south ayrshire
health & social care
partnership

# Live Your Best Life

## South Ayrshire Adult Learning Disability Strategy

## 2022-2027

## *Consultation and Engagement Report*

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# Summary

South Ayrshire’s Adult Learning Disability Strategy 2022-2027 was developed over the past 12 months in consultation with people with learning disabilities, families, carers and staff delivering services. The strategy builds on the progress made in delivering the current Learning Disability Strategy for 2017-2023 and the objectives set out in ‘The Keys to Life’ national strategy to put people with learning disabilities at the centre of the plan.

Initial consultation ran from August to November 2021 which sought to find out what areas where most important to people with learning disabilities. The information gathered was used to inform the content of the strategy. Consultation included an online and paper survey to send to people with learning disabilities, themed focus groups which covered different localities and priority areas, one-to-one interviews with managers, an online staff survey, journey mapping and workshops with third sector organisation and locality planning partnerships.

A draft strategy was created following analysis of the initial consultation and a second consultation took place on the draft to make sure that people felt their views and needs were being reflected in the strategy. The activities carried out were the same as those in the first consultation period, however, focus was solely on the vision, priorities, actions and design of the draft strategy. This consultation period ran for 6 weeks between March and April 2022 and information gathered was then used to inform the final version of the strategy.

This report is a collection of all the consultation and analysis that has taken place throughout the development of the strategy.

# Phase 1 – Initial Consultation

The Adult Learning Disability Strategy 2022-2027 underwent its initial consultation period between August 2021 – November 2021. The consultation looked to engage with those in South Ayrshire with a learning disability, their carers, family, and staff involved in learning disability services.

A survey was produced in collaboration with the Scottish Commission for People with Learning Disabilities (SCLD), League of Champions and Strategy Development and Steering Groups. The survey was based, in part, on the SCLD's How's Life Survey and focused on what mattered most to people with learning disabilities in South Ayrshire and was sent to all service users within South Ayrshire a freepost envelope to return. An online version was also made available for those who would prefer to complete on a smart device/computer and was promoted through the Health and Social Care Partnership channels to reach people who may not be accessing services.

Focus groups were arranged throughout September both in person and virtually, with virtual focus groups covering specific issues such as, employment, education, learning and skills, housing, transitions and support for people with complex needs. In person focus groups were held in Troon, Ayr, Maybole and Girvan and were open for community members, carers and family to attend. The groups were delivered jointly by the Health and Social Care Partnership (HSCP) and SCLD, and a separate focus group was led by VASA and the SCLD with third sector providers to gather their views on the new strategy.

A staff survey was produced for professionals in public, private and third sector whose service supported adults with learning disabilities. The survey invited staff to provide their views on what was good in their services and what needed to be developed within South Ayrshire in relation to learning disabilities.

Other consultation activity included one-to-one interviews with staff members from different areas of the HSCP and Council, and with people who had experience of using Learning Disability Services. Interviews with those who had used services were used to create a visual journey map of their experiences.

The feedback gathered during this consultation period was analysed and used to inform the priorities and actions of the strategy.

# South Ayrshire Survey Report

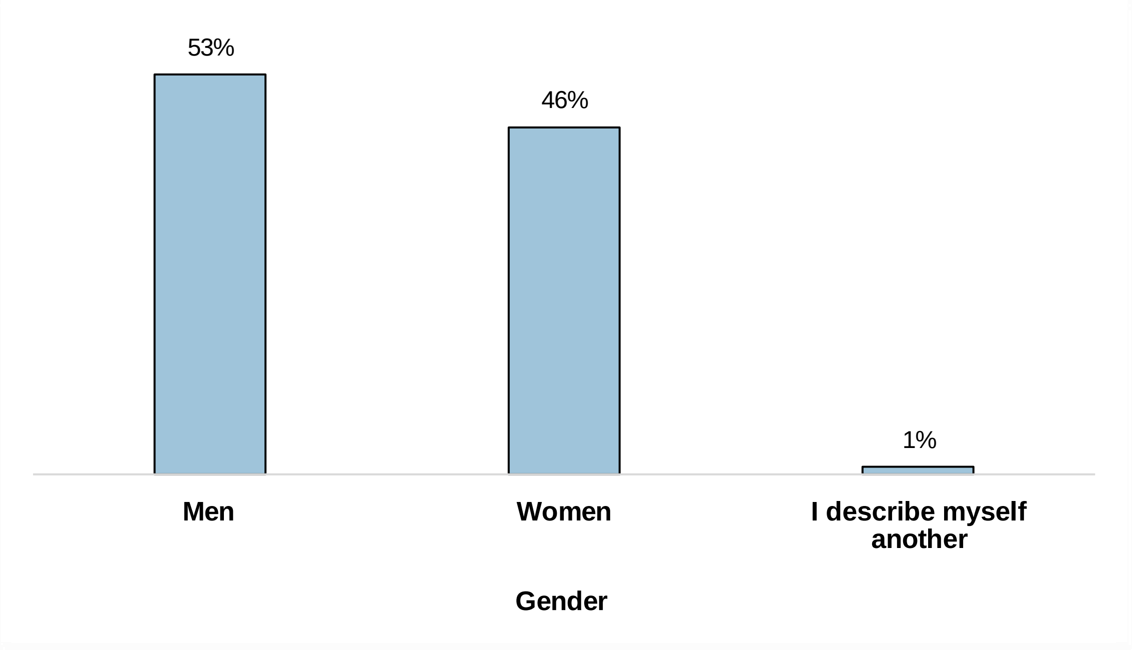
## Introduction

As part of the preparation of the South Ayrshire Learning Disability Strategy update, the Team undertook a survey of service users and asked them to reflect on different aspects of their lives. The Team wanted to find out what people with learning disabilities in South Ayrshire felt about their lives, and to see which areas might need to be the focus of policy over the coming years. The survey was based in part on SCLD's 'How's life?' survey, which was co-produced by people with learning disabilities themselves, and focused on what mattered to them. Some questions were included to reflect the context of the Covid-19 pandemic and the focus on South Ayrshire.

## Who took part in the survey?

A total of 90 people with learning disabilities in South Ayrshire completed the survey. This is around 1 in every 6 people in South Ayrshire who are known to the local authority to be accessing services on the basis of a learning disability. Figures 1 and 2 below show that there was a representative sample in terms of gender and age, which is broadly in line with collated figures from Learning Disability Statistics Scotland.[1]

**Figure 1: Gender profile of survey respondents**



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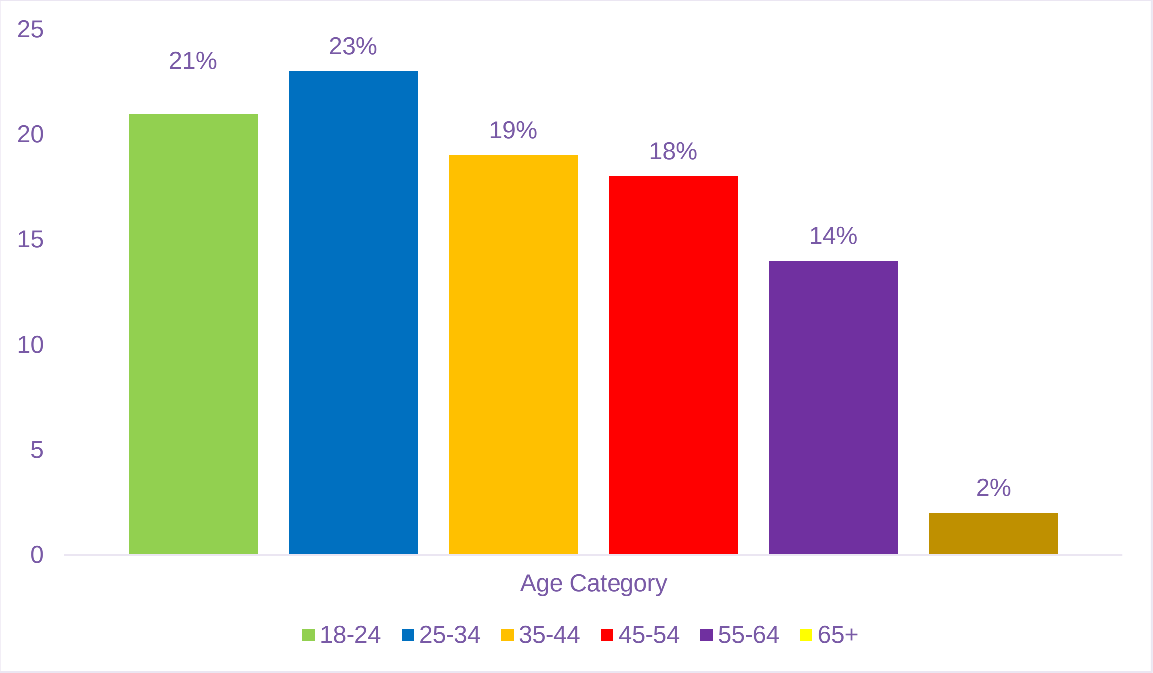
[1] LDSS is the main source of information about the number and profile of people with a learning disability in Scotland. It is an administrative data set published on behalf of the Scottish Government by SCLD. It comprises individual level information collected annually from local authority information management systems on people with learning disabilities and/or autism, aged 18 and over (or aged 16 and 17 but not in full-time education) who have had contact with the local authority in the past year.

**Figure 2: Age profile of survey respondents (%)**



All survey respondents described their ethnicity as white. 82% of respondents described their sexuality as straight.

Figure 3 shows the type of accommodation survey respondents lived in. The vast majority of people (78%) lived in mainstream accommodation. Mainstream accommodation is a house or flat which a person on their family owns or rents, without adaptations. Much smaller percentages of people lived in supported accommodation (8%) and residential care (1%) than is the case across the population in LDSS (17% and 9% respectively).

**Figure 3: Accommodation type of respondents**

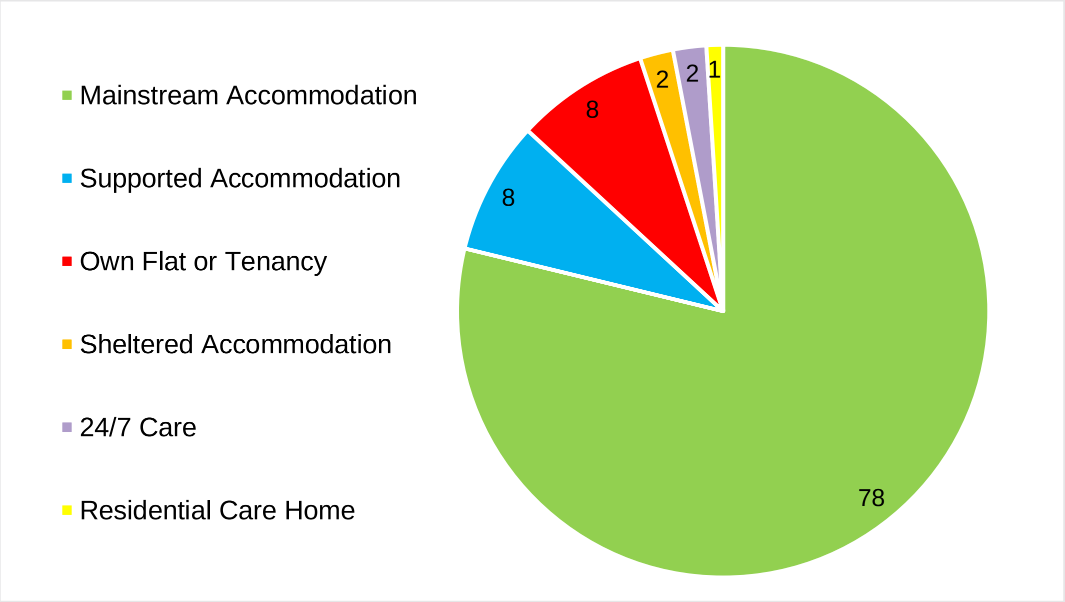


**Figure 4: Area where respondents lived (%)**

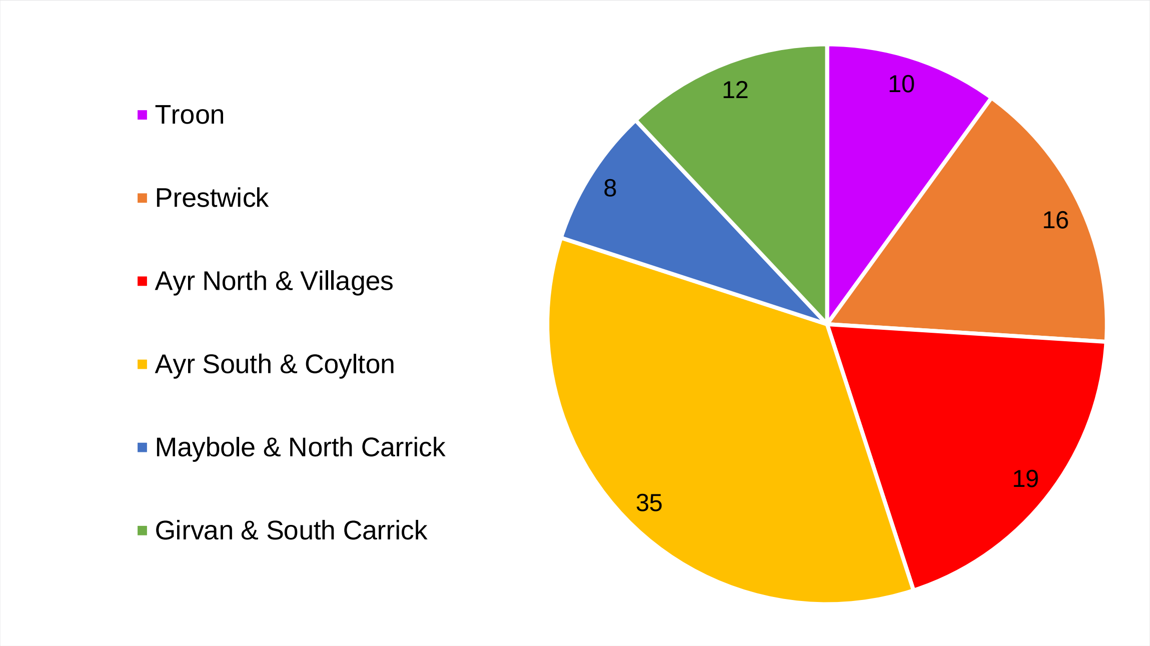
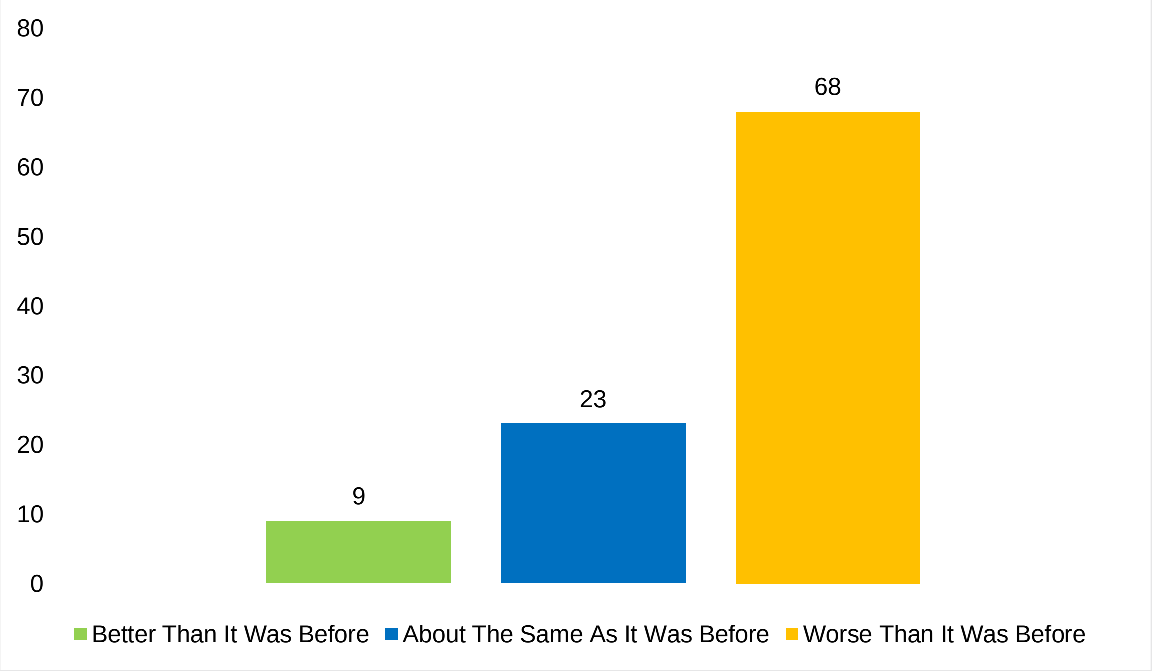


Figure 4 above shows that the sample included respondents from across South Ayrshire, with the majority (35%) living in Ayr South and Coylton.

## Life during the Coronavirus pandemic

The Coronavirus pandemic has had a significant bearing on all our lives, and its impact is likely to be felt long into the future. Figure 5 below shows that while for a small percentage of people (9%) life during the pandemic had been better than it was previously, 68% of people said that life is worse during the pandemic.

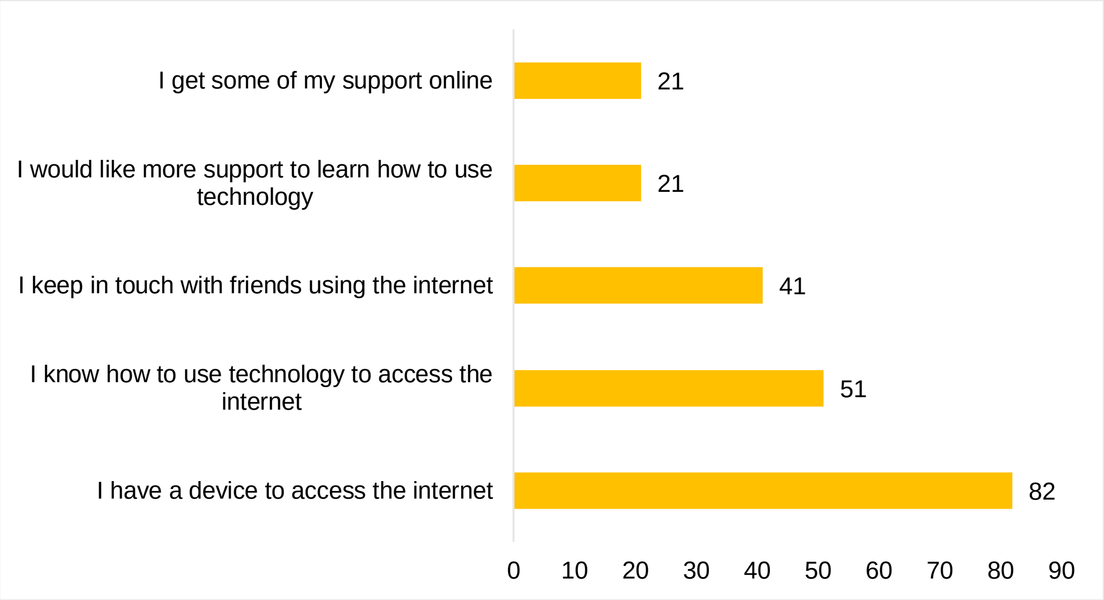
**Figure 5: Percentage of respondents who said life was better, the same or worse during the pandemic**



36% of respondents said they got the same level of support during the pandemic. 18% said they chose to reduce their support. 33% of people said that they got less support during the pandemic, and they had not chosen this. 12% of people got no support at all during the pandemic.

Digital inclusion for some people has been a particular success story of the pandemic. Many people for whom learning to use the technology to access social platforms online would have been considered out of reach have adapted well. As Figure 6 shows, most people who responded to the survey have a device to access the internet (82%). However, only just over half (51%) know how to use the technology to access the internet. 21% explicitly stated that they would like more support to learn how to use this technology.

**Figure 6: Technology use during the pandemic (%)**



## Relationships

*The Keys to Life* recognises that relationships, of all different forms, are essential to the wellbeing of people with learning disabilities, and important for people's sense of belonging and social inclusion. Despite this, people with learning disabilities continue to face barriers that exclude them from relationships of all different kinds.

92% of survey respondents described themselves as single, with the remaining 8% saying they were in a relationship but not married. No one in the survey was married. This compares to 47% of the general population in Scotland who are married.

Interestingly, while 82% of survey respondents were straight, 16% were not sure how to describe their sexuality. This appears to support academic studies that suggest LGBT people with learning disabilities face significant challenges

in terms of their sexual expression and identity. For example, paternalism, heteronormativity, and discriminatory attitudes have been found to exist within support services.[2] Often, support staff also lack confidence to discuss sexuality issues and presume that people with learning disabilities are 'asexual.'[3] Other studies have found that service providers often ignore sexuality concerns, making

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[2] Jukes & Aldridge 2006

[3] Abbott & Howard, 2007

people ‘feel invisible’ in relation to their gay identity.[4]

**Figure 7: Percentage of respondents who see friends and family as much as they would like**

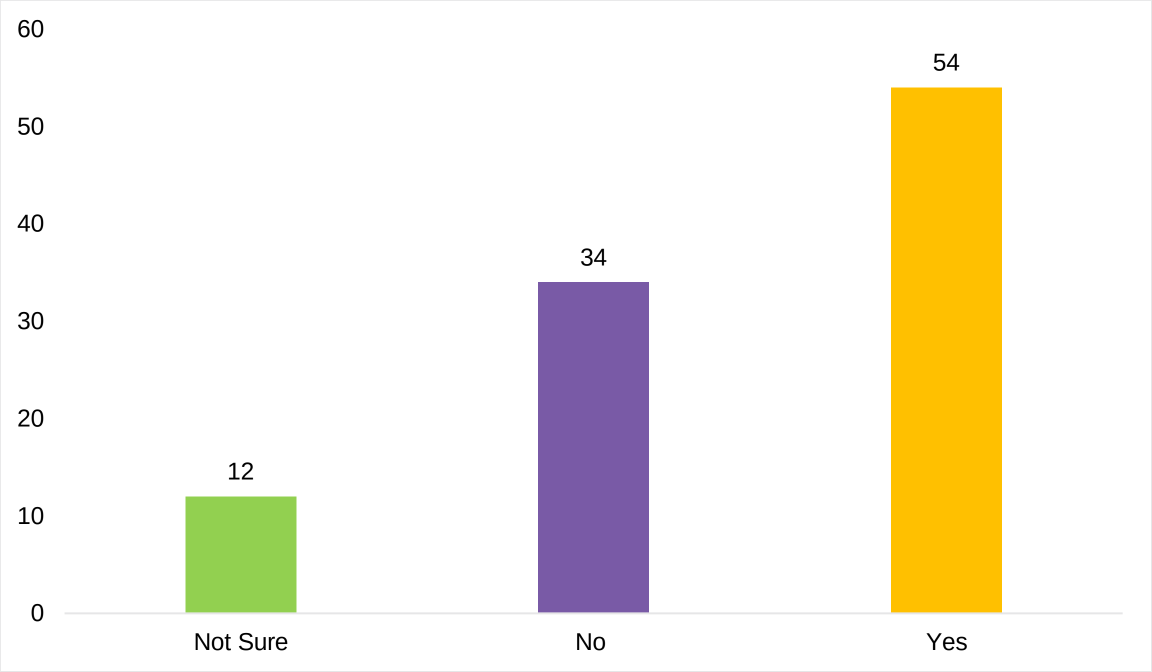
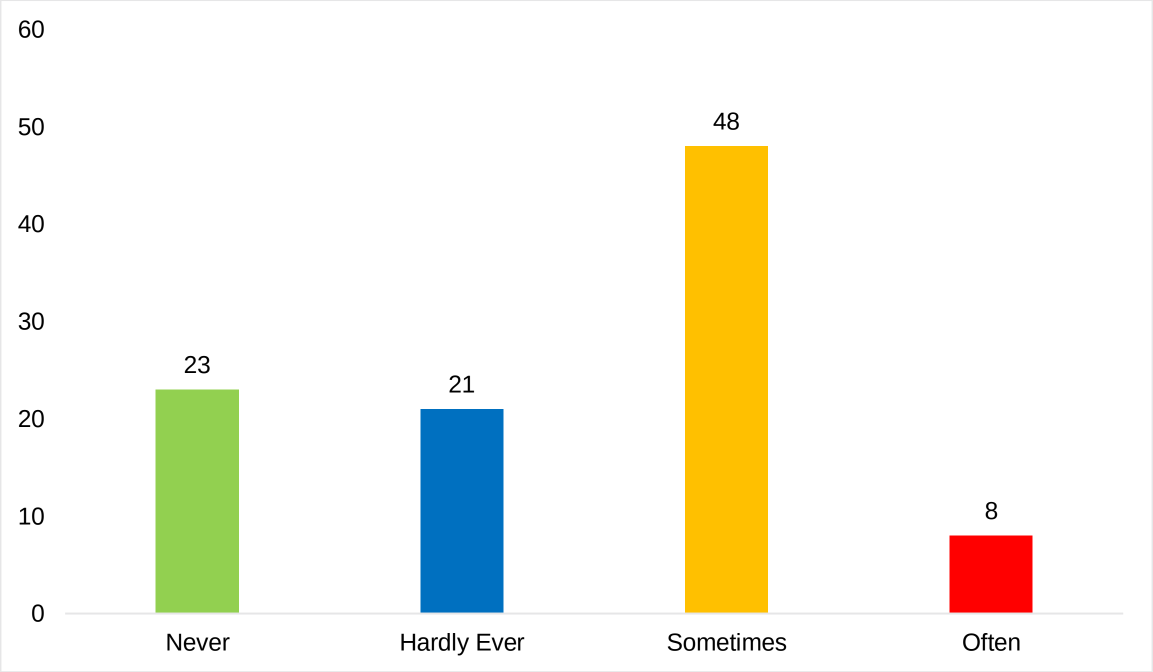


Figure 7 above shows that just over one in three (34%) of people said they did not get to see their family and friends as much as they would like. 10% of respondents said that they had not been able to see as much of their friends and family as they liked before the pandemic.

**Figure 8: Percentage of respondents who felt lonely, and how often**



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[4] Stoffelen et al., 2013

As shown in Figure 8 above, 48% of survey respondents sometimes felt lonely, with 8% often feeling lonely.

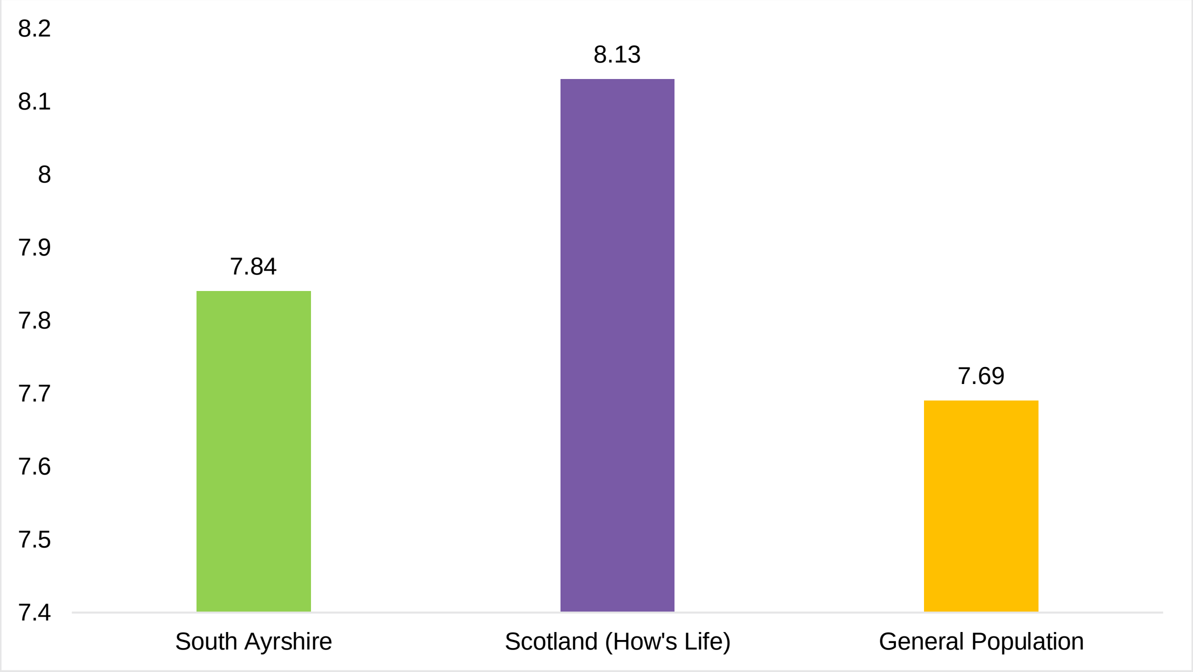
People were given space in the survey to tell us more about their friends and family if they wanted to. 32 people chose to do so. While some people chose to describe their family and friends, the most common themes people spoke of were wanting more support to see friends and family, and missing friends from groups that had not been running through the pandemic.

## Wellbeing

To get a sense of people's wellbeing the 'life satisfaction' question from the Office for National Statistics was adapted and people were asked to rate how happy they were with their lives overall, on a scale of '0' 'not at all happy' to '10' 'very happy.'

Out of 10, the average happiness score was 7.48. This is slightly lower than the general population at 7.69 and lower than respondents to the How's life survey, where the average was 8.13.[5] It is important to note that How's life? was undertaken in 2019, before the Coronavirus pandemic, which is likely to have impacted people's wellbeing.

**Figure 9: Self-rated happiness scores compared with How's life and general population**



Analysis looked at whether there were any significant correlations between people's self-rated happiness score, and other variables in the survey. There was a relationship between where people lived and their self-rated happiness. Figure 10 below shows that people who lived in Maybole and North Carrick tended to rate their happiness as low compared to people living in other areas, though it is important to note that only 6 respondents lived there.

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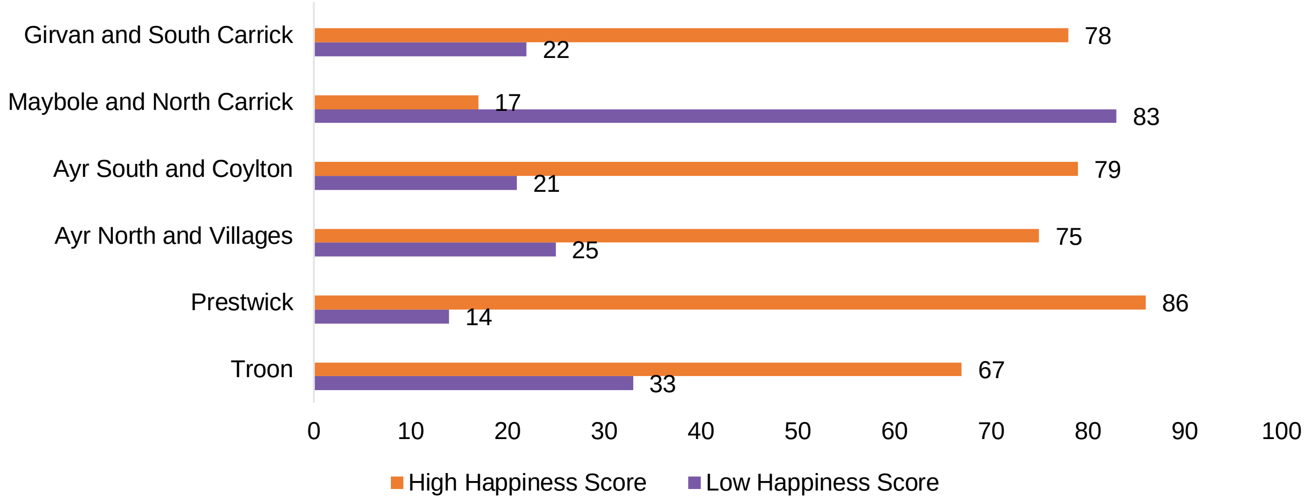
[5] SCLD-Welbeing-Report_Final.pdf (page 18)

**Figure 10: Percentage of respondents who rated their happiness high or low, by where they live**



Unsurprisingly, there was also a significant relationship between loneliness and self-rated happiness. Those who said that they felt lonely sometimes or often, tended to rate their happiness scores as low.

People were allowed space in the survey to tell us more about their answer to this question if they liked. 33 respondents chose to do so. Within these comments many people spoke about social contact with family and friends being particularly important to their happiness. People were clear that seeing their loved ones and having active social lives were very closely tied in with their happiness.

Many also spoke of the importance of being able to get out and about and do new and varied activities, and the role that groups can play in this.

Many people also mentioned that consistency in their support staff was important to their happiness.

Other issues that were mentioned in terms of having a negative impact on happiness included having to continue to shield, having lost a family member, and frustration at some continuing Coronavirus restrictions.

## Support

Figure 11: Percentage of respondents receiving support for specific activities

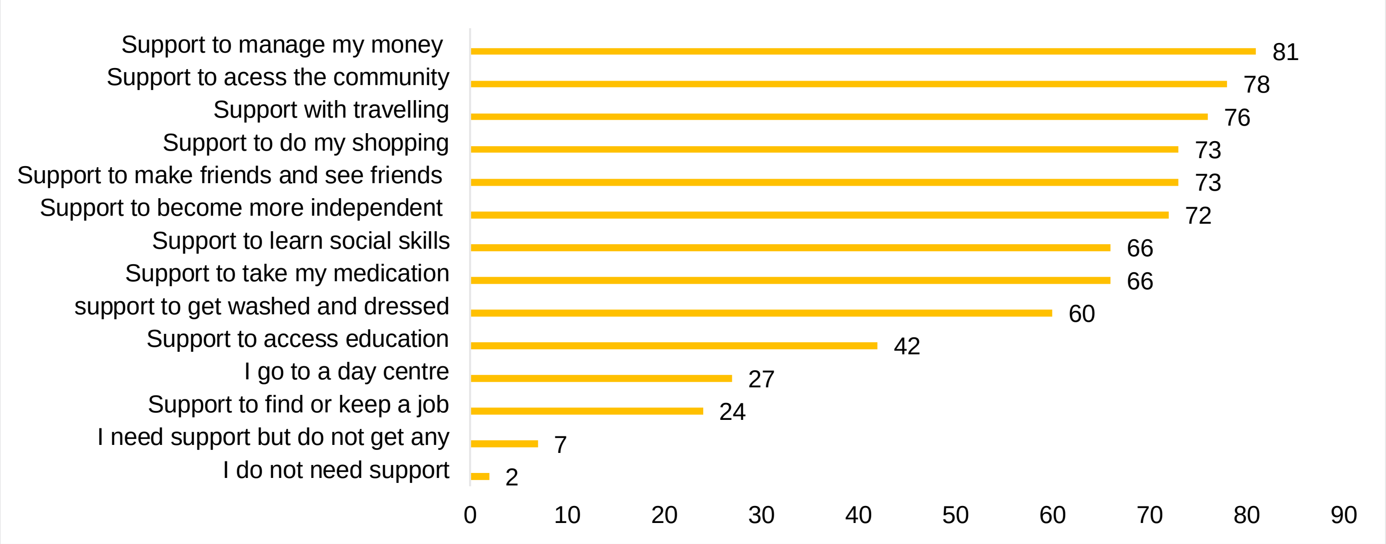


Figure 11 above shows the percentage of respondents receiving support for certain activities. Respondents were allowed to select multiple answers. A high percentage of respondents were receiving social support to take part in activities (78%) or to make and see friends (72%). Only 12% of respondents were receiving support to find or keep a job. A small but significant percentage (7%) said that they needed support but were not getting any.

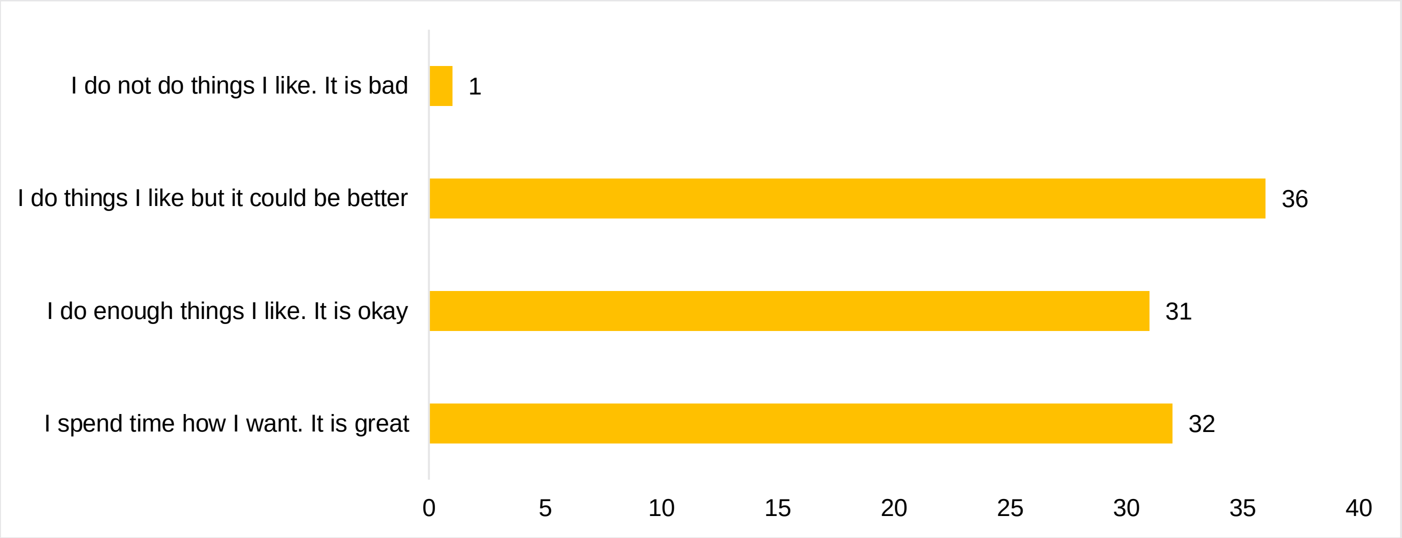
People were also asked explicitly if they received enough support. 59% of respondents said yes, but 22% of people felt that they didn't get enough support. People were also asked if the people who supported them treated them with respect. Most people said they were always treated with respect (87%), with 11% of people saying they were treated with respect most of the time and only 1% saying they were never treated with respect.

Respondents were able to tell us more about their support if they liked. 28 people chose to do so. People talked about their support being good, respectful, and compassionate. However, a few issues that the responses highlighted were that some people would like more support to do more activities, some feeling that their support was under threat or that they did not have enough support hours.

## How people spend their time

The survey asked people how they felt about the way they spent their time. Figure 12 shows that happily, only a very small percentage of people (1%) said that they were not able to do things that they liked. Just under a third of people (32%) said that they got to spend their time the way they wanted, and that this was great. The rest of the respondents said that they got to do some things that they liked but it could be better (36%) or that they got to do enough of the things they liked and felt this was ok (31%).

**Figure 12: Percentage of respondents by how they feel about how they spend their time**

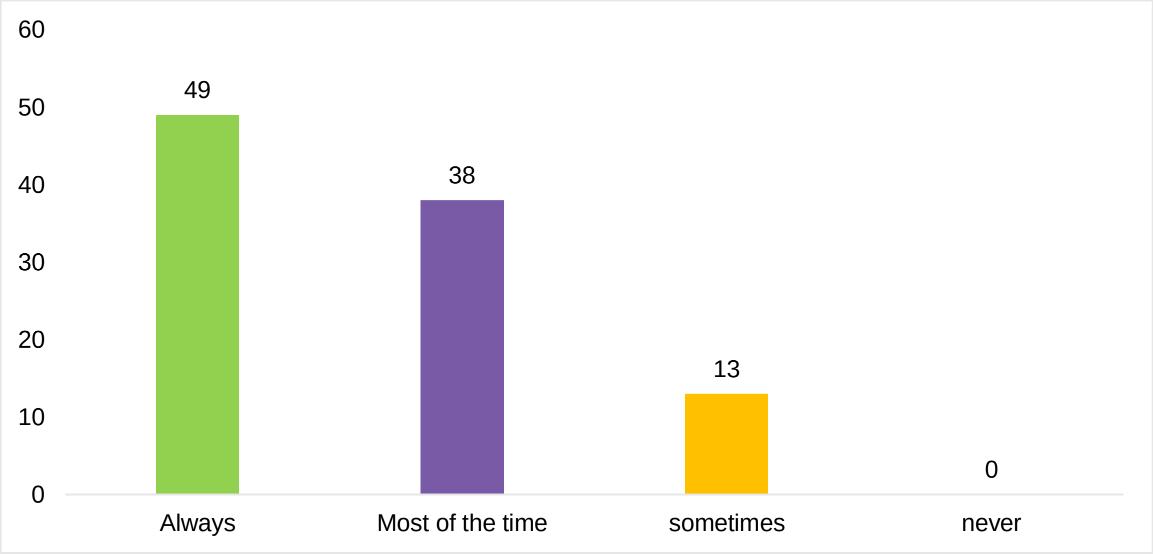


People were given the option to talk more about how they spent their time if they wanted to. 37 people chose to do so. Lots of people talked about the different things that they did with their time. Some people mentioned that they would like to do more and different activities and have support to do more social activities and be part of the community.

**Where people live and how they feel about it**

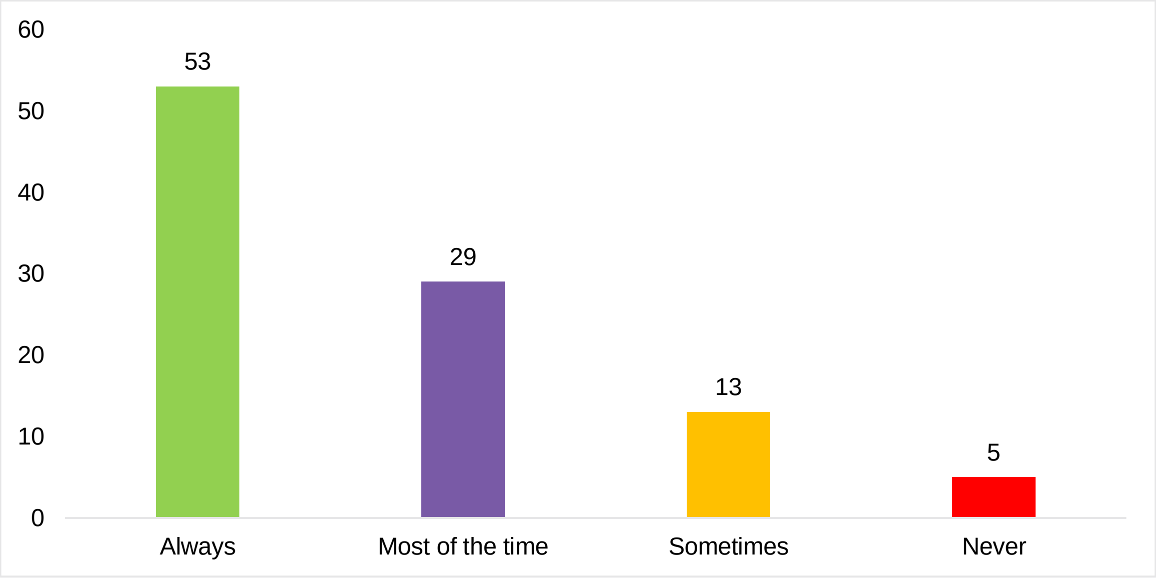
The vast majority of survey respondents were happy with the house that they lived in (92%) and the area that they lived in (90%). However, some people did not always feel safe when they were out and about in the community.

**Figure 13: Percentage of respondents by whether they feel safe when they are out and about**



Some respondents were either never happy with the transport options locally (5%) or only sometimes happy (13%).

**Figure 14: Percentage of respondents by whether they are happy with the transport available locally**



### What are the most important things in life for you?

As part of the survey, people were asked directly what the most important things in life were for them. 80 survey respondents chose to answer this question. By far the most prevalent theme in this question was the importance of friends and family.

Other themes that were prevalent included being able to take part in varied activities, being healthy, consistent support that allowed people to feel secure, feeling safe, feeling valued and being independent.

A few participants also talked about their ambitions for the future such as finding work.

### If there was one thing you could change about your life, what would it be?

The survey also asked people if there was one thing they could change about their life, what that would be. 69 people answered this question. As expected, there were many different answers, reflecting the diverse lives that people with learning disabilities live.

Some people said that they were happy with their lives and wouldn’t change anything. Many people said that they would like to be able to see their friends and family more and to get out socialising. A few people expressed a desire to find a partner.

One of the more prominent themes was around support. Many people said that they want their full support to return to what it was before the Coronavirus pandemic. This included a few who mentioned building based day services. Many people said that they would like the opportunity to do more varied activities, and to get out and about more. A few said that they would like their support to understand them better, while another few mentioned they would like to be able themselves to communicate better.

A few respondents said that they would like to be healthier and more active. Others mentioned that they would like to have more confidence in themselves.

## Concluding comments

The survey has given some useful insight into the lives of people with learning disabilities in South Ayrshire. Most people who answered the survey rated their happiness highly, were happy with the support they received and where they lived. However, there are some important points to reflect on.

- The average happiness score of 7.48 was lower than a sample from across Scotland taken from before the Coronavirus pandemic; it will take a concerted effort to make sure that people's wellbeing returns to pre- pandemic levels.
- It will be important to build on the success of digital inclusion for people, making sure that people are supported to acquire skills to use technology.
- Relationships with friends and family are very important to people, and over a third of people currently don't see their loved ones as much as they like. Getting appropriate support in place to ensure people are able to make and maintain these relationships is pivotal. This will include supporting staff to feel confident to talk to people about these relationships, as well as intimate relationships
- Having the right support was also a prevalent theme in the survey, in particular to accommodate more varied and regular social activities. Over two thirds of people suggested they would like to be able to do more of the things they liked. Ensuring that support is flexible enough to allow people to do the things they want when they want will be an important focus going forward.

As we move forward from the pandemic, the most important thing will be to continually listen to people with learning disabilities and their carers and supporters, about what they need and want in order to live full, loving and equal lives.

## Focus Groups

### Introduction

As part of the development of the Learning Disability strategy for South Ayrshire, SCLD and South Ayrshire HSCP hosted focus groups. These were held both in person in small numbers, in accordance with COVID protocols, and on Zoom.

There were 4 in person focus groups held in:

- Troon
- Ayr
- Maybole and,
- Girvan

These focussed on the facilities and opportunities available to people living in these areas.

There were also five focus groups on Zoom, these focussed on the specific topics of:

- Employment
- Education, learning, and skills
- Housing
- Transitions
- Support for people with complex needs.

SCLD attended a learning disability service providers' forum hosted by South Ayrshire Voluntary Action, where attendees were asked their views in relation to the development of the strategy. SCLD also attended a meeting of some members of ENABLE Scotland's ACE group who are all from South Ayrshire. Both of these took place on Zoom.

There were also additional comments received by email from two parents and one individual video call with a parent.

Information from these sessions was recorded in note form and used to complete this report.

Over the course of the process, we recorded engagement with 34 parents/family carers, 23 people with learning disabilities, and 18 employees of voluntary sector service providers.

Several participants attended more than one event, so these numbers do not fully represent discrete individuals.

A variety of engagement techniques and tools were utilised to aid conversation. These were adapted depending on the format and expected attendees. Information gathered in early sessions gave an indication of the areas we should focus more in depth on in later sessions.

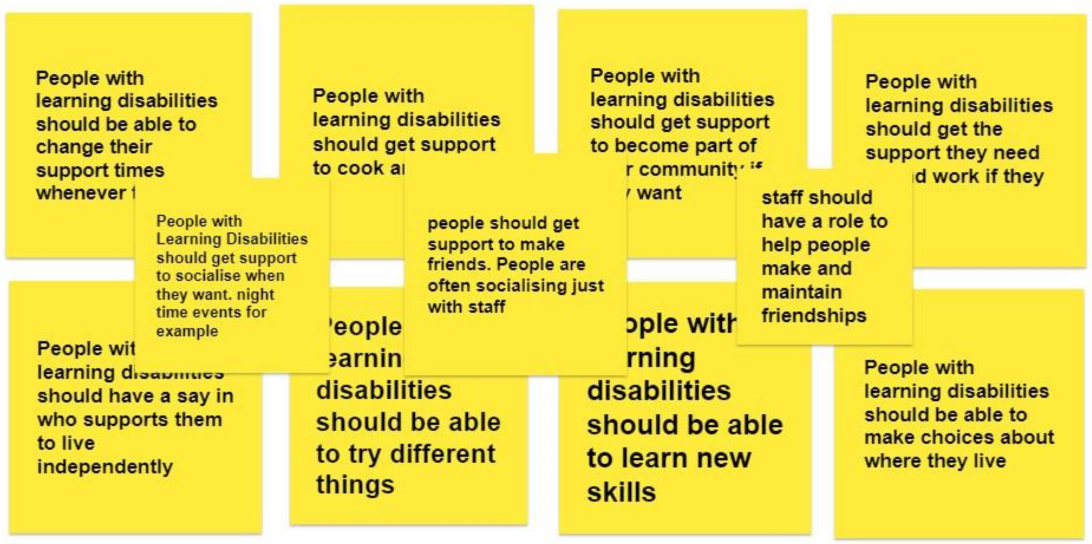
### ENABLE ACE Group

In the Zoom session with ENABLE ACE we used a Jamboard. We asked attendees to agree which statements we should keep and which we could remove. The list of statements was as follows:

- People with learning disabilities should get the support they need to find work if they want

- People with learning disabilities should get free ice cream everyday
- People with learning disabilities should be able to make choices about where they live
- Supporters for people with learning disabilities should be able to tap dance
- People with learning disabilities should have a say in who supports them to live independently
- People with learning disabilities should be able to change their support times whenever they want
- People with learning disabilities should be able to learn new skills
- Supporters for people with learning disabilities should wear uniforms
- People with learning disabilities should be able to try different things
- People with learning disabilities should get support to become part of their community if they want
- People with learning disabilities should get support to cook and clean

The group kept the statements shown in the image below and gave us an idea of the areas that needed to be considered when developing the strategy.



People with learning disabilities should be able to change their support times whenever t

People with learning disabilities should get support to cook ar

People with learning disabilities should get support to become part of r community

want

People with learning disabilities should get the support they need d work if they

People with Learning Disabilities should get support to socialise when they want. night time events for example

people should get support to make friends. People are often socialising just with staff

staff should have a role to help people make and maintain friendships

People wit learning d should have a say in who supports them to live independently

eople earnin disabilities should be able to try different things

ople with rning disabilities should be able to learn new skills

People with learning disabilities should be able to make choices about where they live

Clear messaging came through that people with learning disabilities are looking for support to be flexible and available to help them to participate in many aspects of life. Support to make and maintain relationships, to find and maintain employment, to learn new skills and to be active in their communities all featured.

People with learning disabilities want to be able to make choices about where they live, who supports them, when they get support, what they do with this support and if they want to stay out late at social events.

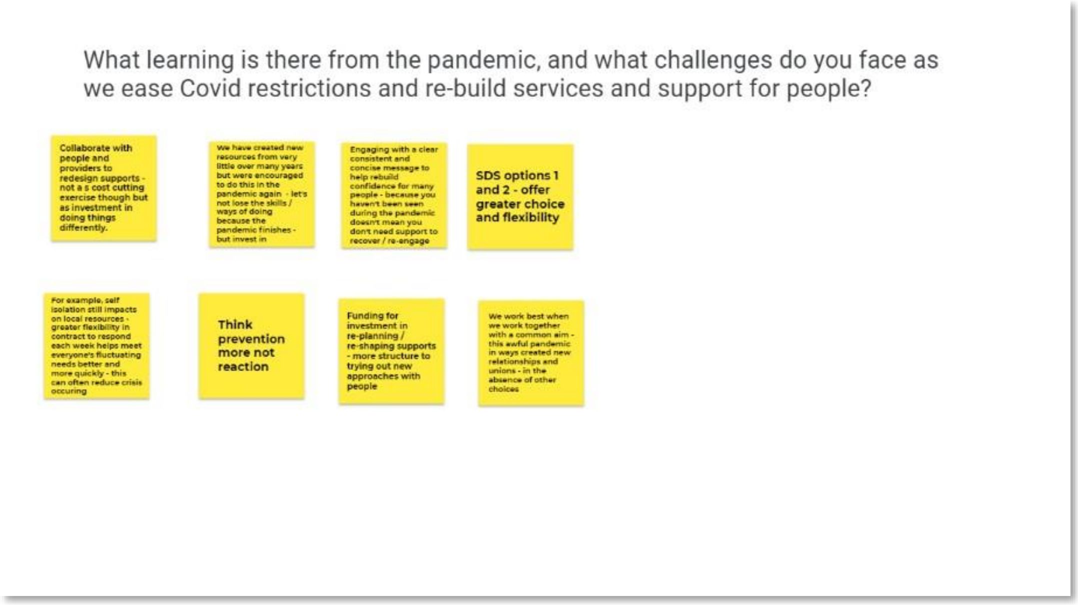
People want to be supported to live full lives. This includes having opportunities to try new activities (including employment) without fear that that their support will not be reinstated if the new venture does not turn out well for them.

**Engagement with voluntary sector employees**

Voluntary Action South Ayrshire invited SCLD to talk to members of the Third Sector Providers Forum. This was on Zoom and took the format of four discussion groups in breakout rooms. Each group discussed the same questions. These were:

- What changes did you make to supporting people through the pandemic and lockdown?
- Are there gaps between what people need to live their life and what you are contracted to provide?
- Do you have access to the information and relationships you need to support and signpost the people you support to access other opportunities?
- What opportunities do you have for developing different ways of working for people going forward?
- What learning is there from the pandemic and what challenges do you face as we ease Covid restrictions and rebuild services and support for people?

Jamboard was used in each group to record the discussion but was also offered as an option if people wanted to add on comments after the sessions. An example of one board is given below.



What learning is there from the pandemic, and what challenges do you face as we ease Covid restrictions and re-build services and support for people?

Collaborate with people and providers to redesign supports - not a s cost cutting exercise though but as investment in doing things differently.

We have created new resources from very little over many years but were encouraged to do this in the pandemic again - let's not lose the skills / ways of doing because the pandemic finishes - but invest in

Engaging with a clear consistent and concise message to help rebuild confidence for many people - because you haven't been seen during the pandemic doesn't mean you don't need support to recover / re-engage

SDS options 1 and 2 - offer greater choice and flexibility

For example, self isolation still impacts on local resources - greater flexibility in contract to respond each week helps meet everyone's fluctuating needs better and more quickly - this can often reduce crisis occuring

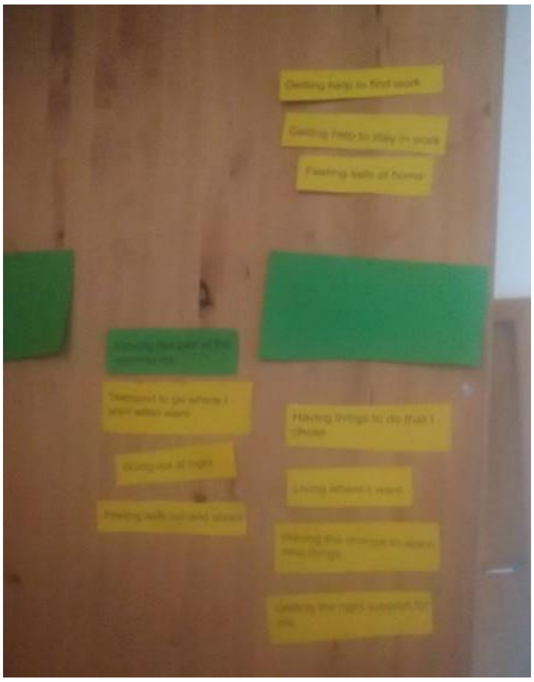
Think prevention more not reaction

Funding for investment in re-planning / re-shaping supports - more structure to trying out new approaches with people

We work best when we work together with a common aim - this awful pandemic in ways created new relationships and unions - in the absence of other choices

### In Person Focus Groups

In the face-to-face sessions we used a sorting activity where attendees were asked to organise the statements into rows based on their experience in their local area and whether they thought it was good, bad or they were unsure. Answers were grouped together, and these statements are listed below:



- Getting help to find work
- Getting help to stay in work
- Living where I want
- Transport to go where I want when want
- Having things to do that I chose
- Getting the right support for me
- Having the chance to learn new things
- Going out at night
- Feeling safe at home
- Feeling safe out and about
- Feeling like part of the community

### Online Focus Groups

These were topic specific discussions. We used the information gained in the previous focus groups and discussions to have more in depth and focussed conversations with attendees.

Questions were not pre-determined, but attendees were asked to share their experiences of the area for discussion and asked what they think would have improved any areas they felt were not as good as they could have been.

### Discussion

These have been grouped thematically. Discussion of the points made, and issues raised will be followed by suggestions made to improve provision in the area discussed. The suggestions were discussed at the focus groups and either suggested by participants or the facilitators.

### Lack of information about the opportunities available

One of the most frequently discussed issues was a lack of meaningful activity for people to participate in as well as a lack of opportunities for people to spend time with groups of their peers. People with learning disabilities, family carers and support workers all commented that they were not aware of what is available or how to access things that are available. This includes opportunities for socialising, exercising, and learning.

Families felt it was left up to them to find suitable activities and to pass this information on to support staff, families said that it was hard to find out this information. At the session hosted by VASA with the Voluntary Sector providers there was a lot of discussion about access to information about activities or services provided by other organisations. Organisations felt that they would benefit from access to shared information about activities they can support people to attend and other organisations who are available in the area who can support people in other areas and how to sign post to these. Families and people with learning disabilities both commented that it tended to be through word of mouth that people would find out about what social or other activities were available. This lack of awareness relates also to specific services such as advocacy and supported employment where families, people with learning disabilities, and support staff all said they would not be sure how to access these services.

## Day Activities/Opportunities

The practice of people spending time with support workers rather than peers was raised by many of the people who shared their views as part of the engagement activities. This was not considered to be the best way for people to have social interaction. Some people had little or no contact with friends from their school or college days, others had very little opportunity to interact with people other than their family or paid staff. It was noted that some of this is because of the pandemic and the need to reduce the numbers of people in one place at a time.

Different people suggested different solutions to this. Several parents wanted a building-based service. The reason given for this was so that the person would have some place to go where they felt welcomed and comfortable and where they knew people and could interact with others. This was particularly requested for people who had more complex needs and who need more support.

Families often had support in their own homes, and this was not a situation that families felt was working well for them as it did not allow for much social interaction, opportunities to do new things, or respite for the rest of the family. Family carers commented in several focus groups that support staff are supporting individuals in their homes but that this support is limited to doing things together in the home. Families were then also made to feel unwelcome in their own homes or were still required to be interacting with the supported person so the family did not benefit from the respite that would usually be provided by time spent with support. This limited the opportunities for the supported person to interact with peers or participate in new activities.

There was some discussion about what this might look like: some thought the service should run with people in similar age groups together, others said they would like this to be mixed aged groups. In the Girvan focus group, we heard positive comments about Girvan Opportunities but this had been closed due to Covid restrictions and people were uncertain if they would get their places back.

Some of the focus group participants with learning disabilities took part in group activities during the day. These were provided by Hansel, they tended to be thematic groups where participants shared a common interest and met together to do a shared activity, one participant had started a gaming group for example. Other people talked about things they did outside of South Ayrshire such as doing educational activities at UCAN in Kilmarnock or drama at Centre Stage in Kilmarnock as well as a football club in Giffnock. We heard about a cooking group in Maybole that some people had enjoyed, we also had comments from family members who said they felt that support staff needed to be better educated about nutrition. Lots of positive things were said about these activities and the opportunities they gave people to participate in something they enjoyed in the company of others. Lack of transport to attend these places was a barrier for some people as they were either unable to travel or had to spend a long time in the car to get to them.

This was also a problem when families had to provide transport as they did not benefit from the respite that would be provided if they did not have to do this.

### Self-Directed Support

During the discussions mentioned above there were suggestions that parents did not know about self-directed support or that they could make choices about the support and activities that their supported person does. When asked about self-directed support and if they had chosen the package, they currently have many families said they were not interested in self-directed support. Further discussion showed that they did not currently believe themselves to be on self- directed support.

Neither were families aware of options such as pooling support budgets to meet their outcomes. Some of the concerns raised by families about lack of choice or not having access to activities they want to do may be alleviated by more support to make full use of the range of options offered by self-directed support.

### Education, Learning, and Skills and Support for Employment

There was a lot of discussion about a lack of opportunity for people to learn. Learning opportunities were limited after leaving school. Some parents said that they thought their children had been deskilled since leaving school. Discussion identified that learning would be different for everyone and that a range of suitable options needs to be available.

College is not a suitable destination for everyone. People with learning disabilities who attended college said that they didn’t find that it met their needs. Courses offered were limited and there wasn’t support for people who wanted to do mainstream courses in subjects they were interested in. If college is a good fit for someone this lasts 3 years. After that there is little else available in terms of lifelong learning.

People spoke positively about some opportunities offered at UCAN, Hansel and Girvan Opportunities. One parent spoke about how their child had been doing exercises along with their dad at home during lockdown. These were repetitive physiotherapy exercises. Opportunities to try similar things like yoga sequences would be great.

One person had one to one support for travel training which they said helped them a lot as they are now able to be more independent.

The supported employment service was not well known, and neither is Project Search and we did not hear from anyone who had used them. We met someone who had been employed and lost their job due to redundancy and were not sure where to begin to look for a new job.

### Transitions

A lot of the people who attended the focus groups were parents of recent school leavers. It was acknowledged that the pandemic has had implications for the availability of opportunities and made it more challenging to develop a full schedule and maintain a routine. This aside there seemed little evidence of people experiencing a well thought out and streamlined transition process.

One parent who attended the focus groups described transitions as “just a change of social worker” and the parents who spoke about transitions said that their child stayed with the children and families social worker until they were swapped to the adult social work team when a social worker was available. This happened some time in their mid-20s. This resulted in not being supported to plan for a move to adult services or to be given the information people needed about access to support, funding, and activities suitable for them in adulthood.

People with learning disabilities who spoke about their experiences of transitions said the experience had been leaving school and being given the option of “college, a day centre, or hee haw” though this had been some time ago and legislation is very different now. Other points of note were that people do not have only one period of transition in their lives. For example other transitions include moving into their own home or the death of their parents. People needed to be supported to plan for other life changes and supported through these times. One person had received very good support to prepare for the move to independent living from Occupational Therapists.

### Housing

Finding the right home, in the right area, with the right support is important. People with learning disabilities who attended the sessions mostly lived independently. They all reported currently being happy where they are and with the support they have. Telecare was reported as being useful to support independent living when it is supported by clear instructions about what to do if, in the example shared, a CO2 alarm goes off. Some people had tried different housing placements and different support providers before finding their current home and support package.

Parents who came to the focus groups mostly said that there was not enough suitable housing for people who may want to move out of the family home but who would be unable to live independently. Discussion around this suggested that a model of sheltered housing or care home style housing for younger people would be seen as more appropriate for people with higher support needs. Other suggested models were supported housing with flat mates for people who would not choose to live alone or a village model along the lines of Camphill Communities.

### Feeling Safe

In the focus groups people discussed feeling safe, both at home and out and about. People who lived in the smaller towns said that locally they were known and recognised and that people looked out for them a bit. In the bigger towns there were reports of anti-social behaviour which had been exacerbated by the pandemic. Being out at night was not something that many did and for most having support to do this, in particular to use public transport at night was considered vital to their feeling safe.

Most people felt safe in their homes with the support they have. Some mentioned success with telecare being used to ensure their safety at home.

There were a lot of people who had experienced a lot of discomfort being out in their communities more than lack of safety. Communities are not always as welcoming and accepting of people with learning disabilities as would be liked.

## Working Together and Commissioning Services

The discussions highlighted that there was not always good information sharing or working together across the Health and Social Partnership and the voluntary sector. Both provide different services, support and activities and people should be able to pick and choose from a menu of available opportunities depending on what they feel would best help them to achieve their desired outcomes.

The discussions highlighted that people were not able to access the information they need to be able to participate in the full range of options on offer in South Ayrshire. Voluntary sector workers shared that they did not always have the relationships they needed to signpost people on appropriately and that these relationships between staff in different organisations and sectors needs to be strengthened. In the discussions with the voluntary sector providers some raised that they felt the services commissioned did not allow for as much flexibility as people with learning disabilities need in order to have the support they need to live full lives. Some said that support was commissioned in a very task- focussed way rather than more of an outcomes basis that would be more in line with self-directed support legislation and the way the voluntary sector organisations work.

## Journey Mapping

Two individuals with experience of learning disability services agreed to share what their journey has been like to help inform the strategy and improve the experiences for others in similar situations.

**Participant 1**

Participant 1 is care experienced and has a learning disability, receiving support from a young age. After being moved from foster care to a respite facility for 6 months, they were moved to a 24-hour care plan at the age of 13. They described their experience as largely negative, stating that “24-hour care taught [them] nothing”, and said that they felt they were capable of more but not given the opportunity to learn. They remained in 24-hour care for 8 years until they began their transition to adult services which was the big turning point in their life. Participant 1 told their adult social worker that they wanted to be independent and worked with their children’s social worker and new worker to create a plan to move out of 24-hour care and work towards becoming independent.

Their new worker was able to move them into core and cluster accommodation, which meant Participant 1 had their own home with a network of peers and support available to them, and reduced support to 26 hours per week. The reduction in support gave them the freedom to take up volunteering opportunities and join a walking group, building on their independence and confidence.  They have continued to embrace their independence and build knowledge and skills, access employment and education and build a trusting relationship with their social worker. The relationship Participant 1 has with their worker has allowed them to reduce their support package again to 16 hours per week and become responsible for their own health and wellbeing. This was a big achievement for them in their journey towards independence, and the next goal for them is to have a home with a garden and a dog.

The key positive in Participant 1’s journey was their transition process, being listened to and being involved in their plan for moving into adulthood.

**Participant 2**

- Receives diagnosis at **3yrs old**
- Begins education

- Allocated social worker
- Accessed respite at **age 4**

- Education going well
- School offers range of activities and experiences

- School started early transition planning **aged 14**
- Planning involved professionals and family
- Process was disjointed and no timeline was established

- Began outreach programme age 18
- Progressed to short breaks every weekend age 19

- Left school **aged 19**
- No transition plan in place
- Unclear which aspects of care were being dealt with by adult's/children's service

- Transitioned to adult social work team **aged 23**
- Processes flowed better following transition
- Moved to residential care
- Previous transition planning from age 14 no longer valid

- Deterioration in wellbeing and behaviour
- accommodation not suitable

- Moved to own tenancy with 24hr support **age 25**

- Provider not able to meet needs or provide consistency
- Behaviour deteriorates
- Provider relationship breaks down.

- Provider withdraws support around 1 year into tenancy
- Family take over all care needs

- New provider slowly introduced

- Small core team takes time to build good, consistent relationship

- 24hr support reinstated

- Begins social outings with support

**Dream for the future:**
*To live the best life and be happy*

Participant 2 also received support from an early age and had a positive experience with services as a child, participating in a range of activities through their school and accessing respite from the age of 4.

In contrast to Participant 1, Participant 2 experienced difficulties as transition planning began at age 14. Transition planning involved professionals and family, but they felt that this was disjointed, and no clear timeline was established for transition to take place. Participant 2 remained in education until the age of 19 and remained with the children’s service until the age of 23, at which point the early transition plan was no longer valid as needs had changed over the years.

Participant 2 moved to residential care, which was ultimately not suitable and negatively impacted their wellbeing, before moving into their own tenancy with 24-hour support. In this case the accommodation was more suitable for them, however, they did not receive the consistency they needed from their support staff which again affected their wellbeing and caused the relationship with their care provider to breakdown. Participant 2 had strong family support to advocate and care for them until a suitable provider was identified that could offer consistency and build a relationship and trust with them and their family.

Having the right combination of support and accommodation has had a positive impact on Participant 2, and they are now experiencing social outings with their support team that they would never have accessed before. This has also had a positive effect on family who now receive updates from the support team and can trust that the right care is in place.

## Online Staff Survey

### Methodology

An online survey was created via Microsoft Forms and issued internally to all staff in the Health and Social Care Partnership (HSCP) and to relevant third and private sector providers. The survey was also shared with members of the Learning Disability Strategy Development Group to be cascaded to other relevant services such as housing, education, and employability. The survey covered three main sections:

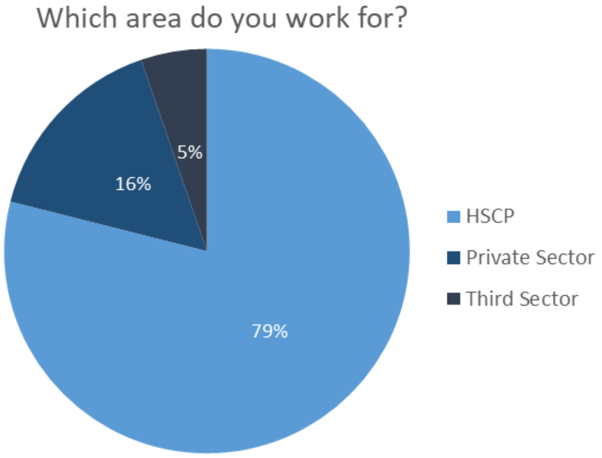
- *What is good about the support your service offers*
- *What is not good about the support your service offers; and*
- *What would make life better for people with learning disabilities in South Ayrshire*

### Overall Feedback

Overall, responses were similar in each section. Most felt that their service was good at offering person-centred support and helping to maximise independence. The COVID-19 pandemic was referenced to throughout the survey, particularly in relation to staffing shortages and reduction of services which are areas staff feel could be better. Training was also highlighted several times with a desire for not only staff training to be increased, but general awareness raising and education on learning disabilities to be carried out across all services and organisations. There was also reference to building-based services as a suggestion to improving the lives of people with learning disabilities, with most respondents stating that meaningful activity and choice being a key part of any building-based service. Some participants also wanted to see recognition of positive work being carried out by teams and a celebration of any improvements that take place.

### Demographics

19 people took part in the survey in total. Most who took part in the survey worked for the Health and Social Care Partnership (79%), 16% of respondents worked for the private sector and 5% for the Third Sector.



Most respondents working in the HSCP advised they were part of the Community Learning Disability Team and roles of those who took part included:

- Occupational Therapist
- Physiotherapist
- Social Worker
- Sexual Health Nurse
- Specialist Nurse

- Team Leader
- Home Support

Those in the Private Sector indicated they held a care at home or community support role and in the Third Sector, a Learning Disability Practitioner role.

### Survey Questions

*What is good about the support your service offers?*

Participants were asked to name three things that were good about the support offered in their service. The majority of respondents felt that their service was good at providing person-centred support and maximizing independence and others mentioned multidisciplinary working and assessments they provided as a positive aspect of their service. Responses are demonstrated in the image below:

*What is not good about the support your service offers?*

Participants were then asked to name three things that were not good about the support offered in their service. Responses to this question reflected the issues that have been seen throughout the COVID-19 pandemic and many respondents referenced COVID-19 as having an impact on their service. The main barrier most services are facing is a lack of staff due to recruitment and absence issues, which has subsequently affected both the amount of services currently on offer and the workload of existing staff. Other areas that respondents felt could be better in their services were training, awareness raising of service and self-referral options, and more opportunities for partnership working. All responses are represented in the image below:

*What would make life better for people with learning disabilities in South Ayrshire?*

Finally, participants were asked for solutions to make life better for people with learning disabilities in South Ayrshire. The most common responses were relating to training, building-based services and employability. Respondents felt that more training and awareness raising needed to take place across all areas of the local authority to ensure that everyone has a good level of understanding of learning disabilities and how to refer to for support. Many responses mentioned increasing the availability of building-based services, with suggestions of 7 day per week services and activity hubs in the community that offered a range of meaningful activities. Several responses echoed the idea of meaningful activities, particularly in relation to employability programmes, with a suggestion that employability and skills and learning disability services could link in better. Other suggestions for improvement included giving people with learning disabilities more choice; making services easier to access – with some suggesting a single point of contact would help in this area; and more funding being made available for learning disability services. All responses are represented in the image below:

*Additional Comments*

Participants were given the opportunity to provide additional comment at the end of the survey, of the additional comments almost all highlighted a desire to celebrate success in learning disability services with respondent indicating they would like to see to see positive information being shared about the work being carried out by teams and information about service development shared with teams.

> Useful to have a whole system review of services/celebration event to recognise improvements and establish future ambitions.

> More appreciation for the job we do

## Staff Interviews

As part of the engagement work carried out to provide evidence for the development of South Ayrshire HSCP's new Learning disability strategy, SCLD interviewed several members of staff, most of whom are in managerial positions. A summary of these interviews is presented here.

**Billy McClean - Head of Community Health and Care Services**
**Summary of key points:**

*COVID-19*

- Some people are still struggling
- Legacy issues, including young people whose transition has been difficult
- Innovative practice to be mainstreamed/embedded post-lockdown

*Transitions*

- Currently not joined up enough
- We need to be better at explaining SDS to young people and their families
- Transition to adulthood should feel like a joint enterprise, not an imposition
- We are developing more options and this needs to continue to improve

*SDS*

- We are getting better; we need to keep improving because we're not there yet
- This should not be the only measure of success; another measure is whether people have felt in control over the process
- All workers involved in having these conversations need to believe in and feel comfortable with the process

*Data collection*

- Data collection does not currently give us all the information we need
- Learning disability data is not generally disaggregated in universal data collection
- We are good at collecting evidence about the impact of our services on people's lives

*Community involvement*

- Commitment to raise investment to £1million per year within two years
- Vibrant, inclusive communities can provide social and learning opportunities for people with learning disabilities in a mainstream setting
- Localities will have autonomy over developing their own communities, including a budget
- Opportunities for leadership from people with learning disabilities in this context

**Sandra Rae – Learning Disability Service Manager**
*Responsible for nursing, social work, day services and respite.*

**Summary of key points:**

*Day services*

- Currently there isn't enough choice within buildings-based day services
- Many people's needs are not met by a 9 to 5 day service
- We should build on opportunities in the community for social support
- Covid has forced us to change the way we do things, and that has provided an opportunity to change long term

*Transitions*

- Transitions discussions need to be more inclusive and transparent
- Discussions with families need to start earlier
- We want to give young people themselves more choice and control

*Housing and Home support*

- The core and cluster developments have been very positive
- There are other successful models
- Innovations in technology enabled care support has given us an evidence base for future support

*Community Inclusion*

- We have started this but there is more to do
- Social support is important for people's wellbeing
- It would be good to offer community led support, separate from social work and not dependent on eligibility

**Health Professionals: Carol Briggs - Nursing Team leader, Dr Karen Stevenson - Clinical Psychologist, Kelly Stevenson – Occupational Therapist, Joanne Neil – Dietician, Fiona Norbury - Charge Nurse**

**Summary of key points:**

*Technology*

- Technology has brought many benefits over Covid, including professional support and social connection, but some people need support to use it.
- We should embed use of technology in our practice and people's everyday lives.
- There could be a role for people with learning disabilities as digital champions.

*COVID-19*

- Many regular health checks were cancelled, and we need to find out if health issues have been missed.
- The activity packs developed by social work have been great.

*Social isolation*

- Linking people in with groups and activities needs a more active approach.
- Seeing friends and family is important to people.
- There are associated health problems with loneliness (e.g., obesity).
- We need to provide opportunities for people to build their self-esteem, feel valued and contribute.

*Employment*

- More employers need to employ people with learning disabilities.
- There used to be good coordination between college and the different agencies involved in supporting people to participate.
- UCAN is a very good model for preparing people for work and independent living. We should have a similar resource in South Ayrshire.
- We should promote social enterprises that provide employment for people with learning disabilities.

*Current strategy and workload*

- The current strategy does inform our work and health work is aligned with strategic aim of reducing health inequalities.
- Trauma-informed care is being rolled out to across other providers after a successful pilot with Hansel.
- We have to balance developmental work with day-to-day duties.

*Joined up working*

- We have developed some good connections, e.g., with GPs, but it could be better.
- IT systems make joint working harder.
- A re-branding would help people we serve to know who we are, what we do, and how closely we do work together.

## John Deans – Commissioning Officer

**Summary of key points:**

*Commissioning issues*

- South Ayrshire’s rurality, financial structures and workforce shortages are starting to make it hard to commission services.
- The increase in hourly rates for sleepovers has had a big impact on the affordability of support packages where sleepovers are a component.
- Core and cluster developments have been good for people and good value. Going forward we should be planning new housing for core and cluster where we can make sure housing design meets people’s needs. This will require greater co-working with Housing and Planning that works with their longer planning cycles

*Joint working*

- We need better data about young people coming from Children and Families so that we can predict demand better.
- Having a dedicated Transitions worker is helping to address issues with transitions.

*Early intervention*

- We should go back to an arrangement where people can get targeted support before their needs become critical, as Feeley recommends.
- We don’t know enough about people with learning disabilities becoming known to the HSCP through another label e.g., drug and alcohol misuse.
- People with a mild learning disability, not eligible for LD support, but with a drug or alcohol problem, are vulnerable to exploitation.
- Currently, there are no community supports specifically commissioned for people with learning disabilities that are ineligible for social care support.

### Kevin Anderson - Service Lead for Policy, Performance and Planning

**Summary of key points:**

*What is going well*

- Change in leadership and better strategic planning means that we are now better at giving people with learning disabilities the housing they need to live independently.
- Core and cluster developments have been good.
- We need a range of housing options for people with a range of needs.

*Communications and joint working*

- We need to make sure that the housing needs of people with learning disabilities are fed into the next Housing Need and Demand Assessment (HNDA).
- At the moment communications between Housing and Learning Disability Services are good, but this needs to be embedded so it is not reliant on individuals.
- It would help Housing to plan if the HSCP was more proactive with communicating need.
- To maximise housing options, we need to broaden the base from just council stock e.g., private rented sector – more choice, more suitability

*Gaps*

- A gap in data is the demand from young people coming from Children and Families.
- A hidden population is people with learning disabilities still living with ageing, frail parents. This situation contains a cluster of issues to be addressed.
- We do not have enough data about people with learning disabilities and autism – this population may have particular housing needs.

*Current strategy*

- Core and cluster has been a big success.
- Technology enable care has been slow to be implemented. It needs a clear strategy to develop it further.
- There are good examples to learn from in other parts of Scotland – Inverclyde is one.
- We need to learn to work in a trauma-informed way
- Some people with multiple labels have huge problems navigating the system, with too many professionals around. Housing First is a very successful model when housing is the initial presenting issue

### Colette McPherson - Employability and Skills Lead

**Summary of key points:**

*Links and joint working*

- It's a worry to think that some young people with learning disabilities might not know about us.
- Most referrals come from schools, colleges and Skills Development Scotland.
- Links with social work aren't as well-coordinated as they could be
- Regular information-sharing meetings at team leader level might help with this and might be able to be more solutions-focussed.

*Data*

- We don't routinely separate out learning disability data from our other disability data, but we could find out how many people with learning disabilities we have supported into work.

*Covid*

- We bought a lot of tablets for people to stay in touch with them.
- We kept engagement up with garden visits and new outdoor activities.
- We had worked hard with people to get them into daily routines and a lot of this was lost.
- Post-lockdown, the jobs market is better than expected, and money is coming in for jobs initiatives like Kick Start.
- Working with the DWP on the Disability Confident Employer Programme is helping us get young people into work.
- We can produce professional biographies for people – a positive document that briefs an employee about someone's support needs and gives them confidence that they can employ this young person.

*What would help?*

- Raising aspirations at an earlier age – parents', teachers' and the young people's own.
- More information and career planning from an earlier stage.
- Start working earlier with people while they are still at college, so they are job ready when they leave – some feedback we've had from parents is that college courses alone don't prepare people for work.
- We want to engage with and inspire reluctant employers

# Phase 2 – Draft Strategy Consultation

The Adult Learning Disability Strategy 2022-2027 underwent its second phase of consultation period between March 2022 – April 2022. The consultation looked to engage with those in South Ayrshire with a learning disability, their carers, family, and staff involved in learning disability services.

Following a similar format to the initial consultation period, a paper survey and online version was produced and promoted to all 750 service users within South Ayrshire and was promoted to HSCP staff and Third Sector Agencies to participate. Production of the survey was made in collaboration with the Scottish Commission for People with Learning Disabilities (SCLD), League of Champions and Strategy Development and Steering Groups.

The paper survey had a higher level of participation from the community compared to the first consultation period. The focus of this survey was to gather feedback from participants on their views of the design and context of the strategy to inform the final version of the strategy.

The online survey was also open to professionals in public, private and third sector whose service supported adults with learning disabilities. The main participants of the online focus groups were from professionals. With a focus being on the strategy the survey allowed for both staff and community members of offer their views and feedback on the design and context within the one survey.

Focus groups were held in a similar manner to the initial consultation with four in person meetings held in Ayr, Troon, Maybole and Girvan. Five Zoom group were organised however participants only subscribed to two groups. The six focus groups were delivered jointly by the Health and Social Care Partnership and SCLD.

Third Sector organisations also participated in their own focus group during the consultation period with the event being jointly delivered by the HSCP and VASA. Five organisations subscribed to this event and provided feedback and support towards the draft version of the strategy.

The feedback fathered during this stage of the consultation has been analysed and will be used to inform the final version of the strategy.

## Draft Strategy Survey Report

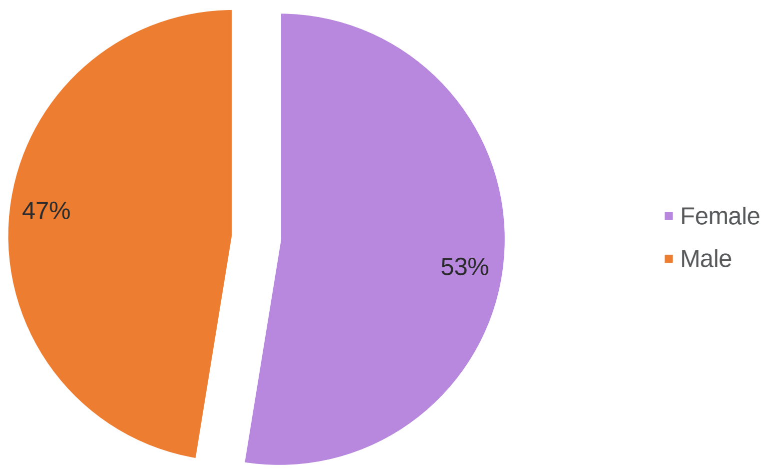
The draft version of the South Ayrshire Learning Disabilities Strategy has now been published and as part of the consultation process feedback surveys were sent to 750 people within South Ayrshire who has a learning disability or supports someone with a learning disability. As well as paper surveys, an online survey form was published where staff, service users or interested members of the public could participate. The survey looked at people's views on the design, information and vision of the strategy and allowed for individuals to comment their views and any recommendations they would make.

### Who took part in the surveys?

A total 117 participants took part in both the paper and online surveys. 98 people with learning disabilities took part in the paper surveys that were sent out. 19 online responses were received, with majority of these participants being carers, staff and interested members of the public. Public Health chose to submit a written response on behalf of their organisation rather than complete the survey individually. Figure 15 shows the gender representation to both the paper and online surveys. Paper responses show a slightly higher male response comparison to the online surveys where the responses were predominantly female. National averages show that there is a higher population of males with a learning disability within Scotland compared to females[6].

The age profile shows that for service users completing the paper surveys the average age for those engaging was between 49-59. This age group differs from the first survey completed during the development stages of the strategy. The average age during those consultations were 25-35. All online and papers respondents described their ethnicity and white.

**Figure 15: Gender profile of survey respondents**



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[6] SCLD (2019)

**Figures 16: Age profile of survey respondents**

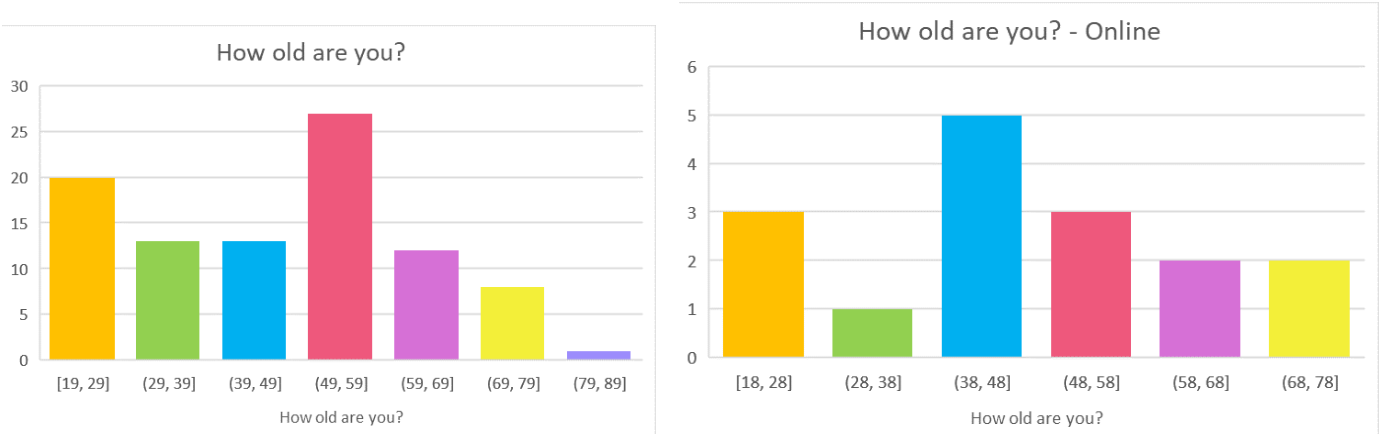
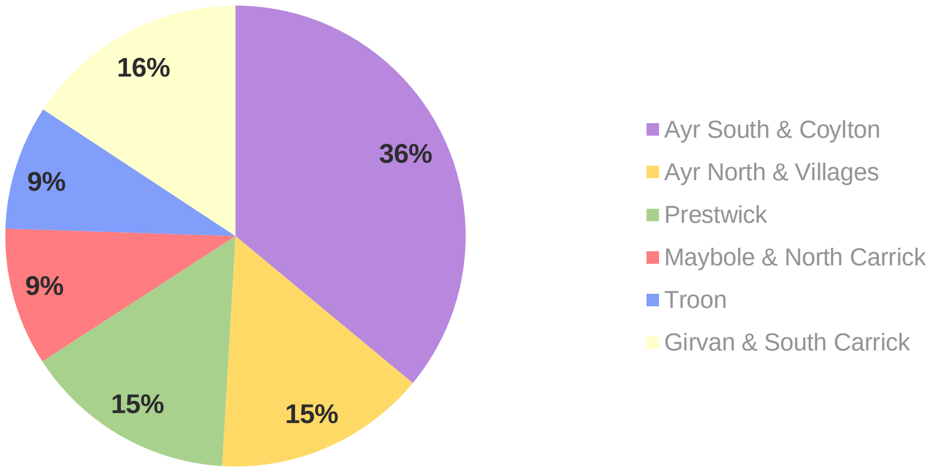


Figure 17 shows the locality areas where respondents live. Ayr South features as the highest locality with 35% of the overall responders residing here.

**Figure 17 Locality Areas – Paper and Online**



## The Vision

Of the 117 participants, 93% agreed with the vision and the remaining 7% selected that there were not sure. For the people who included further comments on their views regarding the vision some of the feedback includes:

> Too many times I have had to fit in with an existing strategy rather than a strategy being developed to suit my needs.

> As a parent of a son with a learning disability, I feel it is very important that getting it right for him to feel included respected in the community, to be accepted in all areas of life, to have his own voice in the community and

> The fact that every person will have the opportunity to have the life they choose and have support to fulfil their wishes and live the best life ever.

Of the 117 responses there were only 22 people included further comments response to their views on the vision. Whilst all these people selected that they agreed there was feedback expressing some concern over how the vision and priorities would be implemented. These comments included:

> The vision is very detailed. I would be interested to know how this is achieved in a practical and deliverable way e.g., how is it funded? What is the service level that can be expected? Will services be funded appropriately? how will transitions be supported as, at present, they can be affected by money/care plans and them not being signed off.

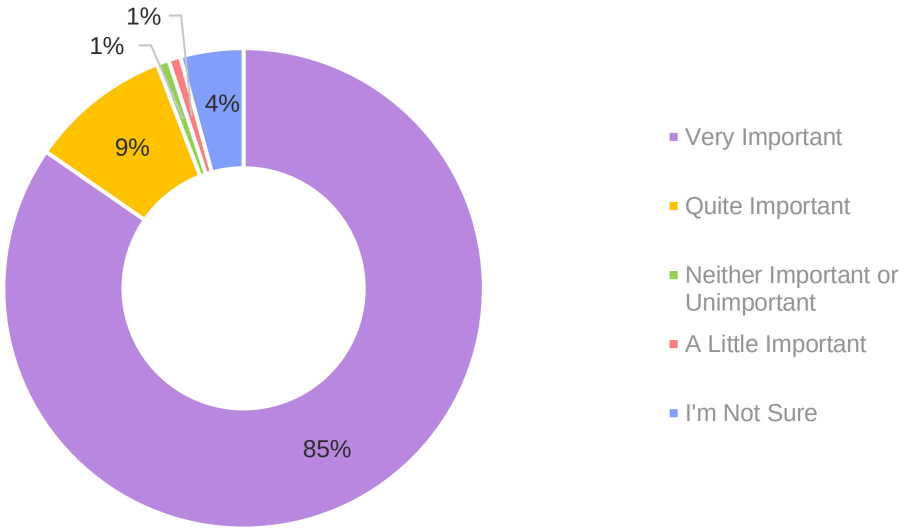
> It's good for younger people with a learning disability but nothing for older people like me!

## Health and Wellbeing

As we come to the end of COVID restrictions, participants were asked how important they feel a covid recovery plan is. Almost all people within South Ayrshire will have faced some level of disruption to their daily lives as a direct result of the COVID pandemic and the vision emphasizes the importance of having a recovery plan in place to help people return to normality.

> *“There is limited information about health improvement/prevention and although covid-19 recovery is vital I’m not sure if the key focus should be about covid-19 recovery although perhaps the detail of this is missing.”*

**Figure 18: How important is it to have a COVID-19 recovery plan?**



Result show that the majority of people agreed that a COVID recovery plan was very important to them, and a smaller number felt it was quite important.

**Health Passports:**

Health Passports can play a key part in ensuring those with a learning disability are seen to in a way that meets their needs at all hospital appointments[7]

The survey asked participates to indicate how important they felt a health passport would be to make hospital visits easier. The 67% agreed it is very important and 12% felt it was quite important. This indicates that health passports are a topic which people within the community are keen to see however 3% did feel it was not important at all.

An additional two comments were received in relation to health passports with one participant advising they have theirs in place. Another individual who felt health passports were very important went on to explain their experience of how these are being used…

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[7] Mencap.org

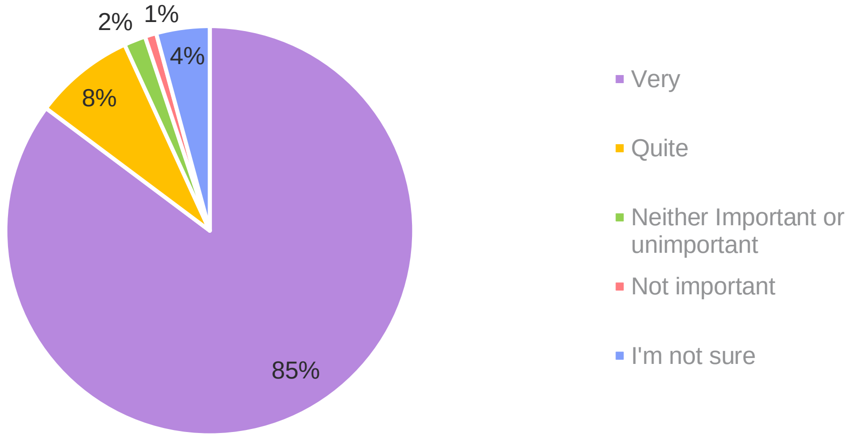
> *"Heath advisors at the hospital should take more time to read the passports as I have experienced them not doing so and was nearly given medication, I was allergic to"*

## Future Care and Older Adults:

Individuals were asked if there felt future care was important and how important they felt it was for older adults with learning disabilities to be cared for in the future. Figures 19 and 20 show the total percentage of people's views regarding older age care. South Ayrshire has an above average older adult population and the oldest population in Scotland[8] so it can be understood why this would be such an important topic for the learning disability community.

> "Family carers could do with knowledge of the range of options that would be available in the future and how it would work in detail"

**Figure 19: How important is it to have a plan for how you want to be cared for in the future?**



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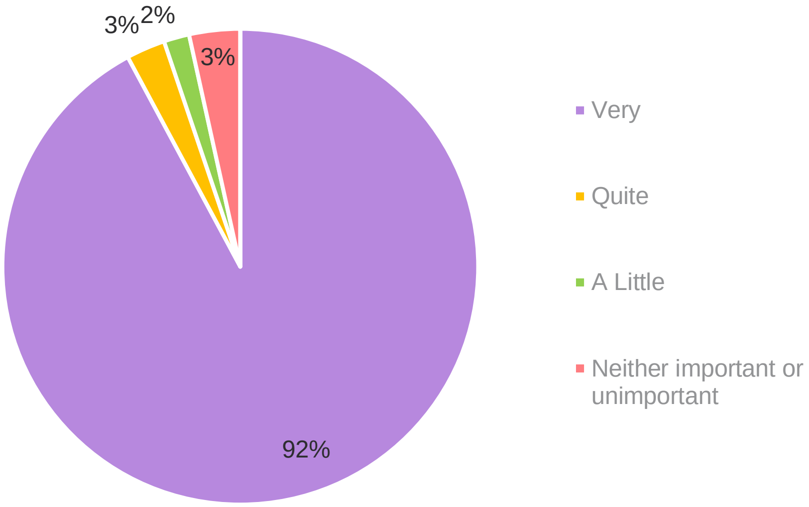
[8] Strategic Plan 2021-31

**Figure 20: How important is it for older people with learning disabilities to have specific help and support?**



## Relationships

The keys to life[9] recognise that relationships, of all different forms, are essential to the wellbeing of people with learning disabilities, and important for people's sense of belonging and social inclusion. Despite this, people with learning disabilities continue to face barriers that exclude them from relationships of all different kinds

71% of participants felt that healthy relationships were very important to them. 73% have described their self as single, 12% as married 11% as in a relationship. 82% of respondents described their sexuality as heterosexual, with 2% of responses describing their self as gay and 5% of responses described their self as bisexual. These numbers follow similar results from the first surveys where 82% responded as heterosexual.

Healthy relationships and friendships have a key theme throughout the surveys. While there were no feedback comments relating to personal relationships several participants have commented throughout the survey their need to maintain friendships and socialisation. Healthy relationships with partners and friends are an important part of day-to-day life for everyone, and people with a learning disability often voice that they are keen to have and maintain meaningful relationships[10]. People with a learning disability may need increased support to maintain relationships but have the right to be entitled to this support. Comments such as these highlight ways people in our community have previously been maintaining their closest relationships:

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[9] The Keys to Life

[10] Marriott (2019)

> *“There needs to be more opportunities to mix in groups and socialize e.g., social evenings, Christmas dances.”*

### Trauma informed services

84% of people responded that they feel it is very important that those who deliver their services understand the effect of trauma. We know that trauma can have lasting effects on an individual emotional and physical health[11] and that individual with a disability may not have their traumas go under the radar particularly in early educational settings[12.] While a high percentage responded they think this is very important to them. Only one comment was received regarding trauma informed practice which gives a viewpoint on their feelings:

> *“There needs to be access to appropriate therapies to support trauma informed practice, learning disabilities nurses are a brilliant resource and need to be enable to practice creatively as they have done to support people to have e.g., vaccinations at home.”*

### Community Safety

Community safety was a subject that was prominent in some focus groups and a key topic of interest for the community. Figure 21 shows the response regarding how important people feel community safety is. Community safety may mean many things for someone from public protection to being able to travel safely whilst using public transport. The main ethos of this priority is to include the wide aspect of what can help individuals in the community feel safe within their day-to-day life.

> *“Our main priority is our health and safety, particularly going out and about learning to stay safe and to feel looked after. It's really important having a voice. We need to take care of going on and off public transport”*

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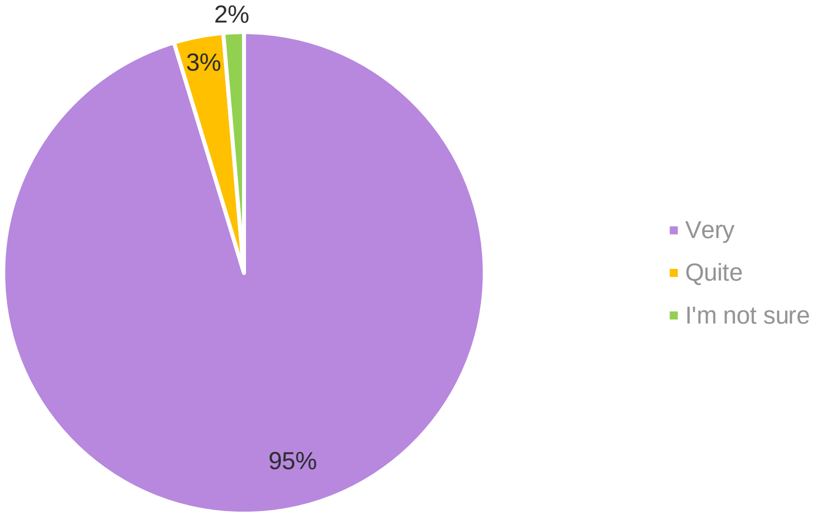
[11] Trauma-Informed Care

[12] Eileen, et, all (2019)

**Figure 21: How important is it to make the community safer for people with learning disabilities?**



## Choice and Control

### Self-directed support:

Self-directed support remains a very important topic for people with learning disabilities. 76% of participants felt it was very important for those with learning disabilities to have choice and control over their support. 11% felt it was quite important, 9% were unsure, 3% felt it was neither important or unimportant and 1% felt it was not important. The topic of self-directed support received in-depth comments:

> *"I think parents and Guardians need to better understand Self Directed Support and the implications of each option. I'm glad that it is acknowledged that the Transitions process needs to be improved. It is important is it that people with learning disabilities are involved in local activities and groups as long as that includes the option of meeting with peers in building based services. It is important is it that carers feel valued and supported."*
>
> *"It's important to have control in our daily lives, for us to feel independent. Human rights are very important for us individually, for us to have a voice. we all care for each other; it is up to us individually on what we want to do in our daily lives."*

Some people also felt that with the care support they receive through Self Directed Support that more emphasis was given to the carers and then the individual:

> *"Sometimes it seems carers are more important than those they care for. For example - carers bringing in own food to eat and client left to have separate meal. I think dinner should be made and eaten together"*

### Transitions

The strategy's vision is clear that transitions are to be improved within South Ayrshire and has already begun to take steps to improve the outcomes for young people with a learning disability to transition from school to adulthood. Comments have also included the importance of choice during a transition and how options once they leave school are very limited. We know that transitions from school to adult services can already be very challenging for people as it combines a change of services and professionals[13], and the strategy is committed to making improvements to how we support transitions in South Ayrshire.

Figure 22 shows that there was a very high level of participants who felt improved transitions are very important to them. Within the online survey, 100% of responses selected very important and within the paper survey there was a mixed response to this question. Feedback from participants includes…

Giving choice of what to do at college. I had to do things I didn't like. Had to do drama and sing and I have a stammer. I hated it!

"Transitions from children's service to adult services can be poor, frustrating for young people and for their parent/carers. There has to be a better way of doing this

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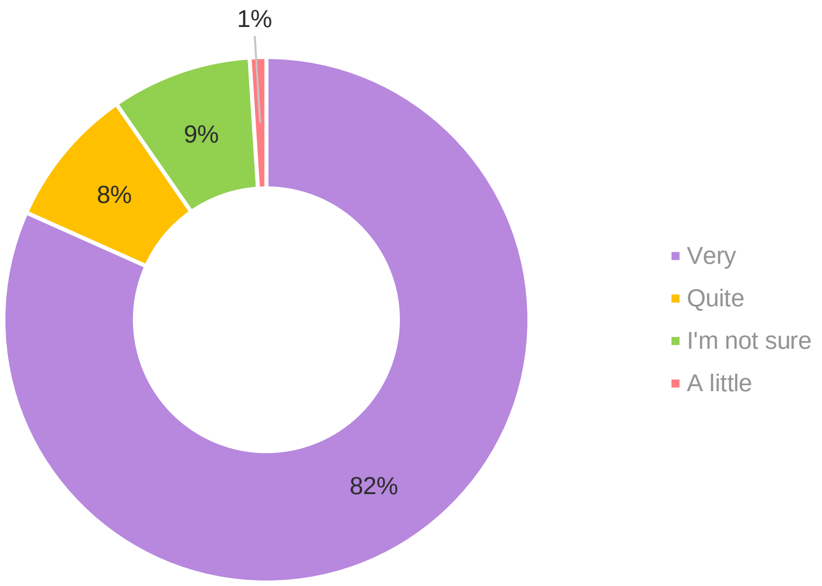
[13] Mencap.org

**Figure 22: How important is it that we improve on the way we carry out transitions?**



## Local Activities and Groups

Survey participants advised on the importance of group settings and accessing more community supports. 86% of participants felt that people with learning disabilities are involved in local activities and groups. The COVID pandemic seen many groups and services suspend the supports the provide in the community and comments reflect the difficult that those within South Ayrshire have faced over the last two years. We know that nation-wide, people with learning disabilities want to go back to their normal routines and be able to see friends and attend community groups again[14].

Although some groups are open to able bodied/minded people, if suitable then should accept people who may be a bit slower if they bring support.

You need to include something about ensuring staff and resources are put into ensuring communication needs of folk with learning disabilities who are non-verbal or autistic. This is vital for properly enabling choice.

Have more support and take people out and about in the community.

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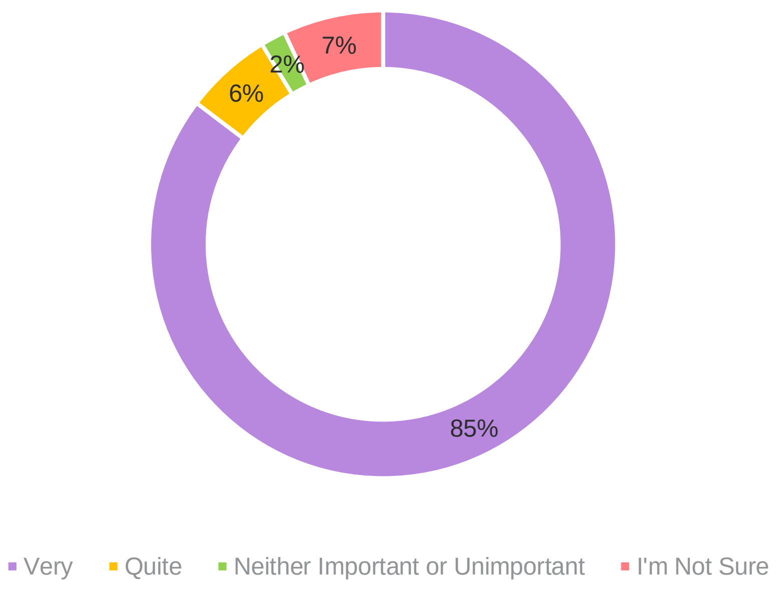
[14] Taggart et.al (2021)

## Advocacy

The number of people accessing independent advocacy has increased in Scotland over the years[15]. There are varying levels of the types of advocacy services available for people with learning disabilities in Scotland, and within South Ayrshire there is currently one service available for adults. Those who participated in the survey were asked how important they felt it was that people with learning disabilities have an independent advocate if they want one. Figure 23 shows the responses received to this.

> *"Some adults or children with disability may not be able to make the decision about their lives or understand how to. It is very important that they are supported, and carers views are taken into account"*
>
> *"Ensure there is the provision for the person with the learning disability to be questioned on their own with staff and not always with the parent/guardian, if discussing choice and control. Need to consider there could be some measure of power or control over the individual unfortunately."*

**Figure 23: How important is it that people with learning disabilities have an independent advocate if they want one?**



## Carers

Many people within South Ayrshire who have a learning disability receive support from paid carers or are cared for by family. It is important that person centred support is provided to support someone to be as independent as possible[16].Carers play a key role to

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[15] SCLD (2018)

[16] Active Support

support the lives and independency of individuals with learning disabilities and it was an important factor to ensure carers had the options to participate in the survey. Many people felt it was very important that carers feel valued and supported within their role. 96% agreed this was very important to them, 1% felt it was quite important and 3% were not sure. Within both surveys people included further comments such as:

> Listen to the person who is the main carer as they know what is best for the person and understand their

> Some adults or children with disability may not be able to make the decision about their lives or understand how to. It is very important that they are supported, and carers views are taken into account.

> support for carers is also vital

> It is crucial that carers are supported by the provisions of activities - e.g., in Hansel and that transport is provided - Particularly as carers get older. Daily activities for me that do not involve input from my parents are my best chances of being able to stay in the family home for as long as possible.

> I think that you much be careful not to overburden family carers with increased admin and organization when they are already very committed.

> How to support the families as well as the individual to get all needs right, with the right support which is best for each individual as not everybody's needs are the same.

> Carers get very little recognition and deserve better pay.

When thinking of choice and control participants were keen to utilise the comment boxes to express further views that they had.

> Choice is key. People have individual needs and require more than a "one size fits all" approach.

> The important thing about choice and control is that the 'person' does have a choice.

### Choice and support for housing

People with learning disabilities all have varying levels of need and some people can live independently in the community and others may need some extra support to do this[17]. Participants were asked how important it is to offer more choice and support for housing participants felt this was something very important to them.

Some responses received described the difficulty some may face when it comes to securing housing on their own:

It is important when the individuals are able to live in supported housing. *Person* would not be able to have a job.

More carers needed to help them in their own home.

Not everyone with a learning disability can make the decision about living independently or take a job.

I think it's a good idea that we all know that there is plenty help and support out there. Making certain the house or flat is adaptable for you, having that alarm system fitted and making certain that you feel safe at all times. life for the person they care for

20 Years ago - lots of people got their own homes - unfortunately as health deteriorates - these homes become unsuitable - forward thinking forward planning is most important, homes suitable for life

The main emphasis from comments were that where it is the right choice for the person to live in their own home, there needs to be a strong support network around them to ensure the property and care is right to ensure it is a lifelong home:

> *"Living independently is not always the right choice, so making sure support is put in place for staying at home and parents and carers are supported alongside to have the best quality home."*

---

[17] Active Support

### Using technology to help people live independently:

Assistive technology is a way to support those with a learning disability to live as independently as possible. The use of technology can support people in ways traditional services may not have been able to.  Just over half of the participants felt that technology was very important to supporting independent living. Figure 24 shows the responses to this question. However, some participants included further comments and most of those that provided their views felt that they would rather care be provided in-person or be able to see their friends face-to- face rather rely on new technology.

---

> *“I don't want technology I want a person to help me if I am scared or ill. to be with me right away.”*
>
> *“Nothing seems to quite fit for people with complex needs, severe learning disabilities and autism – non-verbal etc. There are very limited supported living options available locally. Tech enabled support may not be safe for this client group.”*

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However, others felt having technology was vital to provide a safe setting:

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> *Technology is vital. (Housing) in group settings (safe places) in "nice areas" for people to be safe and good community support.*

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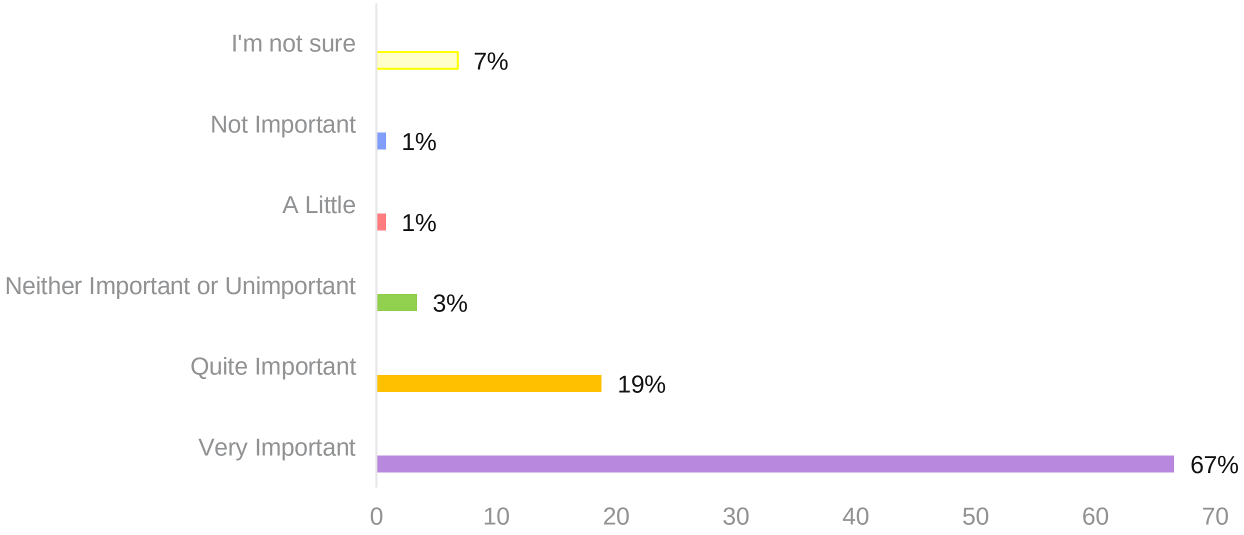
**Figure 24: How important is it to provide more technology that can help people live independently?**



### Working and volunteering opportunities

Many people with a disability can and want to be in employment[18]. People with a learning disability have the same rights as anyone else to be employed and are protected under the Human Rights (1998) Act[19].

Seeking employment and volunteering was a topic many wanted to discuss during the focus groups and remains a very relevant topic within the surveys. Over two-thirds of the participants (68%) felt it was very important that there needs to be better experience with learning and finding a job and 12% felt it was quite important to them. 12% did also advise that they were not sure of this question and the remaining felt it was neither important nor unimportant (5%) or not important to them at all (1%)

> *"Opportunities for voluntary work/jobs are very important. It would be important to make sure that people are ok during their time at these e.g. ask are they anxious, how are they doing?"*
>
> *With a diagnosis of Asperger's syndrome and being high-functioning as I have been told, I can feel frustrated at being too capable for some things but not capable in terms of anxiety of being independent, looking for opportunities."*

Some have spoken about negative experiences where they have tried to gain volunteering roles but been excluded due to their physical needs. This highlights another barrier those may face in the community.

> *"I was excluded from voluntary work due to using a walking aid although able to do what was advertised as work."*

### Taking your views into account to improve services

The ethos of the strategy is supporting those in the community with a learning disability to live their best possible life. An important part of being able to do this is taking people's views in to account especially when improving services. Listening to people and their experience is more than just "good practice" and is what the strategy's aims are moving forward with services. Figure 25 highlights people's views regarding how important it is to have their views included.

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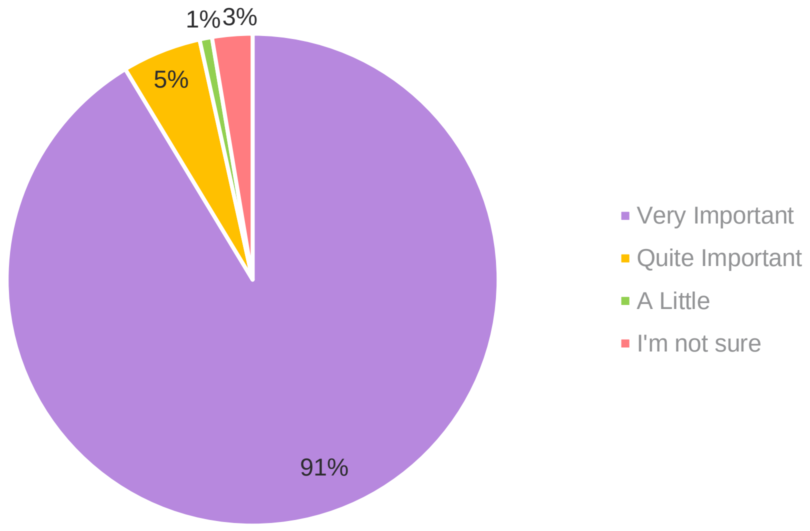
[18] Mencap
[19] Human Rights Act (1998)

**Figure 25: How important is it that we take your views into account to improve services?**



### Active citizenship

### Support options that include building-based supports

Building based services were something people felt were important to them. This question had a higher percentage of quite important responses in comparison to previous questions but still indicate this is a service people are keen to have. Figure 26 show the full percentage of responses.

Different types of comments were received in relation to building based services with the majority being very supportive:

> People with a Learning Disability should be able to meet and socialise with peers and be supported by skilled staff in building based services. In the development of any new such service it will be important to consider the sensory and communication needs of potential users and that consultation with parents and Guardians is undertaken at the earliest stage.

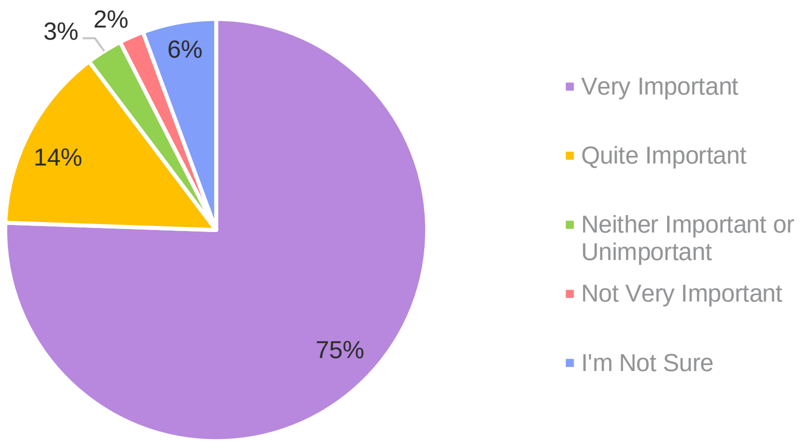
> You really need to address the issue of access to peers and learning opportunities for people with complex needs. A building-based service is a start and a welcome commitment.

> Will I be safe at the building-based services if you let people without a diagnosis in?

> What we really need in South Ayrshire is a day centre.

The feedback would reflect that this proposal is something families and community members feel is needed within South Ayrshire and the feedback informs us that those who will access it want to be part of the consultation process.

**Figure 26: How important is it to have a range of support options that include building-based supports**



### Digital services and socialising

Over the course of the COVID pandemic people moved to using more digital services to interact and connect with friends and families as social distancing stopped us being able to meet face to face. As we increased our use of digital services with many people still using this as a daily form of connecting, it was an important aspect to consult with participants and gain their views.

Similar feedback was found when participants were asked their views on digital supports compared with technological supports with independent living. 65% felt it was very important to them that people are taught how to use digital services to socialise. 18% felt it was quite important, 9% were not use. There was 3% of participants who felt it was not important to them and also 3% who felt it was a little bit important to them and only 1% felt it was neither important nor unimportant.

For participants who felt it was of importance to them they advised that this is because…

---

*"It is good to keep in contact as circumstances change and often opportunities may be missed if not passed through the group."*

*"More classes [are needed] for people to use iPads and connect with families."*

---

However, some were concerned that digital inclusion was not a way to socialise, particular with people who may have more complex needs:

> *“Digital inclusion just doesn't cut it for folk who need to be included in a physical way because their communication needs are such that they cannot make much use of digital interactions. Lack of transport to venues and places is a significant barrier.”*
>
> *“Not everyone can be taught to use digital devices.”*

This feedback would indicate that the use of digital service may be a good provision for some but would need to be on a person-centred basis as not everyone may want or be able to be supported in this way.

**The League of Champions**

The League of Champions are a group of people who have come together to champion the rights of people in South Ayrshire living with a learning disability.

Participants were asked two questions relating to The League of Champions. These were “How important is it that the League of Champions are involved in making decisions?” and “How important is it that we work with the League of Champions to make our paperwork easier to understand?”

Both these questions had a higher response of participants selecting that there were unsure which is shown in figure 27. Comments received may explain why this present as a higher percentage within these questions comparison to others…

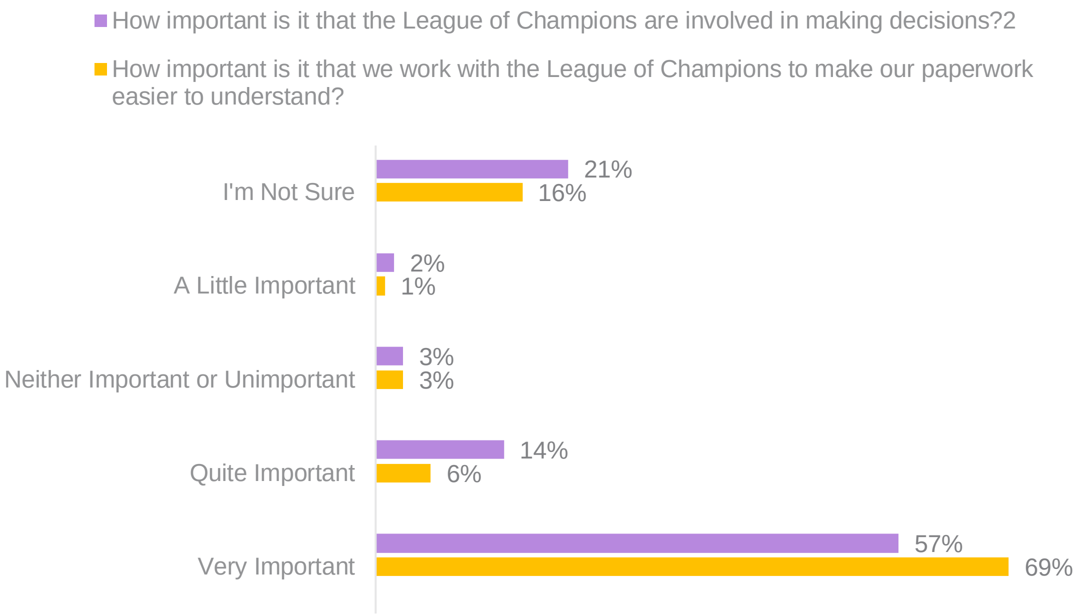
I don't know who the league of champions are and how they could improve my life.

I have no idea how the Board of Champions was selected or how to feed into that forum ongoing if it becomes the voice for local people with learning disabilities

Who is the league of champions?

From these comments we can reflect that we should provide more information to the local community of the League of Champions to ensure everyone has an equal opportunity to be involved and know what work this board undertakes.

**Figure 27: The League of Champions**



## How important is it that we ask people at least once a year how we can make services better?

For those who receive formal service they will have a review on an annual basis to see if their services are still meeting their needs or need to change. When participants were asked how they felt about reviews on an annual basis, 71% felt this was very important to them. Some reflections on this question included:

> *"Regular feedback is essential to avoid complacency All people have a part to play if they wish. Extra support should be offered to those that want/need this."*
>
> *"People and strategies change all the time, people need to be asked how they feel, what support they need, how they want to live to improve services for all"*
>
> *"Everyone receiving care should receive a copy of the national strategy keys to life. If during the lifetime of that or any localized strategy it is found it is found by someone to have missed an element of importance there should be a route to record that need as it occurs rather than waiting for the review period."*

While people mostly agreed reviewing on an annual basis was the right thing to do there have been some reflections that when circumstances change people may need to be reviewed on a more frequent basis.

**How easy was it to understand the strategy?**

They strategy was developed in an easy read format to ensure it was accessible to a wider range of people within the community. Although there is the easy read version, there is more context and in-depth information provided within the strategy. The feedback from participants has been mixed regarding how easy they felt it was to understand (Figure 28) but there has been limited supplementary comments left to advise what may not have been easy for individuals. This makes it challenging to adapt and change elements of the design and context as it’s not clear from responses what people may have found unhelpful within the strategy.

What we do know is that people feel the following could be improved to help set the context better for them:

Some facts are too small. Everything should be legible - even to those with limited vision.

When it comes to more information on our strategy, instead of full page written or typed up words break it down to paragraphs. It should be more graphics and all easy-read. Overall, the design, it looks plain, needs more colourful, to make them actually want to read it. I would say it looks confusing inside.

To make the content of the strategy more user friendly and easily understandable.

Absolutely excellent presentation of a strategy. Only comment is about 'citizenship'

Communication needs are not addressed anywhere in the strategy in terms of practice and service delivery. Systems like symbols, visual timetables, talking mats, Makaton training, communication apps and environments that are

More than half of the participants felt that the overall design of the strategy was good (figure 29). Some feedback can be shown where people have been recommendations for changes to make the strategy look more user friendly. These suggestions of font change are recommendation that will be adjusted in the final version of the stagey.

More pictures and broken down a little bit into shorter sections.

[Make it] Easier to read

Purple writing on purple on page 15. Couldn't read it. Easy read is too simple and closer look to hard to understand for me.

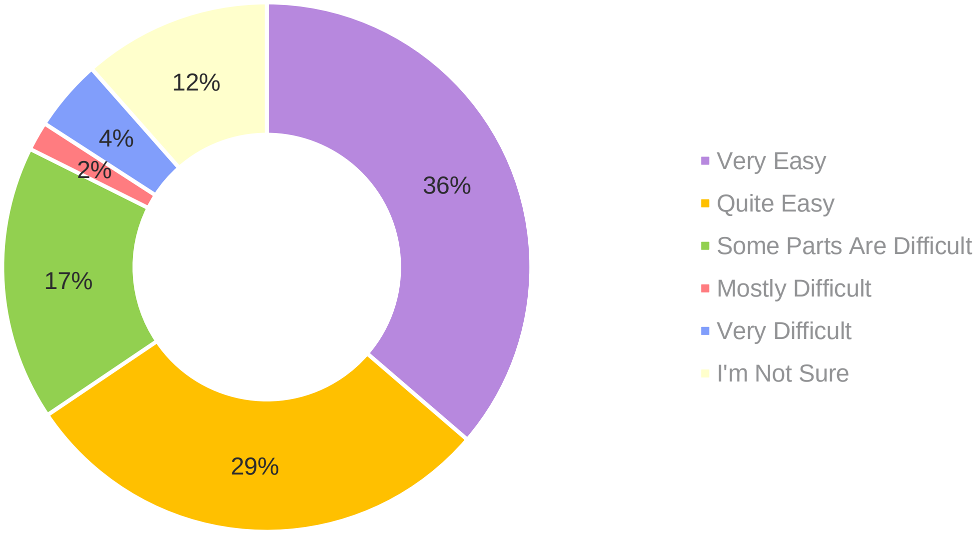
Bigger writing paragraphs

No, it covers every aspect clearly and is easy to read.

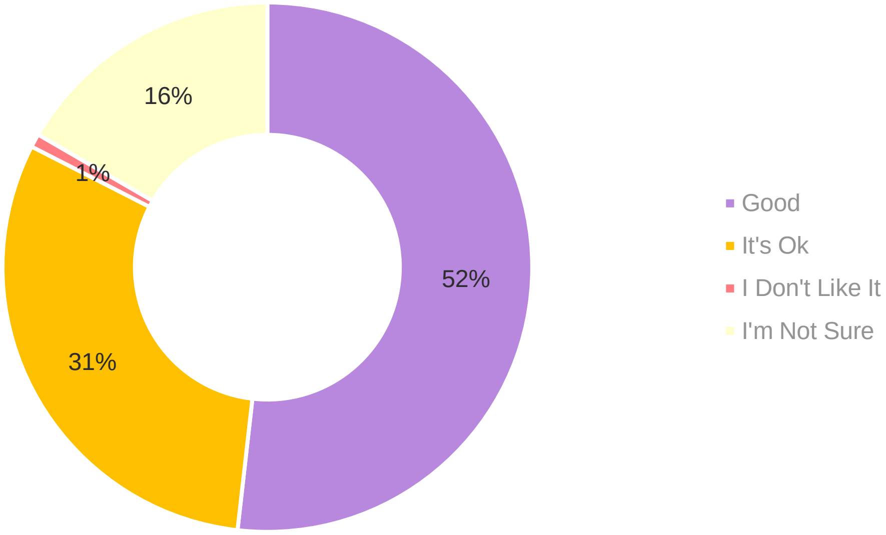
Some bits are hard to read, page 15 tiny text

Bigger writing paragraph

**Figure 28: How easy is it to understand the strategy?**



### Figure 29: What do you think of the overall design of the strategy?



### Public Health Response

The NHS Ayrshire and Arran Public Health department chose to submit a group response to the strategy. They found the strategy to be comprehensive and clear and welcomed the focus on reducing inequalities, early intervention and prevention, being fully supportive of the aims and goals of the strategy. They were also positive about the fact that the aims of the strategy were identified through consultation.

Public Health asked that the following points be considered in the final strategy document:

- COVID recovery plan: include the whole spectrum of healthcare services including dentistry.
- Importance of oral health: Dental services would welcome ongoing conversation regarding the support provided to adults with learning disabilities to access dental services, considering the work the Public Dental Service undertakes, but also how we can support our independent/high street practitioners to provide high quality care for the individuals and their families. We would welcome opportunities to discuss the national oral health programme further should local groups be interested in taking this forward.
- Nutrition: feedback suggests people would like more information/support on nutrition however there doesn’t appear to be anything in the “what we are going to do” section to address this.
- Health literacy: We know that people who have a learning disability are at greater risk of having lower health literacy and we note that the strategy does recognise that some people with a learning disability may need support to understand information. We would recommend that actions to address health literacy – including the development and design of services and supports – be a feature that underpins the strategy and actions and implementation.
- Digital Inclusion: The specific action relating to ‘Choice and Control’ regarding activities and groups being promoted on South Ayrshire Lifeline, so that people know what is available, will likely require additional action and support to ensure digital inclusion – access to digital, ability to use digital and act on the information – all whilst supporting people with a learning disability to be safe online.
- Volunteering: Where there has been suggestion about creating volunteering opportunities, this does not appear to be followed up, neither do comments on lack of specialist groups and the review of eligibility criteria.

## Draft Strategy Focus Group Report

Focus groups were held in person and online using Zoom to gather people’s views on the content and layout of the draft Learning Disability Strategy. These focus groups were hosted by Mark McKinlay from the HSCP and Catriona Rowley from the Scottish Commission for People with Learning Disabilities.

There were 5 in person focus groups held in:

| | |
|---|---|
| Ayr (Group 1) | Wednesday 6th April 2022 between 10am and 12pm |
| Ayr (Group 2) | Wednesday 6th April 2022 between 10am and 12pm |
| Troon | Wednesday 6th April 2022 between 2pm and 4pm |
| Maybole | Thursday 7th April 2022 between 10am and 12pm |
| Girvan | Thursday 7th April 2022 between 2pm and 4pm |

Due to the size and spread of South Ayrshire, these locations were chosen on a basis of geographical location and ease of access for residents.

There were 4 scheduled Zoom focus groups, however participants only subscribed to 2 of the groups. These were held on:

- Monday 4th April 2022 between 10am and 12pm
- Monday 4th April 2022 between 2pm and 4pm

Over the course of this process, we engaged with:

- 24 individuals in total
- 12 of whom were parents, guardians, or family members
- 12 of whom were people with learning disabilities
- 6 of whom were representatives of the League of Champions

### Layout

Overall, people were very positive about the layout of the Draft Strategy, with comments including:

- “I think the pictures were really good, I can understand what the strategy says”
- “The Glossary at the front of the strategy booklet makes it easier to understand what is going to be spoken about throughout the booklet”
- “I like the colours and the high five on the front cover”
- “I like the look and layout of the strategy”
- “I like how some of the strategy is in easy read and some of it goes into more detail”
- “I like the structure of the strategy and think it is important to let people that read the strategy know Where? When? Who? Why? How?”
- “The easy read version of the Strategy is good and meets the needs for the people with learning difficulties to understand it’
- “I like that the Strategy is shorter, much easier to read, and less daunting than the previous document”
- “The colours make it look inviting and friendly”
- “I liked that there were lots of pictures and could understand what it said”

### Layout – Additional Feedback

- “Going from easy read to lots of words was difficult to understand”
- “I struggled to read page 15 because of the font sizes and the colours used”
- “The Glossary can seem a bit overwhelming at first glance and perhaps needs to be spaced out a bit more”
- “I think it should have picture throughout it not just the first part”
- “There was a lot of text to read, and it was quite hard”
- “Spacing within the booklet was a bit too close together and this made it a bit difficult to read in some areas”
- “Some of the info graphics are too small to read”
- “The font should be the same size throughout the document”
- “Some of the lighter colours make areas difficult to read”
- “Subheadings could really help to signpost people through the longer parts of the document. Break it up a bit more”
- “It should be properly formatted for online screen readers to pick up”

### Priorities

Participants were asked about the contents of the strategy and about the four priority areas:

- Health and wellbeing
- Choice and control
- Living independently
- Active citizenship

Comments received included:

### Health and Wellbeing

- “Everyone with a learning disability should have a Learning Disability passport and also a Fastrack Number which would allow people to be seen more promptly in hospital, which would reduce stress and anxiety for them and their carers”
- “Hospital Passports were put in place before by the Scottish Government or local councils, but they have not been fully implemented”. *A minute from a meeting in 2004 where this was discussed was produced to back up this statement.*
- “Health Passports are definitely a good idea, it’s something I could keep on me in my wallet and could bring it out if it was needed”
- “I like that it says you might need more help as you get older, it’s hard to keep healthy”
- “I would like to see better information on NHS appointment letters” and gave an example where her son had received a letter which did not mention he might need an injection. On attending the hospital, he needed an injection. This caused stress and anxiety for both.

### Choice and Control

- “I don’t want people to make decisions for me, I can decide for myself. I wasn’t fully involved in my care choices before and I think that should change”

- “I used to be able to go on cruises and coach trips with Scottish enablement with staff and friends and don’t get this anymore and it’s something I miss”
- “When you left school there was only one college course people with a learning disability could do, and I believe it is still the same. There needs to be more options for training and courses.”
- “I was never explained the choices of SDS and now know I am on option 3 *(4 options were explained to group during the focus group*s) I would like more involvement and control over what care I get.”
- “I think option 3 is used because the social worker knows it’s the best option for the person, but they don’t explain this at the time or allow them to decide.”
- “There should be more clarity around who the Health and Social Care Partnership are, and this would allow people to go to the right place for the right information as a lot of people still think of the council and NHS as different entities when talking about care”
- “I’m not sure what self-directed support is and would like better information about what it is and how to use it.”
- “It is important to improve current plans regarding transitions.”
- “Planning previously has been messy with transitions from school to adult social work.”
- “I feel starting transitions (for non-complex) at 14 isn’t a great idea, my son school until he was 19. All those meetings and documents that went into it were person centred for him between 14-19.”
- “I feel young people can disappear at 18 due to a lack of planning and transitions.”
- “A lot of opportunities have been taken away which has made transitions harder for people.”
- “Maybe if there was volunteers rather than the council (HSCP) having to pay for staff there might be more flexible support to offer.”
- “A carer turned up at my house to support a family member while I went out to work, when I returned, a different carer who I had never met was there”
- “Schools need to be better at supporting people so that adult services don’t need to pick up the pieces so often”

### Living Independently

- “I want a social experience, somewhere to go where I can just be.”
- “I want a care worker that likes to do what I like to do… going walks, watching movies etc.”
- “I want somewhere to go and somewhere to be included.”
- “I have seen people out with carers instead of friends.”
- “Page 25 of the strategy mentions people spending time with support workers instead of peers. But they need to get the balance of support and peers right. There is still a lack of good support for people with communication needs in this area. Touchbase run by sense is a great service, but it is in Ardrossan.”
- “Contact with peers is missing from the strategy, many people remain totally isolated and people who take time to adjust, post covid need the support to reintegrate and need time to get familiarised to new surroundings.”
- “The strategy does not talk about support for people with more complex needs: people with more complex needs need consistency and support as well as stimulation and challenge and to have peers. This needs a building.”

- “I don’t always feel safe when out and about or in the house and feel isolated from others.”
- “I would like a commitment around the keep safe scheme.”
- “I would like a directory of activities as I don’t subscribe to social media.”
- “My son waits for me at the bus stop when it is dark because I am afraid of the dark and this helps me to feel safe.”
- “The Keep Safe Scheme would be good.”
- “The strategy says people that people are getting pre covid levels of support, but this is untrue.”

**Active Citizenship**

- “I used to be able to go on cruises and coach trips with carers and friends but this doesn’t happen anymore and it is something I miss and know others do too”
- “Covid has depleted a lot of social opportunities and many have not started back, are opportunities going to come back?”
- “There needs to be a main site that we can access all the different groups and events going on in Ayrshire. Some people know about some but I’ve been told about things my social worker doesn’t even know about.”
- “The South Ayrshire Lifeline website isn’t very easy to use or to find things. The search function isn’t very good and having to search South Ayrshire Learning Disability team isn’t likely to be what people would search.”
- “Annual or six-monthly leaflets with all social groups, activities etc. might be the best option as not everyone uses the internet”
- “I have been using digital equipment to see friends (during COVID) but I like to meet up and see people.”
- “Lots of us used to go to Active Sport, it was a very safe space for us and we would see friends and be healthy but it is no longer there.”
- “The strategy should have a bit that says we will uphold people’s human rights.”
- “There is a lack of individual advocates within the area, and this should be addressed within the Strategy.”
- “When are we going to be consulted on day services?”
- “How would we get access to Equality Impact Assessments? – would these be sent out or would a link be included in the Strategy?”
- “I have seen some carers spending time on their phones and not paying attention to the person they should be looking after.”
- “I had a carer turn up at my house to support a family member who was visibly tired and said they’d been on night shift. This does not inspire trust.”
- “I had to live with my mum for two years during COVID so she could support me.”
- “I would like guarantees that any supports reduced due to the pandemic or for other reasons would be re-instated.”

**Additional comments made:**

- “The Strategy is very ambitious. What would be the timescales to implement the areas identified?”
- “The strategy is easy to understand and enough is being said within it.”
- “It looks good on paper, but the content is more important. What difference does it really make to us?”

- “There should be better training for care staff.”
- “There should be quality assurance written into commissioning. That would ensure that all commissioned services have well-trained staff”
- “The approach is too risk averse.”
- “The strategy lacks punch. It needs timelines and to say what will actually happen.”
- “The Strategy needs more about communication support and more about complex needs.”
- “The actions need spelled out better.”
- “There needs to be a complex needs protocol.”
- “There needs to be honesty.”
- “There is a lack of trust that this Strategy will change anything.”
- “It would be great to have services South Ayrshire could be proud of.”
- “Commissioning is a weakness in the strategy.”
- “There is a worry that new elected members will be told by senior staff that this is a great strategy and believe them without any real knowledge.”
- “I am generally encouraged by some of the strategy but there is nothing new in it.”
- “It has no teeth; it needs to say how and when things will happen.”
- “The strategy doesn’t mention helping or supporting people who are at risk of coming into contact with the criminal justice system.”
- “I would like all staff trained how to use zoom to allow them to support her son with this.”
- “I would like a commitment that all staff, carers, and clients be trained in Makaton.”

**Analysis**

Within the focus group several topics were reoccurring between groups. People were keen for there to be better and consistent information about local groups and activities and emphasised that due to COVID there has been a breakdown of information being shared about opportunities for people to attend in the community. A consensus of the groups was that from the Strategy there is a commitment to ensuring everyone in South Ayrshire can access information from one main location that is easy to access.

Groups also highlighted the lack of information that can be provided to them regarding Self Directed Support options. There were instances during focus group 2 at Ayr where three people believed they/family were not in receipt of SDS as they were provided traditional home care and were surprised to learn this is option 3. People were keen for there to be better collaborative work between service and clients to fully involve them in controlling their own care.

People expressed that they felt community safety being included within the strategy was a very positive action to have. Some people at the groups who have a learning disability advised they live on their own and want to feel safe, with others also informing they live in deprived areas and would prefer to live somewhere safer. One individual and their parent expressed limited supporting housing options in Ayr with only Blackwood Group offering a two accommodation blocks in town. This person advised they felt they had to accept their current property as there was no other suitable options and are not happy where they live due to their neighbours. People expressed they want to have more choices and control over where they live and want this to be reflected in the strategy more of how this would be achieved.

There was a large discussion regarding education, training and job opportunities for people in South Ayrshire with a learning disability. Many felt there has been a lack of opportunity when leaving school and historically were only given 1 option of collage course to undertake.  People reflected that if they could access better courses that offered things such as numeracy and literacy then they may be able to seek employment or voluntary work. Individuals advised that Enablement offer support, but they are based within Kilmarnock, and it is not ideal for people living in south Ayrshire due to travel. There was a welcome support of the actions around education, training and employment as people would like there to be more information what actions are going to be to support the learning disability community with these areas.

Transitions were an area that individuals and families felt there needed to be a significant change as the current process is not working well. Experiences were shared where people had been unsupported at age 18 and provided no real options when leaving school. Others felt that they started too early with their children at age 14 as it was years of meetings that resulted in the family feeling they were not person-centred and more of a tick box exercise. Many people advised they wanted more to be put into the strategy regarding how the HSCP will be working towards improving transitions and were happy to learn at the focus groups that steps have already been taken to employee a dedicated senior social worker to manage and develop transitions.

People were very welcoming of the draft strategy with many saying it is needed. People did express that they feel there needs to be more information about the actions being taken, with some people also expressing that there is a lack of trust from the promises made. People within the groups expressed views that there need to be more clarity of what the plan is setting out and what steps will be taken to implement actions. Several people have asked of time scales on the actions points.

Emails were received by two parents following their attendance at a focus group to advise they would like to be part of any consultation on building-based services, they would like to see timescales for the actions and would like a specific pathway for people with complex needs.

Others have suggested design changes that may improve everyone’s ability to understand the contents within the document.

## Draft Strategy Third Sector Feedback

Third sector stakeholders were asked to participate in an online focus group to gather their organisational views of the learning disabilities strategy. 6 organisations participated and JamBoard (figure 16) and Padlet were used as an engagement tool to gather their views.

The organisations that were participating withing this event were:

- Enable,
- Ayrshire Independent Living Network,
- Hansel,
- Circles Advocacy
- Key
- VASA

The third sector organisations left the following comments for each section of the priorities within the strategy.

**Health and Wellbeing:**

| | | |
|---|---|---|
| baseline of measurements | 10 pages limit was good | Strategy written collaboratively, does it need big focus on whothe partnership is? |
| Effects of Long COVID | Welcome the inclusion of older people with learning disabilitiesand older carers within the strategy | Is there a South Ayrshire wide plan to roll out trauma informedpractice? |
| Health passports-maybe more awareness training neededaround this for hospital staff | Training required for staff on trauma informed practice. | Managing expectations for support |

## Choice and Control

What Matters To You

Self Directed Support

Self Management

More information is required on SDS

A more streamline transition from children services to adult services

## Living Independently

Transitioning into Independent Learning

The strategy references the role of parents, is there plans toexpand on this and do more work to involve parents more and inparticular parents with a learning need or disability

I live in a rural village, will I get the same services as people inthe main towns?

Do I have access to the assistive technology/equipment I need to live independently?

## Active Citizenship

What / Who are 'Thriving Communities?'

## What can your organisation do to commit to the priorities?

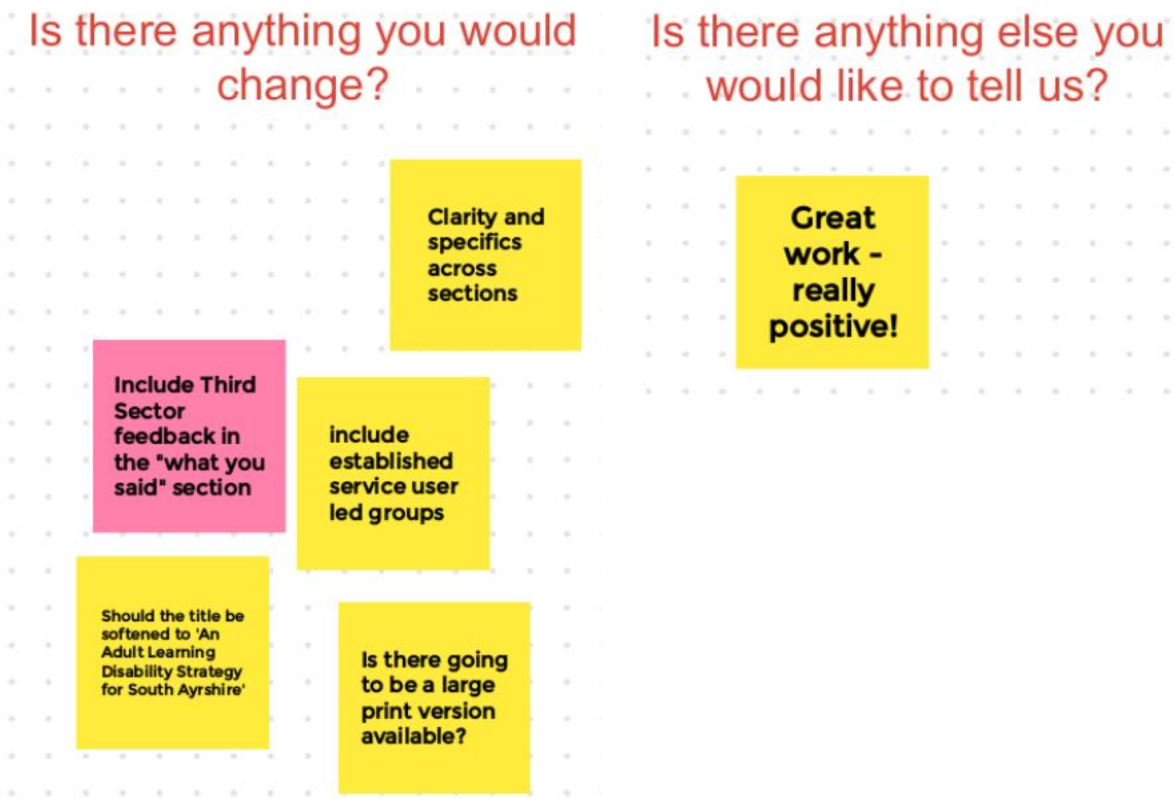
The last part of this section asked the third sector organisations to feedback what their organisations will be able to commit towards the priorities. The feedback was as follow

Third sector networks could join League of Champions as onebig group rather than having separate groups doing the samething

Can third sector have a place to add their own comments within the strategy?

Advocacy would be available to support people to review/createanticipatory care plans

**Figure 16: Jamboard Comments**



Is there anything you would change?

Clarity and specifics across sections

Include Third Sector feedback in the "what you said" section

include established service user led groups

Should the title be softened to 'An Adult Learning Disability Strategy for South Ayrshire'

Is there going to be a large print version available?

Is there anything else you would like to tell us?

Great work - really positive!

The feedback from the participants within the third sector focus group provided valuable feedback. 89% of the participants agreed with the vision with only 11% (1) advising that they were not sure. 100% of participants felt the priorities were right and 100% reported that they think the overall design of the strategy is good.

The comments made follow similar themes from the surveys and previous focus groups with community members and highlight the importance of making small design changes and including extra information about topics such as SDS, Thriving Communities and Health Passports.

The Third Sector organisations feedback shows that there is some interest for further participation from the groups which would strengthen the relationships with organisations have within the strategy.

## Final Thoughts

The survey has been met with mainly positive comments from the 117 participants that took part. Comments for noting is the level of respondents that were supported to complete the survey that have minimum to no comments attached. 30% were supported by a paid carer or advocate and 21% were supported by a family member and 18% had their survey completed on their behalf. Only a small minority of these surveys answered questions with a response that would indicate there were elements they were not happy with and within these surveys further feedback to improve the survey would have been beneficial.

From the comments received we know that moving forward we need to:

- Improve some of the design elements to be fully readable to everyone

- Provide more context around priorities
- Include more context around the League of Champions

Participants have expressed their warm welcome to the Learning Disability Strategy with several feeling it is something that needed and are keen to see how it progresses over the 2022-2027 period.