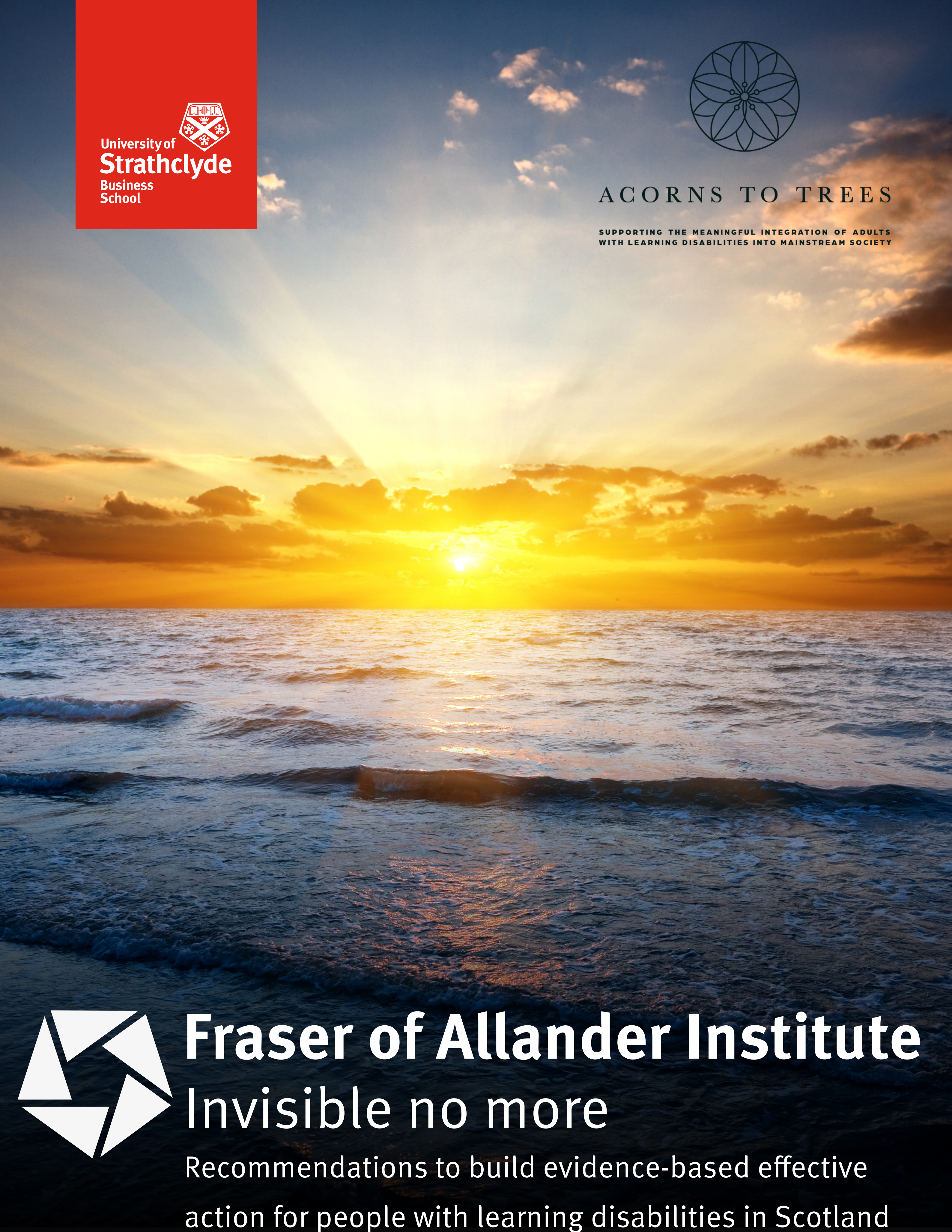

University of Strathclyde Business School

ACORNS TO TREES

SUPPORTING THE MEANINGFUL INTEGRATION OF ADULTS WITH LEARNING DISABILITIES INTO MAINSTREAM SOCIETY

Fraser of Allander Institute

Invisible no more

Recommendations to build evidence-based effective action for people with learning disabilities in Scotland

October 2021

UNIVERSITY of STRATHCLYDE
FRASER OF ALLANDER INSTITUTE

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The Fraser of Allander Institute

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

Over the last 15 months, the Fraser of Allander Institute has looked at evidence and policy for adults with learning disabilities in Scotland. Overwhelmingly, we have found that the evidence on which to base effective policy to improve the outcomes for people living with a learning disability is severely lacking. In this report, we bring together our key findings from the Institute's research so far, and set out a number of recommendations to improve learning disability policy.

At the root of effective policy is evidence. Without better data to underpin policy making, Scottish Government ambitions to improve the lives of adults with learning disabilities are unlikely to be realised.

The 6 recommendations that we have set out could make a significant difference in building better policy and on understanding its impact over time. There are opportunities on the horizon to implement these recommendations that should be grasped to move further towards a Scotland where people with learning disabilities and their families can realise their rights and live as an included and valued part of society.

1. The Scottish Government should recognise that current data is not fit for purpose and that data on adults with learning disabilities should not be used unless appropriately caveated. The Scottish Government should examine approaches to build on existing data to enable understanding of the requirements of people with learning disabilities throughout their life course and to build evidence on whether people are able to realise their human rights.

2. It is important to have a robust baseline of support that is available in terms of financial resources, eligibility and experience of the current social care system. These aspects need to be monitored to understand what is changing, and the impact that this is having on the people that draw on these services. The Scottish Government should take responsibility for this now to ensure that the impact of the new National Care Service can be monitored and evaluated.

3. The Scottish Government must ensure that reforms to Carers Allowance and the National Care Service are considered together so as to provide an integrated package that allows genuine choices for unpaid carers and those who draw on unpaid care support.

4. The Scottish Government should carry out an audit of the current employability support schemes on offer in each part of Scotland for people with learning disabilities, and the routes that people come through to access them. This will ensure a shared understanding across Scotland so that new localised schemes are aware of what they have to build on, can ensure good practice is not lost, and gaps in provision are identified. Robust monitoring and evaluation of outcomes for people with learning disabilities is crucial, including follow-up after 12 months to measure sustained outcomes.

5. The Scottish Government should ensure that reforms, including No One Left Behind and the National Care Service, provide specific proposals that ensure changes made will improve transitions for young people with disabilities. The implementation of these changes should be monitored and the experience of young people with disabilities during the transition period should be routinely captured as part of monitoring and evaluation.

6. The Covid-19 inquiry should consider in detail the damage done during Covid-19, both in terms of the impact on services provided and the experience of life for people with learning disabilities and their families to inform improvements in the future.

Introduction

Over the last 15 months, the Fraser of Allander Institute has been involved in a research programme looking at the lives of adults with learning disabilities in Scotland. In line with the ethos of the institute, our focus has been on investigating and analysing data to better inform and illuminate issues that need to be addressed. Our aim is to be able to better inform policy, both for those inside and outwith government.

This programme of work has been different to much of the research that we undertake. Usually, we are able to bring the weight of economic analysis to a problem using existing data and evidence, and use established analytical frameworks to bring together results and conclusions. We often find new perspectives, clarify and illuminate issues, but data and evidence usually exist for us to build on.

This is not the case with adults with learning disabilities in Scotland. There is a body of policy that acknowledges that the lives of adults with learning disabilities are constrained due to the actions, or inaction, of state, society and the economy. However, data and evidence lag well behind. Inevitably, this means that policy translates into words and ambitions, but often not effective actions.

This is because it is difficult, if not impossible, to effectively operationalise a policy if you have no idea how many people need to draw on support, nor do you know what their current situation is and therefore what assistance they actually require.

It is hard to think of another area of policy where so little is known about a population. This becomes even more difficult to comprehend when it is considered along with the fact that this population has some of the worst outcomes of any group in Scotland, including with regards to life expectancy. The fact that people with learning disabilities do not always have the ability to speak out means that the issues they face are perhaps easier to ignore.

You can tell what is a priority to government by what gets measured. From what we have heard during our research, Scotland has a lot to prove before people with learning disabilities feel like they matter as much as others in the population.

This report summarises the evidence we have gathered over the past 15 months. It sets out some clear steps that the Scottish Government needs to take to ensure it can make evidence-based policy for people with learning disabilities and can monitor the impact of these decisions over time. This is the fundamental basis of policy making, but the capacity within government to ensure this happens with learning disability policy does not appear to be in place.

This report starts with an overview of policy and data, and then moves on to look at specific areas of the lives of people with learning disabilities and their families. This is a complex area, cutting across many ministerial portfolios, and with potential significant budgetary impacts. Getting to grips with this is difficult for any government and the Scottish Government at least does recognise that they need to do more. Our recommendations focus on where data and evidence gathering should be prioritised in order to ensure that policy ambitions can be realised more effectively.

As the title of the report states, in order for change to be realised, people with learning disabilities must be invisible no more.

This report draws together a wide range of research outputs produced since September 2020, all or which are available on the Fraser of Allander website: fraserofallander.org/research/adults-with-learning-disabilities-in-scotland/

1. The big picture

Our first report, published in September 2020, set the scene in terms of data and policy.

In Scotland, there is an established definition of a learning disability that was agreed in 2013 by a group of people living with a learning disability who worked with the Scottish Commission for People with Learning Disabilities (SCLD) and the Scottish Government.

Box 1: The definition of 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*[1]

Since the re-establishment of the Scottish Parliament, the Scottish Government has set out a number of reports that state clear and bold ambitions to improve the lives of people with learning disabilities. However, many ambitions are still far from being achieved.

For example, "The Same As You?"[2], published in 2000 included ambitions, as set out in Box 2.

Box 2: Ambitions stated in The Same As You?

"People with learning disabilities should be able to lead normal lives. We want them to:

- be included, better understood and supported by the communities in which they live;
- have information about their needs and the services available, so that they can take part, more fully, in decisions about them;
- be at the centre of decision-making and have more control over their care;
- have the same opportunities as others to get a job, develop as individuals, spend time with family and friends, enjoy life and get the extra support they need to do this; and
- be able to use local services wherever possible and special services if they need them."

Source: *The Same As You?, Scottish Government*

There are parts of the policy making process that have improved over the past twenty years and work well. The voice of lived experience has been brought into policy making via The Keys To Life Expert Group. In addition, organisations such as the Scottish Commission for People with Learning Disabilities (SCLD) have been funded to work with people with learning disabilities and the Scottish Learning Disabilities Observatory (SLDO) has been set up to focus on health data and outcomes.

Qualitative research, including evidence gathered for this Fraser of Allander Institute programme of work, indicate there is still a long way to go to achieve long stated ambitions. Without better quantitative data however, these ambitions are unlikely ever to be achieved. At each turn in our research, we have found absent or incomplete data, and very little evidence that remedying this is a priority of government.

This is perhaps best exemplified by the fact that there is no data on the number of individuals that have a learning disability in Scotland. There are a number of incomplete datasets, but none of them provide the data that policy makers need to develop policy effectively.

Table 1: Sources of incomplete data on the learning disability population in Scotland[3]

Source	Year	Estimate	Proportion of population	Notes
Pupil Census	2020	12,500 children	2%	Thought to be a top end estimate. Extrapolating to adult population likely to be an overestimate, partly due to lower life expectancy.
Adults who receive support from their local authority[4]	2019	23,500 adults	0.5%	Thought to be an undercount. Not all adults with a learning disability are eligible for support. Also includes some with autism but without a learning disability who use local authority learning disability services.
Population census	2011	21,000 adults	0.5%	Lower than the figure who received local authority support in that year (26,036).
Population census	2011	5,000 children	0.5%	Lower than the pupil census which excludes children not of school age (15,979).

In the 2000 report, “The Same As You?”, the then Scottish Executive also looked at studies from elsewhere to estimate the likely prevalence of learning disabilities in Scotland. It reported that:

> *“On this basis, there are around 120,000 people in Scotland with learning disabilities.”*
>
> The Same As You? (2000), Scottish Government

These figures imply that around 2% of the population lived with a learning disability in Scotland in the early 2000s. The report also stated that the number with learning disabilities was expected to rise in the future as healthcare and life expectancy improved.

So how do we come to an agreement on an estimate of the size of the population? This is not a simple issue to remedy. Learning disability refers to a range of conditions rather than a specific ‘tick-box’ diagnosis. Teachers who see their pupils day-in-day-out may be in a good position to assess whether their pupils align with a definition of learning disability where additional support is needed to support their studies. Once people leave school, there may be fewer places where people with learning disabilities come into regular contact with public services, especially if they do not qualify for local authority social care support.

If children received additional support for learning at school, it is not unrealistic to assume they may need continued support of some sort in future. We know that there are many that feel abandoned when they leave school and do not receive the support they feel they need to transition successfully to life as an adult (see page 12 for more on transitions).

We agree with the Scottish Government in their 2013 “The Keys To Life” strategy[1]:

> *“Determining the most accurate estimate of the number of people with learning disabilities depends upon the purpose for which the information is required.”*
>
> The Keys To Life (2013), Scottish Government

However, we do not believe that the current efforts to gather information are sufficient for policy development at the right scale.

The most recent strategy from the Scottish Government, "Learning/Intellectual disability and autism: transformation plan"[5], the population estimate used was from the 2011 census with no explanation that this figure is likely to be an underestimate when compared to other sources (see Table 1). The risk is that this serves to underplay the size of the population and the scale of policy response required.

It is critically important that this issue is reviewed, although we acknowledge that this is a complex issue to get right. Until then, and as we suggested in an article in December 2020:

> *"Presenting a range with a lower bound informed by the census statistics and a higher bound taken from the pupil census may be the most sensible approach at the moment."*

Fraser of Allander Institute, December 2020

This is before we think about understanding different levels of severity of learning disabilities that would enable the right strategies to be developed depending on the relative needs and wants of what is a diverse population.

Recommendation 1: The Scottish Government should recognise that current data is not fit for purpose and that data on adults with learning disabilities should not be used unless appropriately caveated. The Scottish Government should examine approaches to build on existing data to enable understanding of the requirements of people with learning disabilities throughout their life course and to build evidence on whether people are able to realise their human rights.

2. Social care

Much of our research has touched on the adult social care system. There are many good examples of successful service delivery, but overall, the system as it stands is not doing enough to enable people with learning disabilities to live safe, secure and fulfilling lives.

This is not a finding that stands alone for adults with learning disabilities. The Feeley Review[6] into adult social care, published at the start of 2021 found issues for all people who draw on social care and had a clear message for the Scottish Government:

> *"...it needs to act, we hope with support for improvement from across Scottish civic and democratic society, to deliver a system of social care that takes as its central aim the realisation of every citizen's right to participate fully in society, whatever their needs for support."*

Independent Review of Adult Social Care (2021), Scottish Government

The legacy of the Feeley Review will be the establishment of the National Care Service. It is still in its early development stages and is likely to be implemented across the life of this parliament. For people with learning disabilities, it is crucially important that the new service pays heed to the different needs of different users of the social care service as we said in our report earlier this year:

> *"Whilst there may be common issues across the whole of the social care sector, the experience of people with a learning disability are very different from others and no two people with learning disabilities are the same."*

Fraser of Allander Institute, February 2021

Learning from previous reforms

The anticipated National Care Service is the latest of a number of reforms that have taken place within adult social care for people with learning disabilities, the most significant being the move from long stay hospitals to community-based care in the 1990s and early 2000s. Health and social care practitioners who we interviewed for our research, who were involved in this process, spoke of there being a clear vision, strong leadership and adequate resources at this time of transition. Indeed, we were told of double funding to provide community-based care at the same time as the long stay hospitals were still being closed.

In the last ten years, there has also been the introduction of Self Directed Support (SDS), which allows individuals to manage their own care within a given budget, and a move to integrated health and social care services within local authorities.

Both initiatives were described by those we interviewed in Health and Social Care Partnerships as well intentioned but with shortfalls in implementation which continue to this day.

Self Directed Support was felt to have fallen short of its potential, particularly for people with learning disabilities. Interviewees spoke about there not being the right options and the process being too complicated without the support being there to help people make the right decisions.

Health and social care integration was felt by most interviewees as having some way to go. However, there was a notable disparity between local authorities with some feeling that integration had worked well, and others feeling that it hadn't really happened at all on the ground.

Focus groups and surveys of unpaid carers also spoke about the limitations of the reforms. All but one respondent said they needed more services for the person they care for, both in terms of the variety and extent of support available. This was particularly notable amongst families that have made use of the direct payments option under Self Directed Support. These survey respondents reported a lack of options to spend the Self Directed Support budget on.

The establishment of the National Care Service may be able to solve some of the issues highlighted in this section. For example, a Scotland wide service offer may eliminate some of the disparities between eligibility and provision in different local authorities.

However, the lessons of Self Directed Support and health and social care integration tell us that a strong rationale and good intentions do not guarantee success. Whether or not the reforms over the last decade were hampered by financial pressure is hard to say definitively, but this is certainly the view of many of the people we spoke to:

> *"I've read all the relevant legislation and it all looks great and really empowering. But in reality, it just doesn't happen because the resources fall short."*

Unpaid carer from FAI focus group

The importance and opaqueness of funding

It has been difficult to accurately assess the amount of money spent on adult social care for people with learning disabilities in Scotland, and to consistently track this over time. With the help of government analysts, we were able to piece together some of the statistics provided by local authorities in their annual Local Financial Returns (LFRs) but this was far from straightforward. In the most recent set of LFR data, there is far less disaggregation of learning disability information making analysis of changes over time even more difficult for those looking at the data.

The primary purpose of LFRs are for audit purposes, and therefore it is perhaps of no surprise that they are not user friendly for those seeking them for other purposes. There are accounting distinctions and terms which are not designed to make sense to the general public. However, in the absence of other data, these are the only figures available, and much more could be done to make them more accessible to a wider audience who wish to understand, and track over time, the amount of money spent by the public sector on social care for adults with learning disabilities.

Accessing consistent time series data has been a problem, but our interviews with those providing and drawing on care have been able to fill in many of the gaps.

As we have already mentioned, it was felt that the move from long stay hospitals to community-based care was met with adequate resources. In the years following, before the financial crisis of the late 2000s, there was a general feeling that there was enough financial support available. As we outlined in Chapter 1, not all ambitions were realised, but there was little sense that this was down to financial pressures.

Post financial crisis, the fall in public spending UK-wide affected the support that was offered. Whilst there were obligations to protect statutory services, eligibility for these services and support for issues like employability and community inclusion were squeezed.

Experiences differed by local authority and some interviewees did talk about innovation and creativity in delivering services as a good thing that came out of the drive for efficiency savings. Others spoke about the importance of good leadership within local authorities during this time, and that if the right people were round the table, then solutions could be found despite budgetary pressures. But often, the lack of money was cited as an insurmountable barrier to providing support that would have previously been available.

Our interviews with those who drew on support at this time also highlighted the impact of this support being reduced. Services that were previously free became charged for. Others spoke about the help that they previously received for things like organising finances and paying bills being taken away. Where support was available, services often felt overwhelmed and adequate help was hard to get.

This constrained funding environment appears to be the status quo as we move into the reform period for the new National Care Service and there should be consideration over whether what is provided now is enough.

The information we have gathered from our qualitative research provides evidence where quantitative data has been absent. As well as data on funding over time, there are other areas of evidence that we have sought but not been able to find.

Data on eligibility for services by local authority

It was not possible to reliably find information on eligibility criteria for local authority services, let alone find information on how this has changed over time. This makes it difficult to understand the current state of support available, and it also has implications for the accuracy of the statistics that are collected which are referenced in Chapter 1. For example, a fall in the number of people accessing council services could be due to stricter eligibility rather than a reduction in need.

Data on experience of using the social care system

We are unaware of any regularly collected data that asks about the experience of those drawing on social care. This would be an effective means of understanding the impact of changes to how the system is funded that is absent at the moment.

Recommendation 2: It is important to have a robust baseline of support that is available in terms of financial resources, eligibility and experience of the current social care system. These aspects need to be monitored to understand what is changing, and the impact that this is having on the people that draw on these services. The Scottish Government should take responsibility for this now to ensure that the impact of the National Care Service can be monitored and evaluated.

3. Unpaid care

Any discussion of the lives of people with learning disabilities requires consideration of the role of unpaid carers. Paid-for social care will not remove the role of family carers, but it plays a crucial role in supporting them as well as the person directly drawing on support. Ideally, the social care system should provide options. At the moment, interacting with the system seems more of a battle, even for minimum entitlements.

There are two major reforms on the horizon that need to be thought about together. The first is the National Care Service and the second is the intention to reform Carer's Allowance.

Our research carried out over Summer 2021 took a step back and looked at the contribution of unpaid care. We asked unpaid carers to fill out time use diaries that gave a detailed record of the time they spent providing unpaid care that, in their absence, would have required paid care staff. We found that, on average, the unpaid care provided by our sample would have cost the taxpayer £114,000 per year if it was provided by the state.

The savings that they provide are therefore significant. Our small sample of 16 unpaid carers together yielded over £1.8m per year in savings.

Most of the carers in our sample did receive Carers Allowance. Even with the Carers Allowance supplement available in Scotland, this only totals around £5,000 a year, far less than what they would earn for equivalent hours paid at the Real Living Wage which we estimated to be in the region of £78,000 annually per unpaid carer.

Just over half of survey respondents had income below or around the poverty line. This was due to the obvious consequence of providing full-time unpaid care: opportunities for paid work are constrained. Only where there was a second family member either in paid work or with decent private pension income was financial security not an issue.

The wellbeing of unpaid carers was below comparable population averages. All but one, when asked about future support, felt that they needed more respite and more support from the social care system for the person they cared for.

With the reforms promised both to social care and to Carer's Allowance, the Scottish Government needs to be clear on how it values the work of unpaid carers, and what the state should be providing in return. This should cover both ensuring financial security and an agreed expectation of what the social care system should provide as a minimum in terms of respite and paid-for care.

Ideally the reforms, taken together, should allow for genuine choice on how care is provided and by who, so that paid work becomes an option and the person drawing on care is able to plan for the long term for a time when their unpaid carer perhaps will not be available anymore. This may mean having the opportunity to build skills and resilience to allow for more independent living. The average age of unpaid carers in our survey was 57, with most looking after their adult children, and fears over the future were justifiable concerns of those we spoke to.

Recommendation 3: The Scottish Government must ensure that reforms to Carer's Allowance and the National Care Service are considered together so as to provide an integrated package that allows genuine choices for unpaid carers and those who draw on unpaid care support.

4. Employment

Our first conversation with The Keys To Life Expert Group at the start of our programme of work highlighted the huge issues, and lack of progress, with regards to paid employment.

It was not the case that members of the Expert Group could not or did not want to work. Indeed many were involved in voluntary work but only one person was currently in paid work. All described finding paid employment as difficult. The application process itself was described as hard 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 if 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.

The lack of progress on supporting people into employment was also highlighted in our discussions with health and social care professionals:

> *"We've never really delivered on true employment opportunities for people with learning disabilities. That stands out like a sore thumb because in many ways that's the access to society."*

Social Work Manager

This was also an area that they felt had been disproportionately cut locally due to funding pressures over the last decade. This is wholly counter to the aims of The Keys To Life:

> *"The Scottish Government is committed to helping people with learning disabilities who want to work, and it is our ambition that with the right support, they are able to find work in mainstream employment, suitable to their skills."*

The Keys To Life (2013), Scottish Government

As is a common theme across almost all areas of the lives of people with learning disabilities, data is incomplete.

The most recent data[4] shows that of the 23,584 adults with a learning disability known to local authorities, 4.1% were known to be in employment. After removing "not recorded", the employment rate rises to 8.4%. A very high proportion (51.5%) did not have their employment status recorded.

As explained in Chapter 1, this is not a complete sample, as not all people with learning disabilities are known to local authorities. We have not found any other data sources that are able to provide other estimates of the employment rate of people with learning disabilities or how many people with learning disabilities could and would like to work.

The Scottish Government has a target to half the disability employment gap by 2038. To meet the target they need around 100,000 disabled people to move into employment out of 375,000 currently not in employment. We know that people with learning disabilities are likely to be over-represented in that 375,000 figure because their employment rate is so low. Therefore, meeting the target will likely only be possible if employment for people with learning disabilities is substantially improved.

As our programme of work has progressed, we have unearthed examples of successful initiatives to equip young people with the skills they require and experience in the workplace.

These include DFN Project Search and Breaking Barriers.

DFN Project Search is a year long transition to work programme for young people with a learning disability or autistic spectrum condition.

Each programme works as a partnership between:

- a host employer, which must be large enough to offer interns placements in different roles on a rotational basis,
- an education partner, which in Scotland is usually a college, and
- a supported employment partner, usually a local authority.

Breaking Barriers is a programme offered by the University of Strathclyde in partnership with ENABLE Scotland and host employers, such as Scottish Power. It started in 2018 with 8 students, and had increased to 20 students in the 2020/21 cohort. It offers people with a learning disability the opportunity to gain a Certificate in Applied Business Skills from Strathclyde Business School and the chance to apply the skills learnt on the course via work experience at host employers.

We have heard testimonies from a range of young people who have experience of these schemes. As well as providing skills and experience, these schemes opened new possibilities for what is possible, boosted confidence and provided lasting friendships. In the absence of these schemes, many felt that they would still be at college with little prospect of employment or would be at home.

Many of the employers involved with DFN Project Search and Breaking Barriers are private sector companies, but the third sector are also key employers. Employment in third sector organisations can be a good route for many people with learning disabilities, even if it is just a first step.

This is the rationale for Community Jobs Scotland (CJS), a Scottish Government scheme that funds placements for people with a range of additional support needs, and is currently delivered by SCVO. The account managers we spoke with felt strongly that the third sector can offer the empathy and flexibility to allow for young people to find their feet and build confidence in the workplace. Community Jobs Scotland can also act as part of a pipeline for young people who have experienced schemes such as DFN Project Search and learnt valuable skills, which they can then use and build on within a longer work placement.

The fact that young people earn a wage makes CJS different from volunteering, with employers describing that this means that they assign responsibilities and are able to invest in training, with financial backing from the scheme.

Some of the young people we interviewed had never had a pay cheque before and being paid enabled them to plan for the future and do things that their friends took for granted, like being able to go to a music concert. One other person we spoke to had previously had a very bad experience working in the private sector, but had been really encouraged in his placement so far, and felt it was good to know that there were places where his skills and experience were valued.

Our research has shown that routes to paid employment do exist, although the concern is that these are geographically patchy and it can be the luck of the draw whether a scheme exists at the right time and you are aware or it and/or referred.

The system of publicly funded employability support in Scotland is being changed over the next few years. No One Left Behind aims to bring together the different strands of employability support in Scotland to ensure a more joined-up and straightforward employability system, delivered locally. Community Jobs Scotland is one of the strands that is being brought within this and SCVO will no longer deliver the programme on behalf of the Scottish Government.

The move to No One Left Behind provides an opportunity to improve the experience of people seeking support for employability. However, by bringing schemes together that have been created for distinct needs, there is always the risk that more of a one size fits all approach is taken, particularly if pressures on funding emerge. This is unlikely to be to the benefit of people with learning disabilities.

However, there are reasons for optimism. Many local authorities are already engaged in initiatives such as DFN Project Search, so they will know the value of this type of scheme and how it can fit into a pipeline of employability support. It may also become easier for those already known to the local authority, either through health, social care or schools, to be referred directly to employability colleagues within the local authority so they are not lost from the system. To get this right, the right data sharing needs to be in place, and monitoring and evaluation is crucial to spread good practice.

Encouragingly, the current flagship employability scheme in Scotland 'Fair Start Scotland' (which itself will become part of No One Left Behind) has set a precedent by identifying people with a learning disability within its monitoring outputs. It shows that it can be done.

Recommendation 4: The Scottish Government should carry out an audit of the current employability support schemes on offer in each part of Scotland for people with learning disabilities, and the routes that people come through to access them. This will ensure a shared understanding across Scotland so that new localised schemes are aware of what they have to build on, can ensure good practice is not lost, and gaps in provision are identified. Robust monitoring and evaluation of outcomes for people with learning disabilities is crucial, including follow-up after 12 months to measure sustained outcomes.

5. Transitions to adulthood

“Transitions” refers to the period when young people move from child services to adult services. This is a transition that many young people experience, for example moving from school to university. However, for people who were accessing additional support at school, leaving school can mean the end of this support. For many people who have a learning disability, or indeed a range of other disabilities, there is also the transition from child health and social care services to adult services. Adult services may look and feel very different, and we have heard from many young people that they can be difficult to navigate.

Transitions do not need to be difficult if they are well planned and well managed. However, from our research, we have seen that this is rarely the case. Words such as *‘cliff edge’* and *‘black hole’* are frequently used. Many young people feel abandoned and disappear from the radar of support services.

The Scottish Transitions Forum has published a transitions framework, The Principles of Good Transitions 3[7], in which seven key principles are identified as essential for ensuring best practice and successful transitions to adulthood:

- Planning and decision making should be carried out in a person-centred way.
- Support should be co-ordinated across all services.
- Planning should start early and continue until age 25.
- All young people should get the support they need.
- Young people, parents and carers must have access to the information they need.
- Families and carers need support.
- A continued focus on transitions across Scotland.

The importance of many of these points have been echoed at various times during our research programme, including in conversations with young people, families and health and social care professionals.

During a webinar discussion on employment, a number of points were raised with regards to transitions:

- Support needs to be available long before the final year of school, and to continue after leaving school.
- Some felt that employment is not considered by professionals who work with young people with learning disabilities, and many young people are *“pushed”* into college courses with no long term plan because further education is seen as a safe option.
- This default move to college can also be preferred by some parents. However, it was noted that a narrative of *“overprotective parents”* can be simplistic and that parents also need support. Many are anxious about their children leaving full-time education, which is often borne out of difficult past experiences with trying to get the services their children needed when younger.

- The idea of a work first approach to transitions was discussed, with a career being the default expectation. Some shared stories of colleagues with a learning disability discovering their talents, despite never having expected to work. However, employment will not always be the solution.

In a podcast we recorded with a group of young people who work with ARC Scotland, one interviewee commented that:

> *"The process is often focused on disability and looking at other people with a similar condition and saying 'that's best for you too', rather than looking at the actual person and what their wants and needs are in life."*

These comments raised in the podcast and the webinar echo the need for a person-centred approach that explores a range of different options for each person, allows for mistakes and wrong turns to be made, and focusses on long term wellbeing.

We have heard a range of views on whether a statutory approach for transition planning is the right one, or whether this will lead to a focus on compliance and a tick box exercise above all else. However, there is a clear consensus that improvement is needed.

It goes without saying that ensuring a good transition to an adult life, where wellbeing can be maximised, will have long term benefits to both the person drawing on support, their families and the public purse. The more people that can meet their potential through work for example, the less they will draw on social security and the more they can contribute through taxation. For those where independent living is possible, ensuring that this is realised at the transition into adulthood will set them up for life.

The young people we talked to wanted to be able to have the same options as their friends and brothers and sisters, rather than for options to be closed down and decisions made on their behalf.

Reforms in the pipeline could improve the transition experience. For example, the joining up of employability services at the local level could allow better interaction with schools so that people due to leave school with additional support needs are assigned an employability coach at the appropriate time. The National Care Service could see child and adult social care brought closer together so that the system works as one rather than two separate entities. However, none of this is guaranteed, and the transition experience could easily get worse under these reforms rather than better if it is not prioritised.

Recommendation 5: The Scottish Government should ensure that reforms, including No One Left Behind and the National Care Service, provide specific proposals that ensure changes made will improve transitions for young people with disabilities. The implementation of these changes should be monitored and the experience of young people with disabilities during the transition period should be routinely captured as part of monitoring and evaluation.

6. The Covid-19 pandemic

The impact of the pandemic is summed up best by one of the participants in our first meeting of The Keys To Life Expert Group:

> *"It changed everything"*

Of course, experiences will have differed across the population of adults with learning disabilities, in the same way it differed for the wider population. But there were additional issues for people with learning disabilities.

Firstly, those with learning disabilities were more likely to die if they were infected by Covid-19. Based on linking of Census records, the Scottish Learning Disabilities Observatory found that the learning disabilities population was three times more likely to die from Covid-19 than the general population[8].

Also linked to healthcare, at the start of the pandemic, emergency legislation included provisions that would have meant that people with learning disabilities could be moved without their consultation and that medication could be given without consent[9].

When discussing this emergency legislation in our podcast, People First said:

> *"It sounds like the human rights and safeguards for people with learning disabilities are not important. It reads as if our needs and our rights are a problem for the rest of the population."*

People First, 2020

In England and Wales, there was widespread anger at the imposition of blanket Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders for people with learning disabilities, although as far as we are aware this was not the case in Scotland[10].

The higher mortality threat from the virus, coupled with apparent action on behalf of governments to curtail human rights in relation to healthcare, placed additional stress and distress on people with learning disabilities and their families.

Added to this was the reduction and sometimes removal of the social care support that people with learning disabilities draw on. A survey of people with learning disabilities conducted by SCLD in April 2020 found that 64% of respondents had seen a reduction in care and support[11].

The biggest issue seemed to be for those who lived semi-independently or at home with family. On the other hand, those we spoke to who lived alone but had carers coming in every day to provide personal care did not see reductions in support.

18 months on, our research with unpaid carers found that care provided by local authorities for the people they care for has not returned to pre-pandemic levels and there appears to be no plan in place to make this happen, meaning unpaid carers are still being relied on to fill in the gaps.

The implications of this are likely to be long lasting. For example, in our survey of unpaid carers, some reported that their family member with a learning disability had lost significant progress towards their long term goal of independent living. This was echoed in our interviews with health and social care professionals.

In these interviews many participants expressed pride in the way that teams have been able to find creative solutions to support people through this crisis, alongside recognition that lockdown restrictions had been devastating for many people with learning disabilities and their families.

Several interviewees raised the long term health consequences that they saw unfolding first hand. There was concern that the physical and mental health implications for people with learning disabilities go far beyond those of the general population and will exacerbate existing health inequalities in the future.

It was felt that this will only place greater demand on the support system in future, as support needs are likely to increase as a result of the pandemic. This will require additional resource to be invested in the system in order to maintain the same outcomes.

Beyond that, our interviews threw up a divide between those who see the recovery as an opportunity to deliver support in more creative ways in the future and those who are concerned about what might be lost if more structured support is not resumed in full.

This concern is particularly noticeable around day services. For example, one interviewee commented that building-based day services have *"traditionally been seen as outdated"*, but noted that they have proven themselves to be *"really powerful and good"* models of support *"when done well"*. Another interviewee pointed to their substantial, but often unquantifiable, benefits such as social interaction and respite for families. The latter point was brought up frequently in our survey and focus group with unpaid carers. The experience during the last 18 months is something that the Covid-19 Inquiry for Scotland should look at seriously and evidence will be key in enabling them to do this well.

Recommendation 6: The Covid-19 inquiry should consider in detail the damage done during Covid-19, both in terms of the impact on services provided and the experience of life for people with learning disabilities and their families to inform improvements in the future.

7. Conclusion and review of recommendations

This report brings together our work over the past 15 months. There are many additional areas we could have covered. Some of these have been covered by other organisations as we have been carrying out this work, and others remain areas for further investigation.

Our recommendations focus on data and process. This may seem odd given that our research has turned up many policy issues that need addressing. However, we do not think these issues are insurmountable. We trust that many of these issues can be addressed by government and wider partners if the resources are there, and robust evidence is used to make policy making more effective. Robust monitoring will allow for those making changes to understand whether progress is being made, and allow others to scrutinise progress and hold decision makers to account.

Summary of recommendations

The Scottish Government should recognise that current data is not fit for purpose and that data on adults with learning disabilities should not be used unless appropriately caveated. The Scottish Government should examine approaches to build on existing data to enable understanding of the requirements of people with learning disabilities throughout their life course and to build evidence on whether people are able to realise their human rights.

It is important to have a robust baseline of support that is available in terms of financial resources, eligibility and experience of the current social care system. These aspects need to be monitored to understand what is changing, and the impact that this is having on the people that draw on these services. The Scottish Government should take responsibility for this now to ensure that the impact of the National Care Service can be monitored and evaluated.

The Scottish Government must ensure that reforms to Carer’s Allowance and the National Care Service are considered together so as to provide an integrated package that allows genuine choices for unpaid carers and those who draw on unpaid care support.

The Scottish Government should carry out an audit of the current employability support schemes on offer in each part of Scotland for people with learning disabilities, and the routes that people come through to access them. This will ensure a shared understanding across Scotland so that new localised schemes are aware of what they have to build on, can ensure good practice is not lost, and gaps in provision are identified. Robust monitoring and evaluation of outcomes for people with learning disabilities is crucial, including follow-up after 12 months to measure sustained outcomes.

The Scottish Government should ensure that reforms, including No One Left Behind and the National Care Service, provide specific proposals that ensure changes made will improve transitions for young people with disabilities. The implementation of these changes should be monitored and the experience of young people with disabilities during the transition period should be routinely captured as part of monitoring and evaluation.

The Covid-19 inquiry should consider in detail the damage done during Covid-19, both in terms of the impact on services provided and the experience of life for people with learning disabilities and their families to inform improvements in the future.

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If you would like to contact us regarding any element of this report or our future work, please contact fraser@strath.ac.uk.

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