itself was described as difficult to understand and work through, and some aspects, multiple choice tests for example, felt discriminatory. Whilst it had been possible to tick a box to guarantee an interview in some cases, this was not always the case. There were also issues raised with regards to discrimination from potential employers once they found out that candidates had a learning disability. This highlights how employers and wider society have a part to play and that changes in attitudes are needed to bring down barriers for people with learning disabilities.

One person spoke about how a relatively short period of support to help people into employment would go a long way. This includes with the application process, but also in terms of helping people on interview days to find the right location and some induction support for the first couple of weeks whilst people get accustomed to their new place of work. There was a general feeling that the Jobcentre service had got worse over the last ten years and people were being told to go through the process alone when they previously would have had some support from staff. There was no awareness of employability support available in Scotland other than from the Jobcentre.

It was also noted on several occasions how the work of the third sector has made a significant positive contribution to the daily lives of people with learning disabilities. The invaluable support networks and intangible benefits, such as increased confidence of people with learning disabilities, demonstrate how important the third sector is.

Stress and confusion related to benefits, and Personal Independence Payments (PIP) in particular, came up multiple times. It was felt by more than one person we spoke to that because learning disabilities are lifelong, and not going to disappear, there should not be a need for repeated assessments. A few of the people we spoke to were either going through or had recently gone through the PIP appeals process. Welfare advice was described as hard to understand and access.

It was strongly hoped that the Scottish Government could do better following the devolution of powers on disability and carer benefits to the Scottish Parliament, and there was some frustration that this was not happening more quickly. The inconsistencies of the system were frustrating, with the threat of loss of benefits meaning that often it did not make sense to go into the type of work that they knew they knew they were capable of.

On the positive side, many people spoke about the positive experience of being on the Expert Group. Having a chance to speak about issues and being supported to travel to meetings have helped with self-confidence and provided additional social interaction that people have really enjoyed.

A key theme in the discussions was the impact of COVID-19. One person told us that lockdown had not just changed some things, it had changed everything. A major problem has been access to information on what is happening, and what rules are in place. Although not all support has been reduced, where it has been scaled back, the loss of support has been devastating. Issues related to digital exclusion have been exacerbated and the ability to get in touch with services, like GPs, has been curtailed. We will explore more of these issues related to the pandemic in our work in the near future given their pertinence and importance.

Wider public attitudes

As part of this programme of work, as well as listening to people with learning disabilities, we have been keen to understand how the public views many of the issues we are discussing.

In partnership with YouGov, we undertook a survey of 1,053 people in Scotland in early September 2020.⁴ Around a third (35%) of respondents reported having some direct experience of a learning disability either themselves or with someone they knew, showing that these issues we are discussing are relevant to many people.

However, in terms of visibility in the media, in the last six months only 26% confirmed that they had

⁴ All figures, unless otherwise stated, are from YouGov plc. Total sample size was 1,053 adults. Fieldwork was undertaken between 3rd - 7th September 2020. The survey was carried out online. The figures have been weighted and are representative of all Scottish adults (aged 18+).

seen someone with a learning disability in broadcast media, 14% had seen someone with a learning disability in print media, and 22% on online platforms (including news sites).

Overall, there was majority recognition (54%) that people with learning disabilities should be able to make their own choices, with support amongst younger people aged 16-24 highest in this regard at 68%.

However, there was a sizeable minority (25%) who see people with learning disabilities as patients who should not be able to make their own choices.

There was widespread support for government to provide financial assistance to meet the additional costs associated with their disability. Roughly three quarters (74%) of people agreed that they should receive financial support from the government for this, with only 8% disagreeing (the remainder replied 'don't know').

There was also an awareness of one of the particular risks faced by people with learning disabilities – sexual assault. 66% of respondents recognised that people with learning disabilities are at greater risk than the rest of the public.

Interestingly, in terms of factors that are important to people when buying products from a business, roughly the same proportion (8%) cited that whether they are employing people with learning disabilities was as important as whether they have a gender pay gap (9%), and more important than whether or not they do charity work (4%).

From this public attitudes work, we can see that people do care about the living standards of people with learning disabilities and are aware of at least some of the issues they face, and this stretches far beyond those who have direct experience of living with or knowing someone else who has a learning disability. However, visibility within the media is low and there are still conflicting views about the capabilities of people with learning disabilities. There is work to do, but there is clearly support to improve lives.

Conclusions and next steps

This report kicks off a long-term project researching the economic outcomes of people with learning disabilities and their families in Scotland. During the first phase of this project, we have found that:

- There are many organisations working with people with learning disabilities to make voices heard.
- People with learning disabilities are a significant group in Scotland that experience very poor outcomes. Many do not have the keys to reach their potential and live a fulfilling life.
- Whilst progress has been made, some fundamental issues remain and there appears to be a lack of permeation of understanding of issues affecting people with learning disabilities in parts of government where it is needed.
- There is public support and reasonable awareness of people with learning disabilities and the issues they face, but little visibility in public life and differing views on the capabilities of people with learning disabilities.
- Better data is needed to understand the opportunities and barriers faced by people with learning disabilities. Effective policy making is not possible without it.

So, what next? This programme of research will take its lead from findings made throughout the project. It will be delivered in phases and cover themes that affect the lives of people with learning disabilities:

Transitions out of school for people with learning disabilities

We will look at this vital period of time when people start to make their own decisions on how they live their life.

It is also a period when the support that was available through the education system for people with learning disabilities disappears.

We will research this crucial transition stage and how it affects people with learning disabilities and their families.

The system of support services

We will shine a light on what support is available for people with learning disabilities and how has this changed over time.

We will look at what practical solutions there are to ensure that people can get the support they need.

Social security and the labour market

Employment offers a key for many people with learning disabilities to lead a fulfilling independent life, yet their employment rate is astonishingly low.

This contrasts with the Scottish Government's ambitious targets on disability employment and comes at a time when elements of social security are being devolved. The social security system creates unnecessary stress for people and much more could be done to make this easier.

Employers, many of whom have inclusive employment policies, stand to benefit from employing someone with a learning disability. Yet many are unaware of the opportunities this population offer.

Given these factors, we will explore labour market outcomes for people with learning disabilities in more depth. This includes the role of employability services.

Families, carers and the community

The impact that learning disability issues have extends to families and carers. 31% of adults with a learning disability live with a family carer. 76% of those are parents.⁵

There is a significant age divide, with younger adults much more likely to live with a carer. On top of this, more home care is expected in the future.

We will therefore research the impact that these issues have on families, as well as the capabilities of and support for at-home carers. We will also look at the role of the wider community where people with learning disabilities live and community based development.

⁵ “*Learning disability statistics Scotland, 2019*”, Scottish Commission for People with Learning Disabilities, 2019.
<https://www.sclld.org.uk/2019-report/>

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