Fraser of Allander Institute

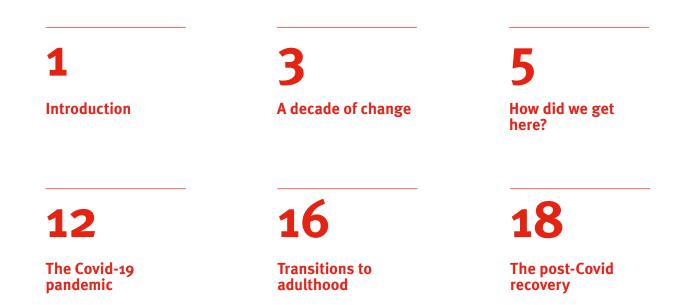Evidence on Scotland's adult social care system for people with learning disabilities

February 2021

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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

The system that delivers social care and support for adults with learning disabilities in Scotland is not doing enough to enable people to live safe, secure and fulfilling lives. This is the clear finding from our analysis in this, our latest report, on adults with learning disabilities in Scotland.

This is not necessarily through want of trying. The last thirty years have seen enormous changes in how people with learning disabilities are supported in society, with a shift from people living in long stay hospitals to community-based support. There have been new initiatives to improve people's choice of care, a move to align their health and social care support, and an ambitious plan articulated by the Scottish Government that recognised that more needed to be done to help people realise their human rights.

Yet at the same time, our study finds that financial pressures have restricted the support that is on offer and there is often a lack of certainty over whether people will get the care they need. For those with mild to moderate support needs, support that enables them to live a fulfilling and independent life, has been taken away or charged for. Our study finds that the response to the coronavirus pandemic has accelerated many of these issues that have been rising up over the past ten years, and it is feared that much of the support that has been lost will not return, or will be significantly scaled back.

Society creates the barriers that bar people with learning disabilities from participating in society. These may be wrongly made assumptions, discrimination, or ignorance. People need support to overcome these barriers and society cannot remove support and expect people to succeed by themselves, or by relying on unpaid support from their family and friends. This is why we have a social care system. Whilst there are many issues with the system, they are issues that can be overcome.

This report is being published in the same week as the Scottish Government's Review of Adult Social Care. Our research looks in more detail at the experience of those with learning disabilities and those who work in Health and Social Care Partnerships that provide support. Our research echoes many of the sentiments expressed in that review but in responding to the review, it is important that the Scottish Government understands that there is no 'one size fits all' solution. 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.

Our research has emphasised that a person-centred social care system, that can flex to different situations is crucial if people are to be able to realise their potential. If not, there is a risk that people are kept locked out of society, which is not a far enough cry from decades past when it was the norm for people with learning disabilities to be physically locked away for decades at a time.

Our key findings from this research are:

- The closure of long stay hospitals and institutions was driven by consensus from policy makers and civil society, and delivered by means of substantial financial investment to help people transition to community-based support. Any future substantial changes in the way care is delivered should learn lessons from how this was achieved.

- Since the financial crisis, there has been a loss in some of the non-statutory support that was so vital for people, particularly with mild to moderate learning disabilities, to live their lives independently. This means the ambitions set out in the Scottish Government's strategy, *The Keys to Life,* have had little chance of being realised.

- It is crucial that there is a system in place that allows people to access the support that they need. Self-directed support should have helped achieve this, but we've been told that the complexity of the system has arguably made it harder for people with learning disabilities to access what they need. This highlights the issue with assuming that all social care users will benefit in the same way from innovations in how support is delivered.

- The transition from childhood services to adult services is a critical time for young people with learning disabilities. There is no question that young people need more support in navigating this time in their lives so that they know what their rights are and how to access the support that can enable them to achieve their ambitions.

- Housing is a cornerstone of independent living, yet an undersupply of quality accommodation for people with learning disabilities constrains choice and results in delays. Suitable accommodation is a vital form of support in itself and accounting for this undersupply will require planning in housing strategies.

- The Covid-19 pandemic has been detrimental to the support relied upon by people with learning disabilities. Some of this has been the result of restrictions on face to face contact, and given the heightened risks that people with learning disabilities face, in many cases this was unavoidable. However, there can be no doubt about the harm this has had on people and their families. Now there are fears that support will not return post-pandemic at the same level it was before. The opposite needs to be true if people are to recover from the harms created over the past year.

Despite the issues that our research has uncovered, the support system for people with learning disabilities features a lot of positive assets, not least the many dedicated people who work in the sector. For example, we heard about many creative solutions that have helped improve lives for people with learning disabilities, but too often this is in spite of, rather than because of, the structures in place.

As we face a crossroads in terms of rebuilding support post-Covid, and renewed focus following the Independent Review of Adult Social Care, we hope that people with learning disabilities and those that work in the sector are listened to carefully. That is what we have done with this research, and it has shown that drastic improvements in people's lives has been possible, but there is also potential for great harm.

We hope that this report can be a step towards understanding some of these issues for both those tasked with making changes, and wider society who may not realise the importance of adult social care services for adults with learning disabilities.

Widespread support for system change was a driving force in the closure of long stay hospitals and many people thrived in the community, thanks to the support that was available. Our research has shown that the last ten years have been more challenging, and shows that there is much that could be done to ensure that the right support structures in place so everyone in Scotland can, at the very least, realise their basic human rights and have the best chance of fulfilling their potential.

Introduction

To realise our ambitions and live a fulfilling life, we all need support at times. People with learning disabilities are no different. But they face societal barriers to achieving this that other groups of the population don't encounter, and are often unaware of.

To remove these barriers, a network of support services have been established in Scotland with the aim of enabling people with learning disabilities to live as independently as possible and attain a good quality of life. This follows the rationale of the social model of disability – that people are disabled by barriers in society, not by their impairment.

What support is available in Scotland?

In Scotland, support is available through various means. The social security system, for example, provides financial support. Employers can access funding to make small adjustments that support people with learning disabilities into the workforce. But perhaps the most practical day-to-day support is available through a system of support services commissioned at a local authority level through Health and Social Care Partnerships (HSCPs). It is this network of support services that form the focus of this report (see Box 1).

Access to this support is dependent on meeting eligibility criteria, against which an individual's support needs are assessed. Whilst a National Eligibility Framework[1] exists, the decisions made on support available for adults of working age are made locally.

However, what is and is not available to people with learning disabilities is difficult to pin down. The National Eligibility Framework states that local eligibility criteria for social care must be *"clear, published and accessible"*, yet we have struggled to find an adequate detailed explanation of what services are available to adults with learning disabilities in different parts of Scotland, how the system fits together, or how things have changed over recent years.

From discussions with people living with a learning disability, there is a general feeling that the support available has reduced over the past 10 to 15 years, or support that was previously free now needs to be paid for. We heard that this makes it harder for people with learning disabilities to realise their human rights and live as equal citizens.

This report attempts to document what has happened with support provided for people with learning disabilities over the past ten years. For example, what decisions have been taken in light of funding pressures following the financial crisis, and what impact do those on the front line feel that this has had on the support they are able to provide? As well as looking back, we also look forward to see what people who work in learning disability support services, and people with learning disabilities themselves, would like to see changed.

Important decisions lie ahead

The Covid-19 pandemic has affected much of the support provided to people with learning disabilities. Restrictions have forced much support to be withdrawn or closed, and changes in the way support is delivered have had to be enacted at speed.

This means we are at an important crossroads. The harm caused by Covid-19 restrictions on people

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1   https://www.gov.scot/publications/self-directed-support-practitioners-guidance/pages/6/

with learning disabilities will have long lasting consequences. And, as the restrictions imposed due to Covid-19 recede, decisions will need to be made on how services are resumed. With an election imminent and a high-profile review recently published, this is clearly a time when we would expect politicians from across the political spectrum to be considering how to move forward.

As with many areas of policy, understanding how we arrived at where we are now provides invaluable evidence for where best to go next. In this report, we highlight the impact that support services have on the lives of people with learning disabilities, we examine how recent changes have impacted the sector, and consider where to go from here.

There is also a special section on transitions to adulthood. This is a crucial stage in any person's life and for a young person with a learning disability leaving school, planning what kind of life they want in adulthood and their transition to adult health and social care services requires support. We consider whether sufficient support is currently available and draw on a case study involving a group of young people with a variety of additional support needs.

Box 1: Examples of support

The nature and complexity of support will be different for each individual, as this is a diverse population with each person having a unique set of needs and aspirations. In this box, we set out some practical examples of support services to illustrate this broad range, although this is by no means an exhaustive list.

For example, those with profound and multiple learning disabilities can live a fulfilling life with specialist care to support them. This might be in a residential setting, in supported living services or in the home of their family or carer. This is likely to be a mixture of health and social care, for example help with daily routines as well as opportunities to engage with friends and the wider community.

Day services have long been a feature of the support on offer. Support can also be embedded within communities. For example, people living with a learning disability can be supported to do activities they enjoy, or community clubs can offer social interaction and friendships. There are also more structured day services, which can be community-based or building-based and offer purposeful activities, learning opportunities and respite for families.

As well as day-to-day support, people with learning disabilities can access help that enables them to plan for the future, such as employability support or support with managing their finances. This is particularly important for those who have low to moderate support needs, and can enable them to live independently if the right support is there. This is where advocacy support can be crucial, to ensure that someone with a learning disability has their voice heard and is provided with accessible information about decisions that affect their lives.

For young people, there is an important period of time when support is needed with the transition into adult services, which look very different from what the young person will have been used to, for example at school. Getting support right at this point gives each young person the best chance of maximising their quality of life as adults.

The delivery of these support services comes from a range of organisations, primarily in the public and third sector, but also indpendent providers. Funding is provided via local authorities if eligibility criteria are met, although there are charges for some services.

Methodology

Throughout this report, we piece together a wide evidence base, using reports, quantitative data and other evidence in the public domain. We also touch on some financial analysis conducted in our previous report, Scotland's Invisible People.

But by far the most informative evidence we use to compile this report is qualitative data generated by a series of in-depth interviews with professionals who work in HSCPs, as well as conversations with people with learning disabilities (in particular the Scottish Commission for People with Learning Disabilities (SCLD) Expert Group) and their families. We also detail the experience of people with learning disabilities and additional support needs in case studies.

The interviews of HSCP professionals who work in the sector were conducted anonymously and lasted between 40 and 60 minutes. The interviewees came from several local authorities, some of which were urban, some of which were more rural. They work in a variety of different posts and at different levels within their organisations. Furthermore, some were relatively new to the sector, whereas others have more experience of the support system. This gave us a breadth of vantage points.

This report focuses on local authority delivered services, and hence is only a partial snapshot of the views of providers of social care, a large part of which is delivered by the independent and third sector. In this report, we make reference to some particularly pertinent issues with regards to the sustainability of third sector contracts and we will return to this in more detail in a later report when we consider issues related to the terms and conditions that care is delivered in, which can look quite different depending on who delivers the care.

HSCP interviewees became involved in the research by contacting us following a request for participants through professional networks. The formal interviews were semi-structured in two parts. The first followed a chronological sequencing of the key events identified in section 2 of this report. Interviewees were asked a number of questions depending on their relevant experience that elicited how each key event has impacted learning disability services. The second part was open to the interviewee to reflect on the long-term consequences of the Covid-19 pandemic and what they thought should be prioritised going forward.

Conclusions have been drawn based on the commonly reported themes that came out through the interviews and conversations with people with learning disabilities. These have been supplemented by some individual insights that add an interesting perspective to the findings, and supported by other evidence where possible.

As such, this report is not intended as a representative overview of the experiences of professionals working in learning disability services, or of people with learning disabilities and their families. However, the key conclusions drawn from it are based on common themes that received widespread agreement.

It was striking how passionate and dedicated all of the interviewees were. They all had some thoughtful and balanced insight to add, which forms the basis of this report. We thank them for their involvement in this research.

Ethics approval for the research was granted by the University of Strathclyde's Economics Department Ethics Committee, in line with the University's procedures.

A decade of change

A lot has changed in the sector over the last ten years. In order to analyse the system of support services, it is important to set out these changes and explore their impact on how the system operates. In this section, the key events that have changed the landscape for learning disability support services have been identified.

Box 2: Timeline of events

Pre-2010
The introduction of community-based support

The years leading up to 2010 saw the closure of long stay hospitals, as care and support moved from institutional settings towards community-based settings. This approach was formalised in the Scottish Executive's first learning disability strategy, *The Same As You?*, published in 2000.

2010
A changing fiscal landscape

The financial backdrop for local authorities and the wider the public sector has changed over the last decade. Managing these pressures has changed the financial environment for learning disability support services.

2013
The Keys To Life

The Scottish Government introduced a new learning disability strategy to update *The Same As You?*. It covers a broader scope than its predecessor, with a rights-based approach to living, learning, working and wellbeing.

2013
Self-directed support

The Scottish Parliament legislated to introduce self-directed support in 2013, with the aim of personalising budgets for social care and support. People with learning disabilities who are eligible for support from their local authority can now choose one of four options:

1. Direct payment to the individual, who then arranges their support.

2. The individual chooses and directs the support, which is then arranged by a provider or local authority.

3. The local authority commissions and arranges support.

4. A mixture of the above options for different types of support.

2014
Integration of health and social care

Local authorities and health boards are integrating health and social care into a single system, with joined up budgets and services. People with learning disabilities who are eligible for support services are likely to have health care needs too, which means integration has changed the way that they interact with these services.

2020
The Covid-19 pandemic

The pandemic and associated restrictions have disrupted service provision and changed the way many people with learning disabilities are supported.

How did we get here?

In this section, we draw on our evidence base to consider how the key events set out in section 2 have impacted the way that adults with learning disabilities are supported in Scotland.

Community-based support

In the decades leading up to 2010, and particularly around the turn of the century, a significant change in the way people with learning disabilities were supported in Scotland was established.

In the 20th century, the practice of placing people with learning disabilities in institutions was commonplace. More than 20 long stay hospitals were built, which were permanently housing more than 7,000 adults and children by 1960. In these hospitals, people were usually isolated from their families and communities. In 1988, over 70% of inpatients at Scotland's long stay hospitals had been there for more than ten years. Many children had been in hospital more than five years[2].

Starting in the 1990s, there was a drive to move more care and support from institutional settings into the community. It was part of a wider recognition, in Scotland and across the UK, that people with learning disabilities should be included in their communities and entitled to the same rights and opportunities as everyone else. The then Scottish Executive's landmark learning disability strategy, *The Same As You?* recommended that the remaining long stay hospitals were closed by 2005.

The move to community-based support was delivered via a network of support services in communities throughout Scotland, which are illustrated by the examples of services in Box 1. These were funded through social care budgets at a local authority level, which is the structure that still broadly exists today.

However, there still remain people living in institutions when it is generally agreed they should be in the community, known commonly as 'delayed discharge'. The Scottish Government report Coming Home, published in 2018, reported that there were 67 known people with learning disabilities who were delayed discharge as of 31st January 2017. More than 22% had been in hospital for more than 10 years and a further 9% had been there for between 5 and 10 years. The report described this as a concerning *"loss of opportunity for an ordinary life"*. We understand that delayed discharge remains a significant problem in Scotland.

Nevertheless, the period leading up to 2010 clearly saw positive change. Some of our interviewees were working in the sector at the time and we asked them what led to this change. Those who were asked acknowledged that additional resources were made available to enable community-based services to be established.

> *"There were resources for double funding to develop the community-based services as hospitals were closed."*
>
> Social Work Manager

But every interviewee also pointed to a clear vision from government, effective leadership and buy-in from key stakeholders.

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2   https://www.scld.org.uk/wp-content/uploads/2015/06/ncf_report.pdf

> *"There was a very clear sense of direction, with strong leadership and the resources to be able to do that. Expectations of all the partners involved in the change process were clear."*
>
> <div align="right">Social Work Manager</div>

> *"There was more vision of what we were going to achieve at that time."*
>
> <div align="right">Allied Health Professional</div>

Without being prompted, every interviewee contrasted this with the environment around *The Keys To Life*, which they felt was missing some of these elements of success (see below).

We also noted some regret that the optimism around at the time has not always delivered the results that were hoped for. Employment opportunities were pointed to by one interviewee as an obvious example.

> *"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."*
>
> <div align="right">Social Work Manager</div>

A large minority of interviewees also questioned some of the assumptions behind the move to community-based support.

> *"The notion that you can go out and join in with everyday activities in the community is a wonderful vision, but the community is not that accepting yet."*
>
> <div align="right">Allied Health Professional</div>

The post financial crisis period

Other than the issues discussed above, interviewees did not mention any changes of particular note during the ten years following publication of *The Same as You?* in 2000. Some frustrations with getting support for people not previously known to local authorities was mentioned by one interviewee, but overall, it was felt that there was generally enough money around to deliver a good standard of support.

Following the financial crisis and recession of the late 2000s, the financial backdrop in the public sector changed significantly. In particular, local government, which is responsible for commissioning learning disability services, has seen relatively steep budget cuts compared with other areas of spending, as highlighted in our 2019 Budget Report.

The analysis in our previous report, Scotland's Invisible People, shows that learning disability services have largely been protected from the most severe funding cuts, with real terms gross expenditure growth in six of the last seven years for which data is available. But this masks a more complicated picture.

Local authorities must meet several statutory obligations to deliver some key services, many of which apply to adults with learning disabilities. Funding for services that deliver these statutory responsibilities have therefore been protected.

But given funding pressures on local government this inevitably means that local authorities' ability to deliver non-statutory support has been affected. For example, several interviewees noticed that eligibility criteria have been tightened to manage financial pressures. At times, this has resulted in

certain services becoming unavailable to an individual without their needs assessment changing. One interviewee noted that in some cases, those with mild to moderate learning disabilities are not entitled to any support.

Several interviewees noted that particular non-statutory support services, such as those around employability and community inclusion, have been most vulnerable to financial pressures. This aligns with findings from our discussions with the SCLD Expert Group.

The financial pressures felt by interviewees differed depending on the local authority. For example, in one local authority which was described as being quite affluent, one interviewee noted that whilst there had been efficiencies made, this was not always a bad thing and had led to more innovative ways of delivering services. Another interviewee talked about the importance of leadership, and that things could be made to happen if the right people were in the room together.

> *"If you can get people round a table – the community team, council provided services, third sector providers – and say, "these are this person's needs, what can we do?", pretty often you can make things happen. Some people will knock down walls, but in other areas there's an attitude of "well there's no money so we just can't do that"."*
>
> Allied Health Professional

One interviewee also pointed out that people with learning disabilities often use services such as libraries and community clubs, in part as a vital social hub. Whilst not typically regarded as a 'learning disability' service, changes to these services can have a disproportionate impact on the learning-disabled population.

The Keys To Life

The Scottish Government's latest learning disability strategy was published in 2013. It therefore appeared at the same time as local authorities were starting to grapple with funding cuts. The loss of non-statutory support services that appears to have happened in many places is contradictory to the desired outcomes in *The Keys To Life*, which sets out the right for people with learning disabilities to have *"equal access to all aspects of society"*[3]. This goes beyond minimum statutory requirements and can include, for example, healthy relationships, involvement in local communities and paid employment.

Generally, interviewees struggled to identify concrete ways in which the strategy has had an impact on their work, either positive or negative. When asked, no interviewee said they felt included in its development and a majority felt it was a missed opportunity to change and improve the support available to adults with learning disabilities.

> *"It was a missed opportunity... Some of the consultation that claimed to be with people with a learning disability wasn't meaningful. It was with their carers. Which is fine, as long as you say that's what you're doing."*
>
> Allied Health Professional

It was noticeable how most of the professionals we interviewed referred to *The Keys To Life* as a *"document"*, rather than as a strategy that has impacted their work. One interviewee commented that *"we see it as a tick box thing to be honest"*. One member of the SCLD Expert Group used the term *"gathering dust"* when asked about the purpose the strategy served.

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3   https://keystolife.info/strategy/

However, there was acknowledgement that the strategy has raised expectations of people with learning disabilities. When we spoke to the SCLD Expert Group, their aspirations clearly chimed with the ambition put forward in *The Keys to Life*. However, they too felt that little progress had been made on many of the issues it mentioned.

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Box 3: Independent and third sector provision

Our interviewees have been drawn from HSCP employees who provide in-house services. However, a large amount of social care is delivered by the private and third sector. The market these third sector organisations compete in for contracts has been described as monopsonic, in that there is a single buyer (the local authority) for social care services provided by a number of independent or third sector organisations in an geogrphical area[4]. The culture of competitive procurement driven by price considerations has long led to concerns over the quality of services that are being procured and whether providers are able to deliver contracts that they had won. The only course of action that is open to these providers if they can't deliver at a low enough cost is to hand back contracts or to not bid in the first place.

The latest Coalition of Care Providers in Scotland CCPS Business Resilience Survey found that around 20% of those surveyed had handed back contracts in the last year and just under half had abstained or withdrawn from a procurement process in the last 12 months. Financial sustainability of contracts was said to be primary consideration when deciding whether to bid for contracts.

In their concluding comments in the survey overview, the CCPS state *"it is not sustainable to continue to expect social care providers to pick up this cost for unsustainably funded services"*.

According to the Scottish Government, *"best value"* in relation to procurement of care and support services means[5]:

"An appropriate balance between the quality and cost of services, having regard to efficiency, effectiveness, economy, equal opportunities and sustainable development. Local authorities have a statutory duty to secure best value in the performance of their functions and the continuous improvement of services."

Third sector providers are reporting that funding pressures are getting worse. Referring again to the CCPS Business Resilience survey, only 39% reported that the vast majority (over 75%) of their services were financially sustainable compared to 57% in 2017. This is clearly not evidence of effective *"best value"* procurement in action and suggests continuing downward pressure on the price that local authorities are willing, and perhaps able, to pay. The implications for the quality and continuation of care services is concerning.

The figures in this box refer to all social care provision, not just for learning disability services but we hope to return to this issue in more detail later in the year.

Self-directed support

Self-directed support (SDS) was another change that happened around the same time as *The Keys to Life*. SDS is described as *"Scotland's approach to social care support"*[6]. It is aimed at providing flexibility, choice and person-centred support by enabling the personalisation of social care and

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4   http://www.ccpscotland.org/wp-content/uploads/2019/05/Handing_Back_report_CCPS.pdf
5   https://www.gov.scot/publications/guidance-procurement-care-support-services-2016-best-practice/pages/13/
6   https://www.gov.scot/publications/self-directed-support-strategy-2010-2020-implementation-plan-2019-21/pages/2/

support budgets. Its application can differ between local authorities, which can lead to very different experiences of the system depending on where a person lives.

Those who are eligible for support from their local authority can now choose between receiving a direct payment and arranging their own support, and allowing their local authority to commission and arrange their support for them. There is also a hybrid option for a provider to arrange support at the direction of the individual. Users can choose different options for different types of their support.

SDS, in theory, was perceived to be a good thing. Given the diverse nature of the learning-disabled population, the support they receive cannot meet their needs and aspirations without a degree of flexibility and choice.

Interviewees were able to provide examples of how effective SDS can be for people with learning disabilities when used well. One interviewee said that it *"has opened up options"*, for example, when a third sector provider can meet an individual's needs better than the services offered by their local authority.

However, there was consensus amongst the interviewees that the potential benefits of SDS are yet to be realised by learning disability service users. This is supported by a 2017 progress report by Audit Scotland[7] which found *"examples of positive progress"* but *"no evidence that authorities have yet made the transformation required to fully implement the SDS strategy"*.

The interviewees in our study gave varied explanations for this conclusion, although they tended to fall into one of two broad reasons. First, most interviewees felt that there are too few services available for people with learning disabilities, which constrains choice regardless of how the support is paid for or arranged.

One interviewee pointed to a lack of *"adapted specialised activities"* and noted that a lot of these have been lost without being replaced. There was some concern that the move from building-based to community-based support has narrowed options for those who prefer building-based services.

Second, there was strong consensus that people with learning disabilities are not given sufficient support to make informed choices about their support and care. No interviewee suggested otherwise. One interviewee felt that *"a lot of people don't fully understand their options"* and this results in people *"taking what they're given"*. Another commented that:

> *"We need a paradigm change in the way people are supported to make decisions"*.
>
> Social Work Lead

> *"These are very abstract concepts. "Which of these four options, none of which you have experienced, do you want to choose?" Very few people with a learning disability have the level of comprehension to understand that. So, it's not the person themselves making the choice."*
>
> Allied Health Professional

> *"We need a broader set of options where people can try to find what works best for them, where trained staff around them can help the individual make an informed choice."*
>
> Social Work Manager

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7   https://www.audit-scotland.gov.uk/uploads/docs/report/2019/ir_191217_self_directed_support.pdf

This conclusion is supported by a 2019 event report on SDS by the Health and Social Care Alliance Scotland[8], which highlighted the need for *"an increased focus on supported decision making"*.

Given that the support services people with learning disabilities receive can fundamentally change their experience of life, this is not something to overlook. It raises complex questions around advocacy, which is a human rights issue, as it concerns the application of Article 12 of the UN Convention on the Rights of Persons with Disabilities.

In our conversations with the SCLD Expert Group, we heard frustrations about people with learning disabilities not knowing what their rights were. This leads to situations where people with learning disabilities do not feel they can ask for changes in the care that they are receiving, and a feeling of the social care staff being 'in charge'. This highlights the importance of advocacy services to ensure people with learning disabilities have their voices heard in decisions made about them.

Similar issues were highlighted in Audit Scotland's 2017 report[9] and are perhaps best summarised by this response:

> *"We need a broader set of options where people can try to find what works best for them, where trained staff around them can help the individual make an informed choice."*

<div align="right">

Social Work Lead

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When asked about the benefits of SDS, some interviewees highlighted that these tend to be realised by younger service users, whose only experience of adult services is with SDS, and by those with family members who are able to help them choose and arrange support.

Without being asked specifically, a majority of interviewees noted that those with more forceful and assertive parents tended to be more successful in getting the right support arrangements. Families who simply trusted that the system would deliver the best for themselves or their loved one often ended up with a worse support package.

The interviewees highlighted this as unfair, especially as it was felt to be in part linked to the family's socio-economic status and whether parents had the time and resources to 'fight' the system.

SDS could in theory empower people with learning disabilities to shape the support that enables them to live the life they choose. However, the general consensus from those we interviewed was that the system has not improved outcomes for many of those who could benefit from SDS.

Integration of health and social care

One of the more recent changes that have happened over the past ten years is the move to formally integrate health and social care services. The Scottish Parliament legislated to integrate health and social care services across Scotland in 2014, although in practice integration had already been adopted in some areas before this.

The Act[10] created 31 integration authorities, most of which established an integration joint board between local authorities and health boards. Responsibility for integrated service delivery and control over resources and key functions were delegated to integration joint boards. The aim is for health and social care services to operate within a single system.

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8   https://www.alliance-scotland.org.uk/wp-content/uploads/2019/12/ALLIANCE-MECOPP-Masterclass-Report-SDS-Human-Rights-and-People-with-Learning-Disabilities-.pdf
9   https://www.audit-scotland.gov.uk/uploads/docs/report/2017/nr_170824_self_directed_support.pdf
10   https://www.legislation.gov.uk/asp/2014/9/contents/enacted

One key rationale behind integration has been *"the projected increase in demand for health and social care as a result of an increasingly ageing population"*[11]. Whilst these demographic changes are happening within the learning-disabled population, people with learning disabilities are more likely to engage with health and social care services throughout their lives.

All interviewees felt that the integration of health and social care services has some way to go. This is not surprising, given the findings of recent reviews into integration, such as Audit Scotland's 2018 progress report[12]. This found that progress had been held back by financial planning that is insufficiently long-term or outcomes focused, as well as several *"significant barriers"* such as a lack of collaborative leadership, high staff turnover in leadership teams and unwillingness to share data.

Adding to this, our fieldwork found concern that integration appears to be taking a top-down approach, with one interviewee commenting that, in practical terms, integration has not happened on the ground. One factor that was repeatedly highlighted as important was health and social care teams sharing the same work space.

> *"There are still major differences in what health and social care teams do and how they operate, almost as two separate entities that have been told to work together. They haven't quite explored all the synergies yet and it's down to a lack of finances and resources."*

<div align="right">Social Work Manager</div>

However, there was a noticeable disparity between different local authorities, with professionals in some areas reporting far higher levels of integration. In some local authorities, integration of health and social care for adults with learning disabilities predates the 2016 initiative.

In local authorities where the process of integration has been longstanding, there was clear support for this way of working. It was regarded by some interviewees as impossible to deliver quality adult learning disability services without an integrated approach, particularly for young people transitioning to adulthood.

> *"When it works properly, you get joined up services and a holistic view of what the person's needs are and how best to meet them. So it's a more person-centred way of working".*

<div align="right">Allied Health Professional</div>

> *"Where we have seen real benefits is in transitions to adulthood. There's a much better process with a joined up approach."*

<div align="right">Social Work Manager</div>

11   https://www.parliament.scot/ResearchBriefingsAndFactsheets/S5/SB_16-70_Integration_of_Health_and_Social_Care.pdf
12   https://www.audit-scotland.gov.uk/uploads/docs/report/2018/nr_181115_health_socialcare_update.pdf

The Covid-19 pandemic

Whilst significant change has occurred over the last 20 years, nothing has been as dramatic as the Covid-19 pandemic. In this section, we analyse the consequences for learning disability support services and consider what the long-term effects of the pandemic might be.

The efforts of those working in the sector have often been remarkable and dedicated throughout this challenging time. During our interviews, many participants expressed enormous pride in the way that teams have been able to find creative solutions to support people through this crisis, alongside recognition that lockdown restrictions have been particularly devastating for people with learning disabilities and their families.

All interviewees recognised that support for people with learning disabilities was facing significant challenges even before the pandemic and some interviewees expressed anxiety about what will emerge post-pandemic. There is clearly widespread concern that a 'new normal' will emerge where support that has been removed is not fully replaced once restrictions are lifted.

The harm caused by Covid-19 restrictions needs to be urgently addressed and it was felt by many interviewees that there is an opportunity both to do this, and to make changes that will improve the system overall.

The impact of the pandemic on people with learning disabilities

Before considering where the pandemic might leave the support system in the future, we look back at some of the key concerns that have arisen over the last 11 months.

Sadly, the direct impact of the virus has seen a mortality rate amongst people with learning disabilities that is far higher than the general population. Whilst Covid-19 data regarding people with learning disabilities is not regularly published in Scotland, interim findings of a study by the Scottish Learning Disabilities Observatory[13] has found that:

"Overall, people in the learning disabilities population were more than three times more likely to die from Covid-19 than those in the general population … and twice as likely as those in the general population to become infected".

These interim findings reflect health inequalities that existed before the pandemic.

Perhaps equally as concerning is that several interviewees raised the long-term health consequences that they see unfolding first hand. There is concern that the physical and mental health implications go far beyond those of the general population and will exacerbate existing health inequalities in the future.

> *"The pandemic has had a far greater impact when there's already been underlying mental health issues. It's just added extra stresses on top of that."*
>
> Social Work Lead

During the pandemic, face to face support has been restricted, the clearest example of which was the closure of day services. A survey of people with learning disabilities conducted by SCLD in April

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13   https://www.sldo.ac.uk/our-research/life-expectancy-and-mortality/covid-19/

2020 found that 64% of respondents had seen a reduction in care and support[14]. This has shifted support roles onto unpaid carers, which has placed an unsustainable strain on their wellbeing and many are not coping. We heard evidence during our interviews suggesting that unpaid carers who are struggling could become at risk of needing crisis support.

> *"A lot of families have coped better than we had expected them to, but I think that's just storing up more crises for the future."*
>
> <div align="right">Social Work Lead</div>

The manner in which some people's support packages were suddenly withdrawn has caused distress, as evidenced throughout a November 2020 report[15] by the Scottish Human Rights Commission. It was noted that the withdrawal of support packages has had *"a detrimental effect on people's human rights, including those protected by the European Convention on Human Rights"*.

Some interviewees noted that these restrictions will exacerbate the effects of social isolation for many people with learning disabilities, who formed friendships with professionals providing support that has been restricted and have been unable to attend day centres.

Furthermore, many people have endured long periods with little or no contact from family, as restrictions over visiting residential care settings have applied to supported accommodation for people with learning disabilities. We heard concern from family members that this will have long-term consequences for their loved ones' health.

During the interviews with professionals, it was also pointed out that many people with learning disabilities will be losing skills that might take years to reacquire. These include skills that enable people to live independently and, in some cases, carry out paid work.

Emergency legislation

Furthermore, the implementation of emergency legislation at the beginning of the pandemic has raised concerns around human rights breaches for people with learning disabilities, amongst others. In April 2020, a report[16] from People First detailed the impact of this emergency legislation.

"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."

A number of specific concerns were noted, including around provisions for people with learning disabilities to be moved without their consultation and that medication could be given without consent.

On top of these specific issues, there are concerns over the procedure followed, for example the Scottish Human Rights Commission[15] found that *"the implementation of the legislation lacks transparency"*.

Our podcast with People First provides more detail.

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14   https://www.scld.org.uk/wp-content/uploads/2020/06/SCLD-Coronavirus-Report-FINAL.pdf
15   https://www.scottishhumanrights.com/media/2102/covid-19-social-care-monitoring-report-vfinal.pdf
16   http://peoplefirstscotland.org/wp-content/uploads/2020/04/LaHRG-statement-on-Covid19-FINAL.pdf

How have support services responded?

Despite the severe impact that the pandemic is clearly having on people with learning disabilities, we have heard examples of dedication and compassion exhibited by staff who work in the sector.

During the interviews, we asked how teams have responded and several interviewees reflected that this period has opened up opportunities to think creatively about how best to deliver support. Some of this innovative delivery has involved technology, such as video calls for online classes and social contact, which highlights the importance of digital inclusion.

The pandemic also seems to have given many professionals working in the sector time to reflect and produce work that would not otherwise have been completed, such as easy read guides. However, this raises questions over whether the system was sufficiently resourced before the pandemic, as much of this work is valuable in normal times.

Another conclusion from our interviews is how different the pandemic response appears to have been across different local authorities, both in terms of the way that teams have worked and the type of support that has been delivered. This difference was more apparent when discussing the early stages of the pandemic.

The long-term consequences

The effects of the pandemic will clearly be lasting and won't disappear once life returns to a sense of normality. We asked interviewees what they thought the long-term consequences of the pandemic could be for learning disability support services.

The clearest conclusion is that many peoples' long-term health prospects are deteriorating. This will 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.

We also heard concern from one interviewee around a cliff edge between specialist and mainstream health services for people with learning disabilities, with one interviewee questioning whether more could be done to ensure mainstream health services are appropriately supporting people with a learning disability.

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.

On the other hand, it was noted by a small number of professionals that we interviewed that a *"return to normality is unlikely"*.

"There's been a significant impact on carers, particularly where people live at home with their carers. All carers want is for things to go back to normality, to go back to the way they were before. We don't envisage that that's going to happen and that's going to be a really painful journey."

<div align="right">

Social Work Manager

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It was also noted by interviewees that some people with learning disabilities may not want to return to the kind of support they received before the pandemic. This highlights the fact that people with learning disabilities are a diverse population with different needs and preferences, and that the support they receive should reflect that.

Transitions to adulthood

The transition from school to adulthood is one of the most important times in a person's life. For people with learning disabilities, this period can entail a cliff edge, in which a childhood spent in a supportive and consistent environment comes to a sudden end. At this point, a young person with a learning disability might engage with adult health and social care services for the first time and be faced with life changing decisions.

Transition planning is a key support system that assists young people with learning disabilities and other additional support needs through this period. It aims to take away the cliff edge and ensure young people and their families are supported. However, our interviews suggest there is widespread recognition that the transitions support system in Scotland could be significantly improved.

With this aim, the Scottish Transitions Forum has published a transitions framework, The Principles of Good Transitions 3[17], in which seven key principles are identified as essential for ensuring best practice and successful transitions to adulthood:
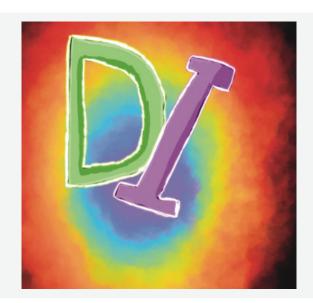
- Planning and decision making should be carried out in a person-centred way.
- Support should be co-ordinated across all services.
- Planning should start early and continue until age 25.
- All young people should get the support they need.
- Young people, parents and carers must have access to the information they need.
- Families and carers need support.
- A continued focus on transitions across Scotland.

The Scottish Transitions Forum are also developing a process of monitoring outcomes and measuring success. During our interviews with professionals from HSCPs, we noted some desire for an agreed way of measuring whether the transitions process is delivering for young people. In practice, this can be difficult, as defining 'success' will be dependent on each individual's aspirations and priorities, in line with a person-centred approach.

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17   https://scottishtransitions.org.uk/summary-download/

Case study

ARC Scotland's 'Divergent Influencers'

- Five young people with additional support needs shared their transitions experiences.
- A lack of information and available options were common themes.
- Evidence that the transitions process is not person-centred was shared.

In The Principles of Good Transitions 3, it is noted that transitions are *"not a single event, such as leaving school, but a growing-up process"*. We spoke with five young people with additional support needs about their process of transitioning to adulthood in order to provide evidence of how the transitions process is working in practice. All five are working with the Association for Real Change, or ARC Scotland, through their Young Leaders Project. Their experiences varied but some common messages were apparent, some of which demonstrate that the principles set out above are not always followed.

The first was frustration around a lack of information about available options and support. Some of this relates to a lack of information about the opportunities that were available to them, whereas some relates to a lack of practical information that could have made their experiences easier once they had left school.

It was also felt that the transitions process was insufficiently person-centred. 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."

Another clear conclusion is that the transitions process did not raise or meet their aspirations. For example, one interviewee who had ambitions of going to university was repeatedly told *"I wouldn't manage it"*. They ultimately studied at university, but this was despite, rather than because of, the transitions system.

Finally, there was frustration around the lack of options for young people with a learning disability or other additional support needs to transition to. This finding was also reflected in our interviews with professionals who work in the sector, particularly when discussing the impact of SDS.

You can hear more details in our recent podcast on transitions to adulthood.

The post-Covid recovery

The pandemic has given us all a chance to reflect and consider what kind of recovery we want. This applies to the support system for people with learning disabilities. We asked interviewees to consider what opportunities and changes they see as important for the future. A number of interesting points were made and some common themes emerged.

The value of health and care workers

The first is that care as a career needs more respect and recognition. The pandemic has highlighted how undervalued this work can often be, but the concerns raised in our interviews went beyond a sense of unfairness. Every interviewee who raised this issue pointed to the detrimental impact it has on the quality of support that can be provided.

For example, one interviewee highlighted that many people with learning disabilities form friendships with the professionals providing their support, but these friendships are often short-lived due to staff turnover. This can result in a *"life of continual loss"*.

Care as a career is an issue that we intend to return to in a later stage of this research project.

Employability support can be improved

There was a general consensus amongst interviewees that employability support is not sufficient. This is concerning, as *The Keys To Life* recognises that many people with learning disabilities see work, not as a means to a financial end, but as a way of being included in society and enabled to live the life they choose.

Employment opportunities for people with a learning disability are clearly insufficient, as evidenced by an employment rate below 10%[18]. We will return to this in greater detail in a future report.

Quality housing as a right

Scotland's learning-disabled population live in a range of different housing types. 62% of those known to local authorities live in mainstream accommodation, with the remainder living in supported housing or an adult care home[19]. During the interviews with professionals, we heard evidence that more residential options that are suitable for people with learning disabilities are needed, and frustration at a lack of long-term strategic planning.

> *"When people want to move on and leave home, the system falls apart. There's one person I know who has been waiting 8 years. His parents are into their 70s now but because of his complexities, there's no suitable accommodation for him."*
>
> Social Work Lead

> *"The problem is a real shortage of social housing. Housing strategies don't even consider the impact on adults with additional support needs. There needs to be a national drive around that."*
>
> Social Work Manager

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18   https://www.scld.org.uk/wp-content/uploads/2018/12/Employment-Task-Group-Report_FINAL_copy.pdf
19   https://www.scld.org.uk/wp-content/uploads/2019/12/Learning-Disability-Statistics-Scotland-2019.pdf

A safe place to call home, and the sense of place and belonging that can provide, is especially important for a group of the population that is often marginalised and excluded from society. Testimonies from people with learning disabilities highlight this.

Mancap's recent housing study[20] points out that housing is a route to independent living, which is a human right, as enshrined in Article 19 of the UN Convention on the Rights of Persons with Disabilities.

A recent review of housing for people with learning disabilities in Scotland[21] pointed to a lack of supply and choice as the fundamental reason why some people with learning disabilities are forced to live significant distances from their families and often face long waits for accommodation.

Support for rural areas

Interviewees from rural local authorities highlighted the unique challenges faced by rural areas, with fewer opportunities for community-based activities and different logistical needs. It was pointed out that this places an additional burden on rural areas and there was some frustration that this is not always recognised.

The future of support services

During the interviews, there was some enthusiasm for considering new ways of delivering support to people with learning disabilities, albeit with some scepticism around *"big new ideas"*. One interviewee was keen to explore potential opportunities presented by technology to enable people with learning disabilities to live more independently. It was noted that new technologies are often resisted, due to issues around safeguarding and digital exclusion, but that these barriers can be overcome.

On top of this, it was noted that a lot of the innovative service delivery during the pandemic has been delivered by third sector and community organisations, and some interviewees saw opportunities to work more closely with these.

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20   https://www.mencap.org.uk/sites/default/files/2016-08/2012.108-Housing-report_V7.pdf
21   https://www.scld.org.uk/wp-content/uploads/2017/10/Improving-Outcomes-84pp.pdf

Case study
Shared Lives

- Shared Lives is a model of social care that provides support for many adults with a learning disability.

- An adult with support needs is matched with a trained, self-employed Shared Lives carer.

- Support can take the form of long-term live-ins, day support or respite breaks.

- Abby and her Shared Lives carer, Louise, reflect on the difference it has made to both of their lives.

During this research, we have heard many success stories and examples of good practice, which we are keen to highlight. As we consider the future of support services for people with learning disabilities, one model of delivering care and support has delivered notably positive outcomes.

Shared Lives is a model of social care, in which an adult who requires long-term support is matched with a trained self-employed Shared Lives carer. Adults with learning disabilities are among those who benefit from this model of support. The matching process is voluntary, so that both parties have chosen their Shared Lives arrangement. These arrangements can take the form of day support, short respite breaks or a long-term live-in arrangement.

Schemes are assessed by the Care Inspectorate and results are very positive, with 78% of schemes receiving a grade of Very Good or Excellent, the remainder receiving Good. There are also intangible benefits, such as 88% of people with a learning disability in a Shared Lives scheme reporting improvements in their social life[22]. This is based on an outcome measuring tool developed on the basis of research conducted by the University of Kent[23].

Furthermore, research by Social Finance[24] points to an average cost saving of live-in arrangements of £26,000 per person per year. However, Shared Lives comprises a relatively small proportion of social care in Scotland, with 15 schemes in operation supporting 550 people.

We interviewed Abby, who has lived with her Shared Lives carers, Louise and Andrew, for 12 years. She talked about the positive impact that the stability of her Shared Lives arrangement has had on her life, particularly when comparing it with life before Shared Lives.

We also spoke with Abby's Shared Lives carer, Louise, who noted that *"we're family"*. Louise was honest about her concerns going into the scheme, especially given how big a change it would be for her. But she reflected that *"I don't think of it like a job and I've never regretted it"*.

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22   Data provided by Shared Lives Plus
23   https://kar.kent.ac.uk/52950/1/DP2895.pdf
24   https://www.socialfinance.org.uk/sites/default/files/publications/sf_shared_lives_final.pdf

Conclusion

This report is the latest in a long-term research project analysing the support and opportunities available to adults with learning disabilities in Scotland. It focused on a range of support services that are commissioned at a local authority level.

The key conclusions to be drawn from the evidence we reviewed in our fieldwork are that:

- Every person with a learning disability has a unique set of needs and ambitions, and the support they receive should reflect that. Support services are not 'one size fits all', which can in turn make it difficult to pin down what support is available.

- The changing public sector financial backdrop has resulted in the loss of non-statutory support services, even though these services are often vital for enabling people with learning disabilities to realise the desired outcomes in *The Keys To Life*.

- The Covid-19 pandemic has completely changed the way support services are delivered and will have lasting consequences for adults with learning disabilities. Action will need to be taken to address these.

- There is concern that support that was available before the Covid-19 pandemic won't be reallocated in full.

- Adults with learning disabilities are not given sufficient support to make informed decisions about their lives, including decisions over the care and support they receive. This means that many who could benefit from self-directed support are not able to.

- Housing is a cornerstone of independent living, yet an undersupply of quality accommodation for people with learning disabilities constrains choice and results in delays. Accounting for this will require planning in housing strategies.

- The transition to adulthood is a crucial time in the life of someone with a learning disability, yet quality person-centred support does not appear to be delivered in a systematic or structured way.

Ultimately, these findings raise questions about what the system of support for adults with learning disabilities is designed to achieve. Is it there to help people 'get by' and respond to crises, or should it act as an enabler for people to live a fulfilling life and access their human rights?

The evidence base that we have reviewed suggests that the system does not enable everyone with a learning disability to attain the quality of life that was envisaged in key government strategies.

How policy makers address these challenges is a complex question. But, as the recent Independent Review of Adult Social Care in Scotland makes clear, *"it is vital that we amplify the voice of lived experience at every level"*. Meaningful consultation of people with learning disabilities deserves care and attention, and is something that policy makers must take seriously.

As we approach a new Parliament and a recovery from the pandemic, we are reaching a key decision point and what happens next could be crucial to the support and opportunities available to adults with learning disabilities in Scotland.

What next?

Whilst this report focuses on learning disability support services, many of the issues raised go far wider than health and social care – they go right to the heart of what kind of society we are. In a way, this is not surprising. Outcomes for adults with learning disabilities are so far behind other groups in society, that this cannot be explained by a narrow focus on one policy area.

As this research project progresses, we will move on to look at other aspects of public policy that affects people with learning disabilities. In particular, social security, employability support and community development tie in with much of what people with learning disabilities have told us is important to them.

You can read more on our website, www.fraserofallander.org/learning-disabilities.

Acknowledgements