

# DRAFT

Enc. 2.1

## Living well with a learning disability on the Isle of Wight

Public consultation

1<sup>st</sup> December 2017 – 31<sup>st</sup> January 2018

Summary of feedback

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## Introduction

It has been a long-term ambition of the Isle of Wight Council, Isle of Wight Clinical Commissioning Group (CCG) and Isle of Wight NHS Trust to co-produce with people with a learning disability and their families a strategy to support adults with a learning disability, autism and/or challenging behaviour living on the Isle of Wight.

In January 2017, a Peer Review of the Isle of Wight's learning disability services was commissioned, and the resulting report from their visit recommended development of this strategy.

Initially we sent out a questionnaire asking people with a learning disability what was working well and what was not working well for them on the Island and what was important to them.

People with a learning disability told us that the three areas most important to them were;

- Living my life
- Keeping safe
- Staying healthy

Therefore these are the three main aims that the strategy has been based on.

The strategy also includes our joint Hampshire and Isle of Wight transforming care plan, and follows national guidance, including;

- [Transforming Care](#)
- [NICE Draft Guidance – Learning Disabilities and Behaviour that Challenges – Service Design and Delivery](#)
- [Building the Right Support](#)
- [Guidance for Commissioners](#)
- [National Service Model](#)
- [Valuing People](#)

Following this initial engagement, the draft strategy was co-produced with the Learning Disability Partnership Group. The draft strategy was then published for a two month consultation period to enable people with a learning disability and their families to further contribute to the coproduction of the strategy.

Nine consultation events were scheduled with members of the Integrated Commissioning Unit attending with representatives from People Matter IW and an expert by experience. During this time the Learning Disability Partnership Group also met to discuss the strategy and progress of the consultation. People were encouraged to share their views on the telephone, or via email or written correspondence, or by completing a survey, on paper or online.

The consultation was publicised through the Isle of Wight Council, NHS Trust, Clinical Commissioning Group and People Matter IW web pages and newsletters, as well as through the local media, and social media channels with a wide local reach.

This report reflects the opinions and views shared through the consultation period. This has been divided into three sections;

- feedback from consultation events
- the easy read survey
- the longer survey.

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## Consultation Events

During the consultation period, two public consultation events were scheduled, alongside seven visits to speak to focus groups within a school, a college, residential providers, day opportunity providers and a self-advocacy group. Attendees included people with a learning disability, their families and carers, staff, and wider stakeholders.

Due to the nature of some of the events, it was not possible to collate exact numbers of attendees. However, over 116 people were consulted, including over 78 people with a learning disability. A breakdown of events and attendees can be seen below.

1 <sup>st</sup> December 2017	Public Consultation Event	32 attendees, including 15 with a learning disability and 6 family carers
20 <sup>th</sup> December 2017	Haylands Farm and the Phoenix Project	20 attendees, including 15 people with a learning disability
9 <sup>th</sup> January 2018	People First	9 people with a learning disability
11 <sup>th</sup> January 2018	Ryde House	4 attendees including 3 people with a learning disability
12 <sup>th</sup> January 2018	Way Forward	Responses collected from 9 people with a learning disability <sup>1</sup>
16 <sup>th</sup> January 2018	St. George's School	6 attendees, including 5 young people with a learning disability
29 <sup>th</sup> January 2018	Public Consultation Event	3 attendees, including 1 person with a learning disability and one family carer
30 <sup>th</sup> January 2018	Pathways, IW College	22 attendees, including 13 people with a learning disability
1 <sup>st</sup> February 2018	Kingston Farmhouse <sup>2</sup>	11 attendees, including 8 people with a learning disability

A flexible approach was adopted during the consultation events, to meet the needs of the attendees.

Recurring themes included;

- safety concerns, especially regarding Southern Vectis and Newport Bus Station
- benefits information and advice
- employment – although fewer people raised employment support with the team, those who did expressed it as a high priority
- reasonable adjustments within healthcare, particularly within hospital

There was also discussion about making the easy read survey accessible to a younger audience.

<sup>1</sup> Members of the Isle of Wight Council, CCG and People Matter IW attended Way Forward during a busy lunch period. More people were consulted, but responses were not able to be collected from all participants.

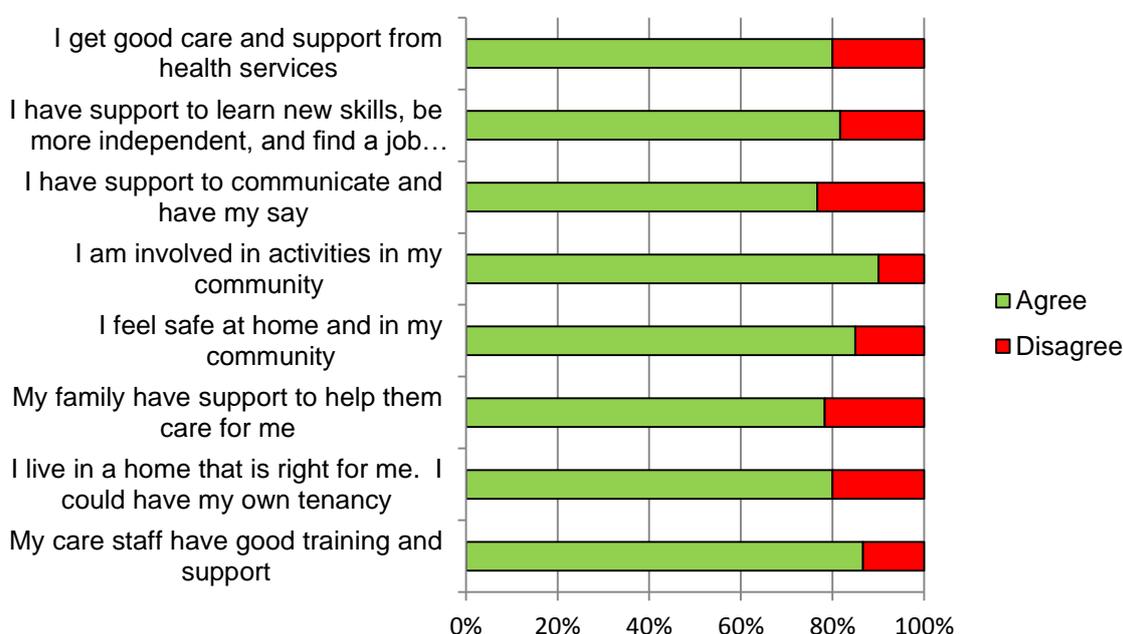
<sup>2</sup> Although the consultation period ended on 31<sup>st</sup> February 2018, it was agreed to reschedule the event at Kingston Farmhouse in the interest of accessibility and inclusivity.

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During the public consultation period, 60 people with a learning disability were taken through the Easy Read strategy, and in particular the section 'What does it all mean for me?'. They were asked whether they believed it was important for themselves and others living with a Learning Disability to be able to say the following eight statements;

- My care staff have good support and training
- I live in a home that is right for me. I could have a tenancy agreement
- My family have support to help them care for me
- I feel safe at home and in the community
- I am involved in activities in my community
- I have support to communicate and have my say
- I have support to learn new skills, be more independent and find a job or volunteering
- I get good care and support from health services

The graph below illustrates the responses to that question.



These results were reflected in people's individual comments;

*'I like everything.'*

*'The document is quite good.'*

Feedback was also received from Autism Inclusion Matter (AIM) Isle of Wight, the Isle of Wight NHS Trust, residents from Southern Housing Group, and the Jobcentre Plus

Gaps included;

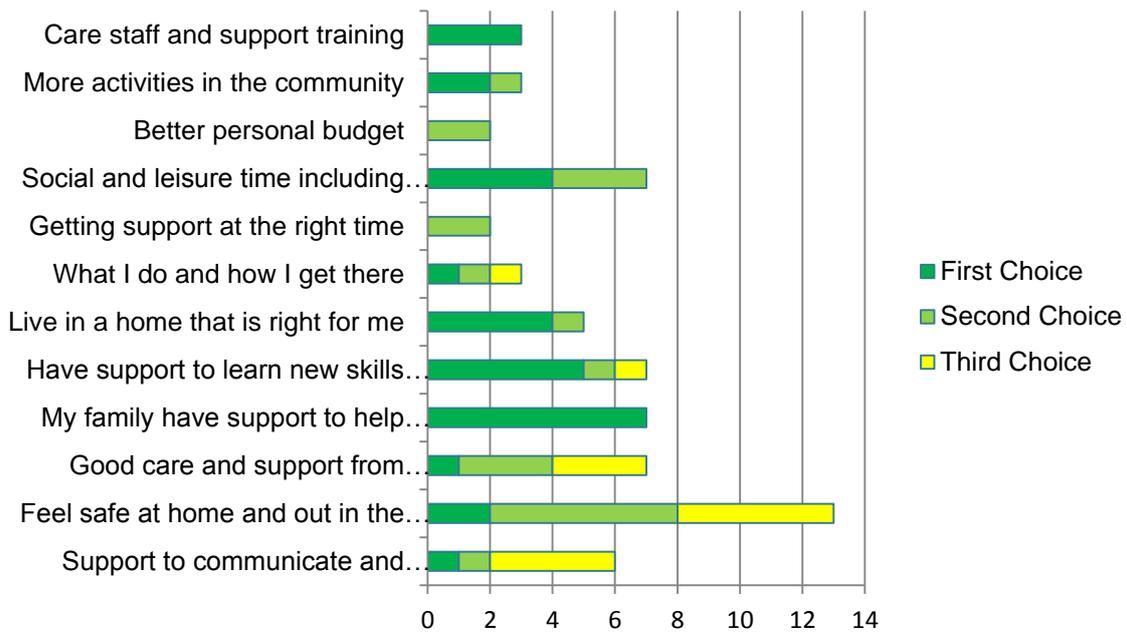
- Safety online
- A focus on women and girls' health screening and pregnancy
- Support for parents with autism.
- The importance of volunteering as well as employment
- Safeguarding
- Housing information

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## Easy Read Survey

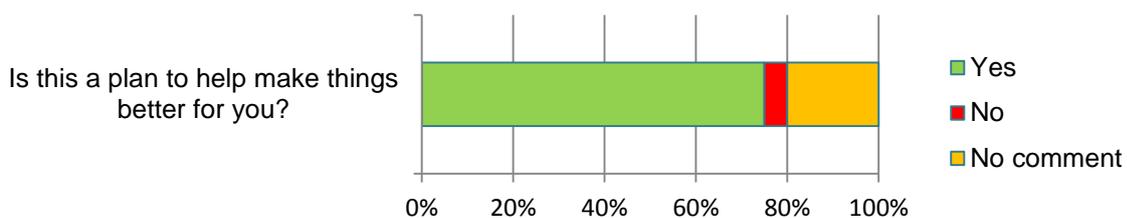
People Matter IW received and collated 21 responses to the easy read survey. All responses advised that they were from someone with a learning disability. The survey requested that people chose a first, second and third choice of the twelve action points from the strategy, of what were the most important things to them.

The graph below illustrates the response to that question.



Comments received were mainly positive about the plan, and agreed with expanding the housing options in particular.

Respondents were then asked if they believed that the plan would make things better for them. Responses are illustrated in the graph below.



Comments included;

*'Quite good. Gives some hope.'*

*'It is the start of a good plan.'*

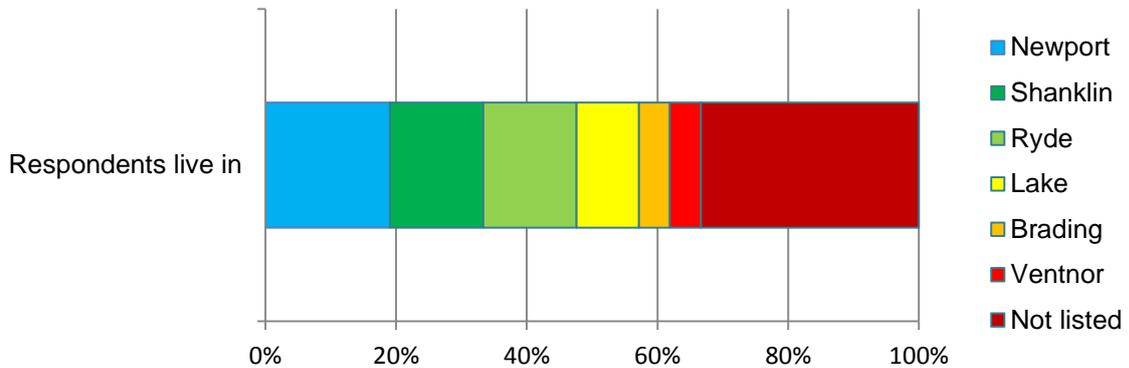
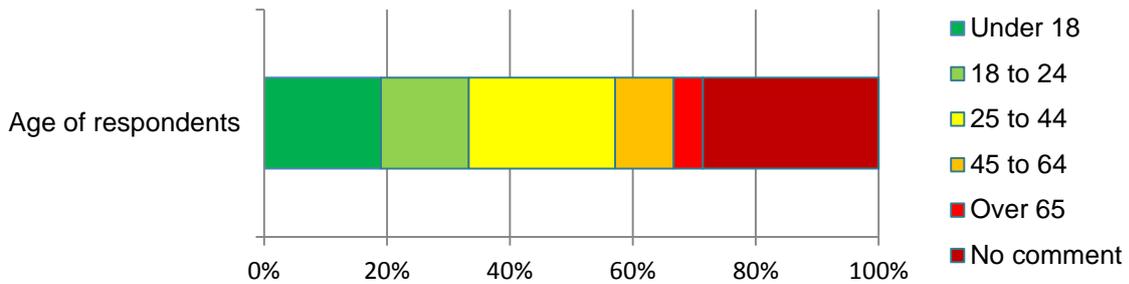
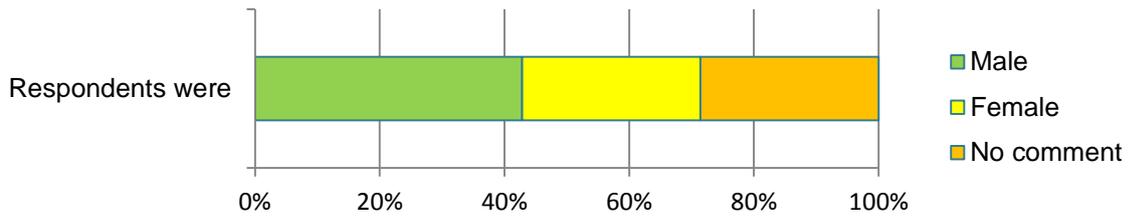
*'It seems to be quite a good plan.'*

Respondents were then asked 'how can we make this plan better? Answers included the following themes:

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- Remembering that people with learning disabilities can also be carers, and offering the relevant support
- Transport
- Making the document more accessible
- Support with independent living skills.

The respondents were also asked to provide their gender, age, and their nearest town. Responses can be seen below.

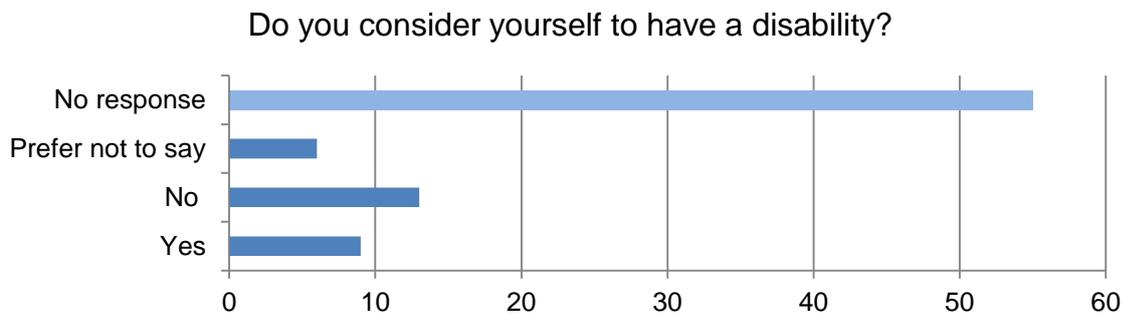
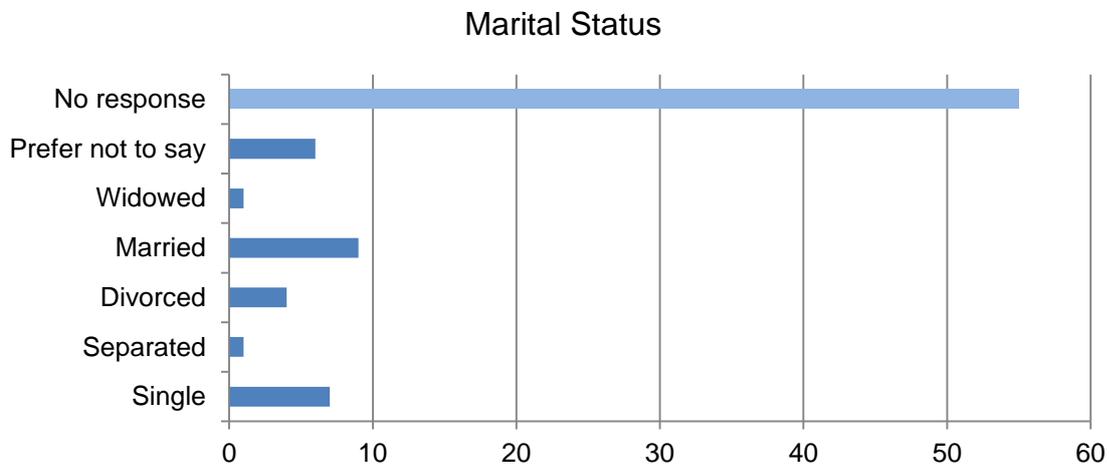
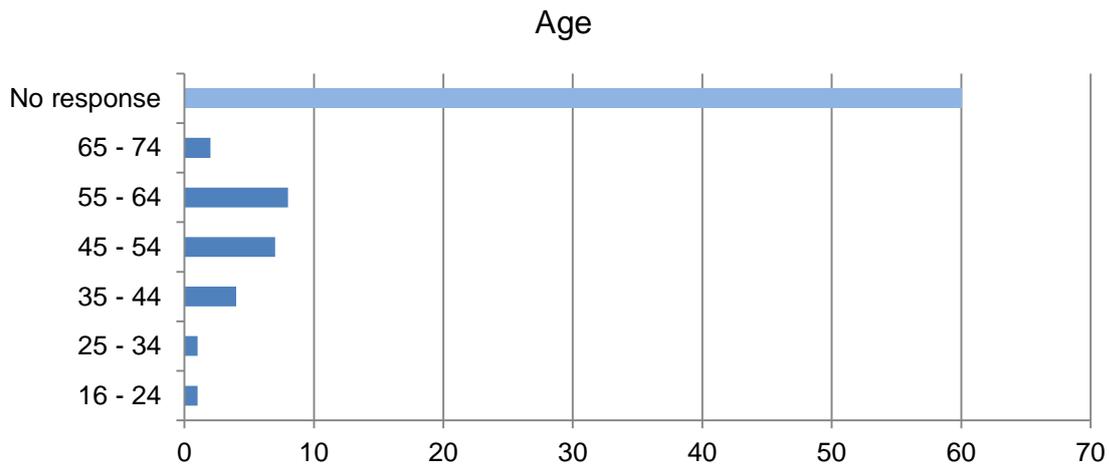


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## Longer Survey

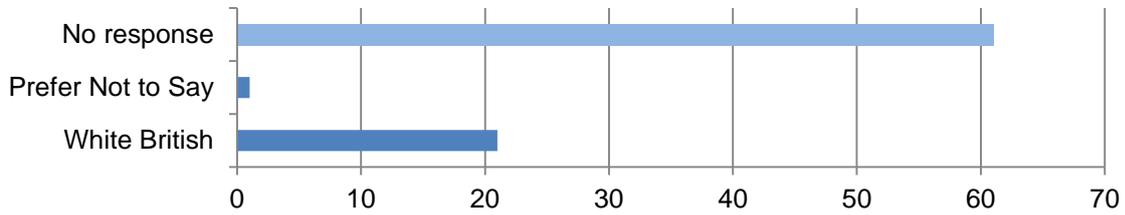
A longer survey was available, both as a paper copy and online. 83 responses were collated.

The respondents were asked to provide their gender, age, marital status, and other details. Responses can be seen below.

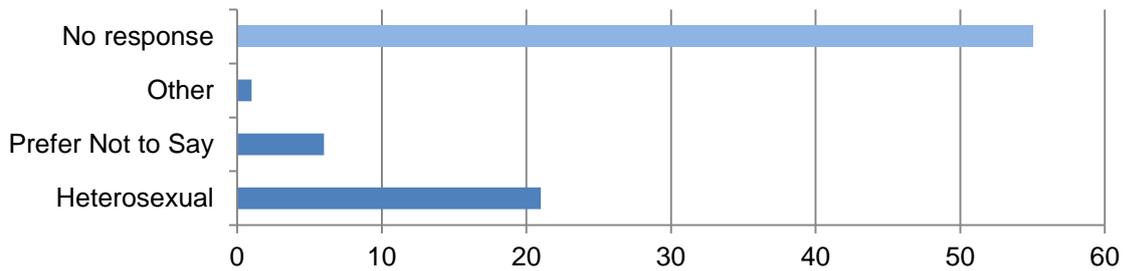


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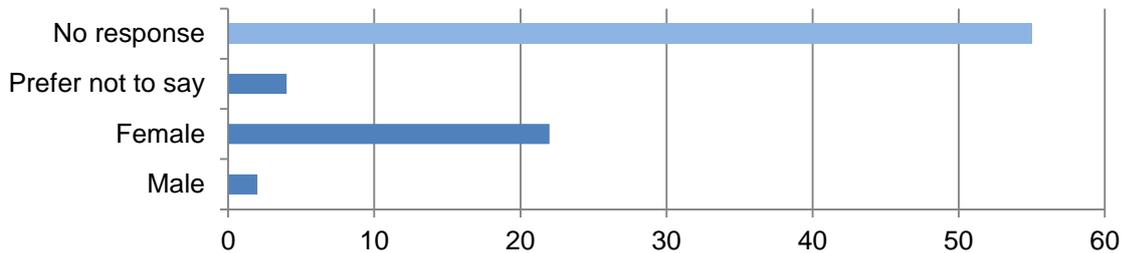
How would you describe your ethnic group?



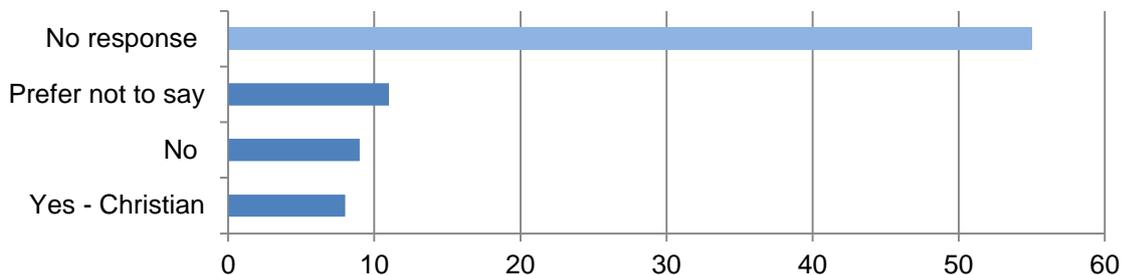
Which of the following options best describes how you think of yourself?



Which of the following options best describes how you think of yourself?



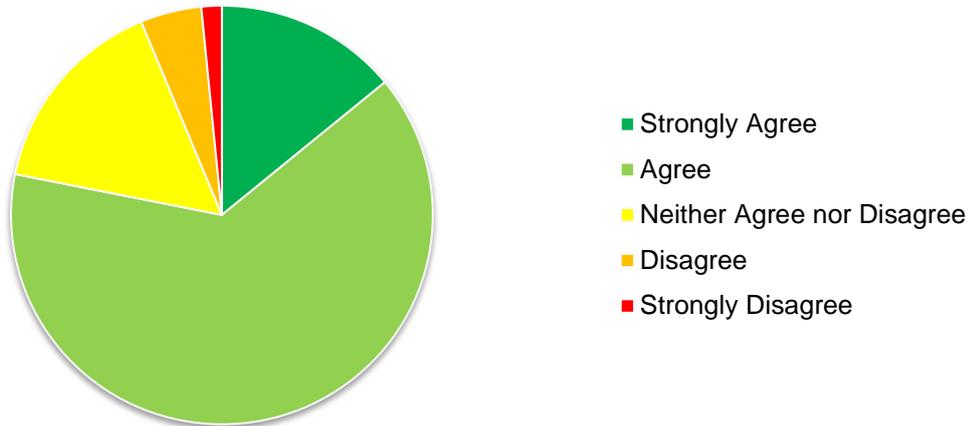
Do you have a religious belief?



Respondents were asked 15 questions, ranking answers from strongly agree to strongly disagree. The charts below represent their responses. Respondents were also given the opportunity to provide more detailed feedback, and this is also collated below.

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1. Do you agree or disagree that *Living Well with a learning disability on the Isle of Wight* sets out a good plan to help improve services for people with a learning disability on the Isle of Wight?



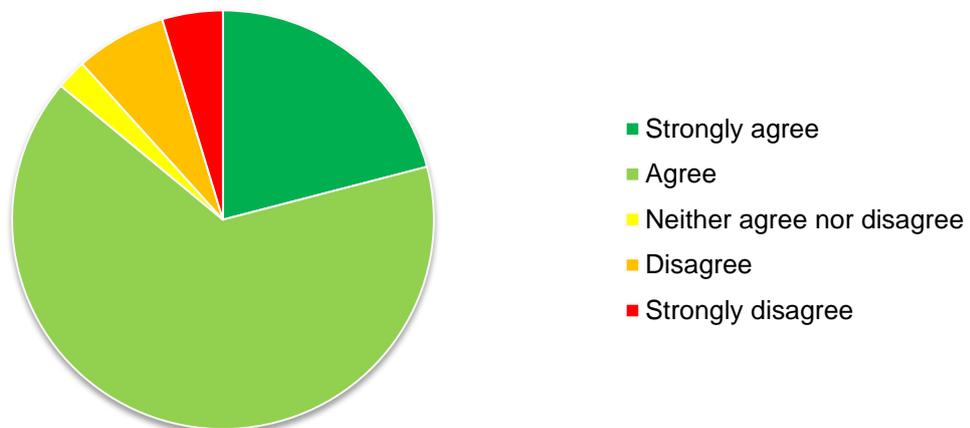
*'If all the suggestions in this plan were carried out there might be an improvement in the lives of people with a learning disability. However, there is no mention of how or when all the suggestions will be implemented or who will pay for them which makes me feel it is just a paper exercise.'*

*'More a set of ideals rather than a plan for how to achieve them'*

Respondents were then asked - **Looking at the sections in the draft plan, do you agree or disagree that the 'We will' action points are a good way forward to improve support for people with a learning disability living on the Isle of Wight?**

The answers for this question can be seen in charts 2 to 14.

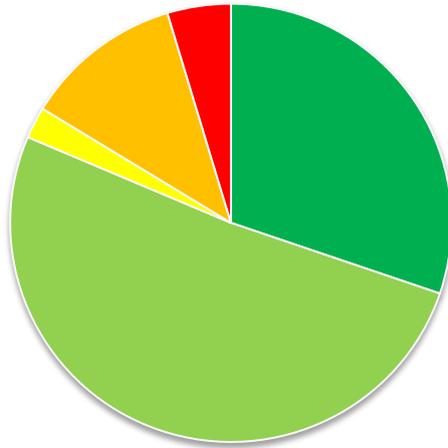
2. Living my life



*'It doesn't have anything about supporting to make choices but ensuring that the choices are safe.'*

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## 3. Keeping safe

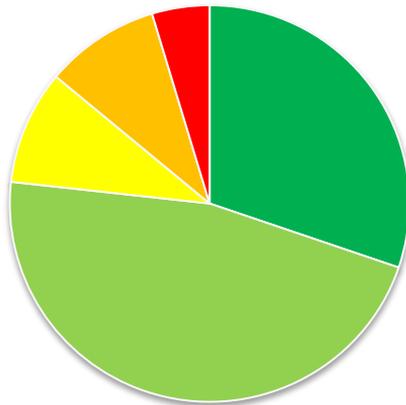


- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

*'I feel safe but would like more Easy Read information about this.'*

*'I would like more training about Hate and Mate crime.'*

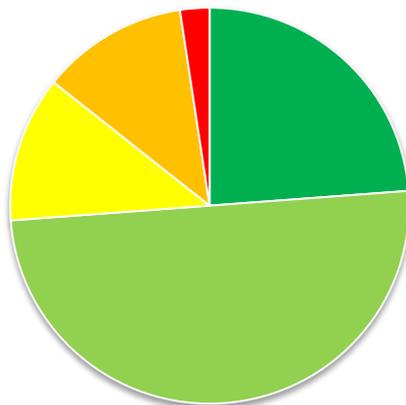
## 4. Staying healthy



- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

*'Doctors' appointments are difficult to get.'*

## 5. Where I live



- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

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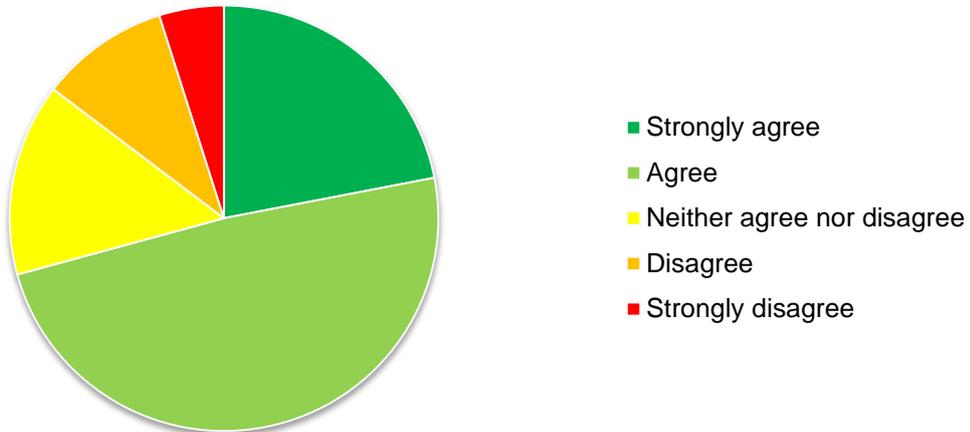
*'On Island accommodation'*

*'I would like to see Residential Care not being seen as a negative for everyone. My son, for example, does not need a roof over his head. He needs care and a community ethos that ensures my son will be involved with activities and not isolated.'*

*'I want to live more independently in a sheltered flat.'*

*'On page 13 the statement 'make sure people who want to are SUPPORTED to move out of residential care' should read 'make sure people WHO WANT TO are supported to move out of residential care'.*

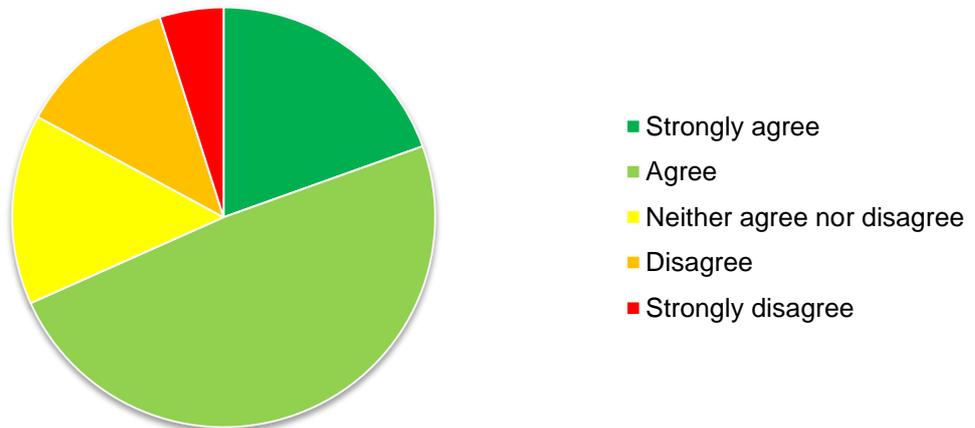
## 6. Help I need



*'A properly trained carer would be able to liaise between social services, other professionals e.g.: health, carers and those being cared for, in a much more person centred way'*

*'Experienced social care workers who know their clients'*

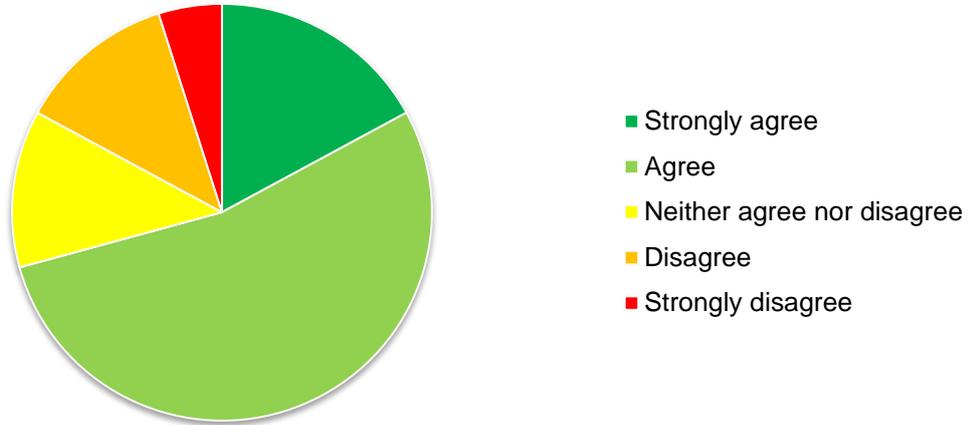
## 7. My education



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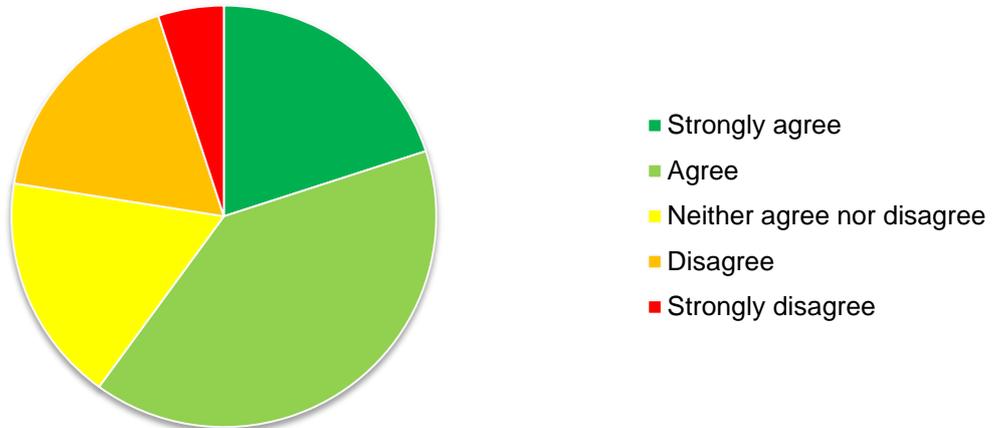
*'Staff have supported me to keep my college place and go to Cowes Yacht Haven.'*

## 8. Becoming an adult



*'There is not enough put in place, especially around communication, for young people entering adulthood.'*

## 9. My job

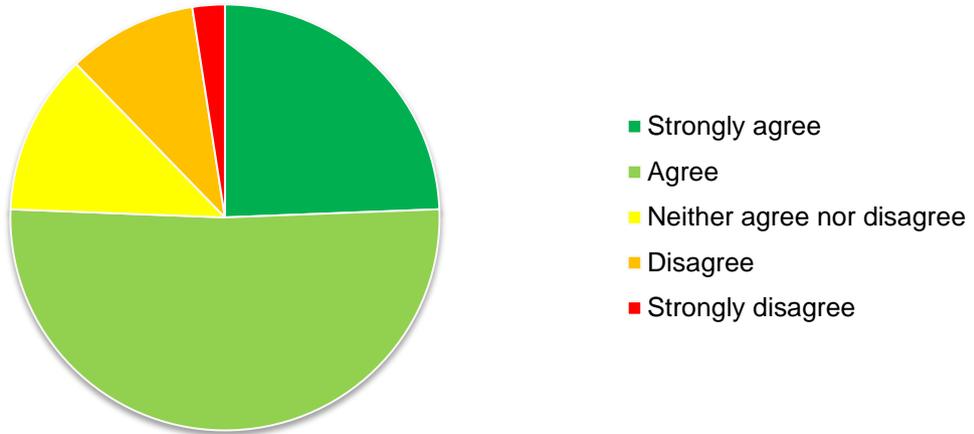


*'Some of us are worried about the word employment – does this actually mean employment or voluntary work? What about our benefits or not being able to hold down a paid job?'*

*'It would be really good if we could add something in around raising the aspiration to work as many children with learning difficulties do not consider employment as an option available to them. We have Jobcentre Plus Support for Schools Advisers who could help with this.'*

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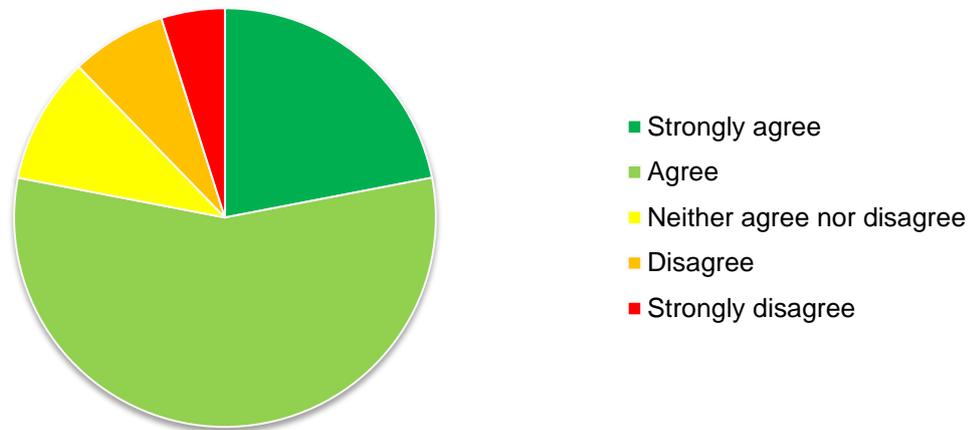
## 10. Helping my family



*'Stop wasting money on desk jobs and surveys and put more money in to families trying to cope!!'*

*'A real 'wage' for carers'*

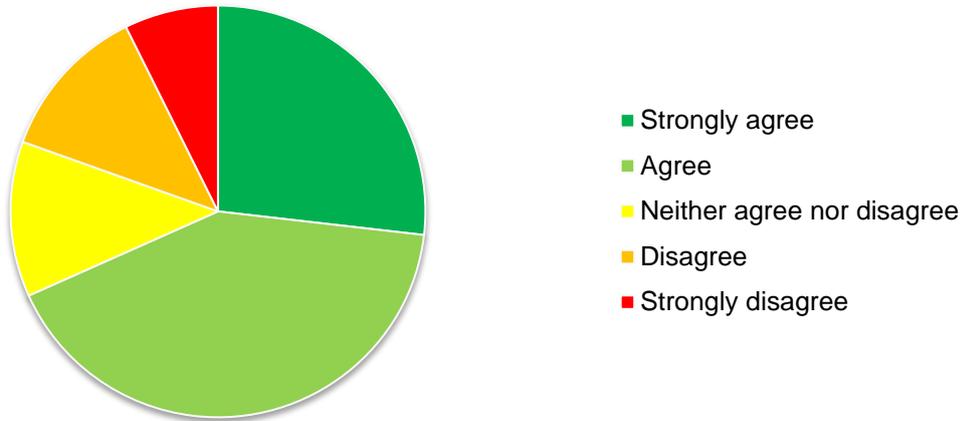
## 11. My friendships and relationships



*'My support plan has a bit about me and two friends going on holiday with staff this year. I am really excited and get to choose where to go.'*

*'There aren't enough groups for people with learning disabilities to make new friends and talk about things like sexual health.'*

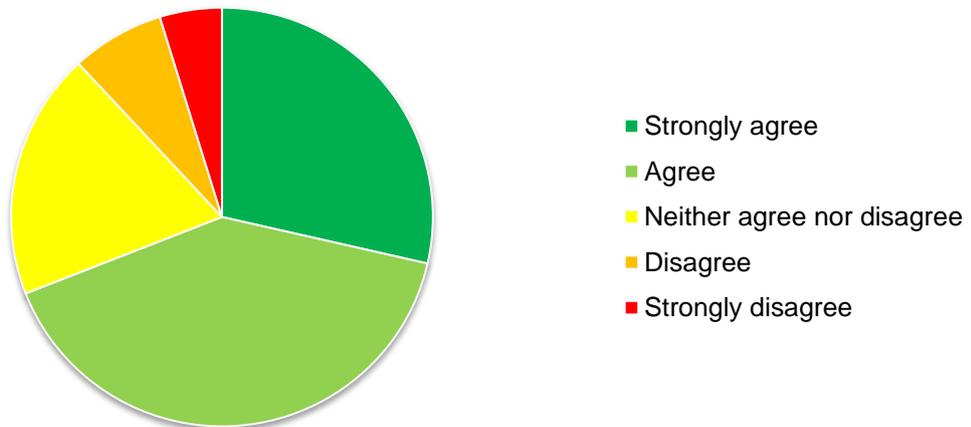
## 12. What I do and how I get there



*'The buses and bus stations are not safe.'*

*'Provide white busses again for transport i.e. to Haylands Farm etc.'*

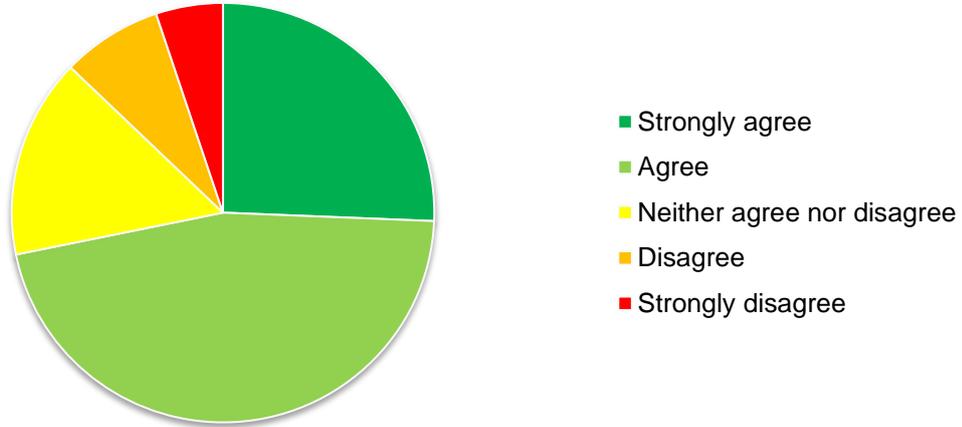
## 13. Support for people with autism and other vulnerable groups



*'More positive behaviour therapists'*

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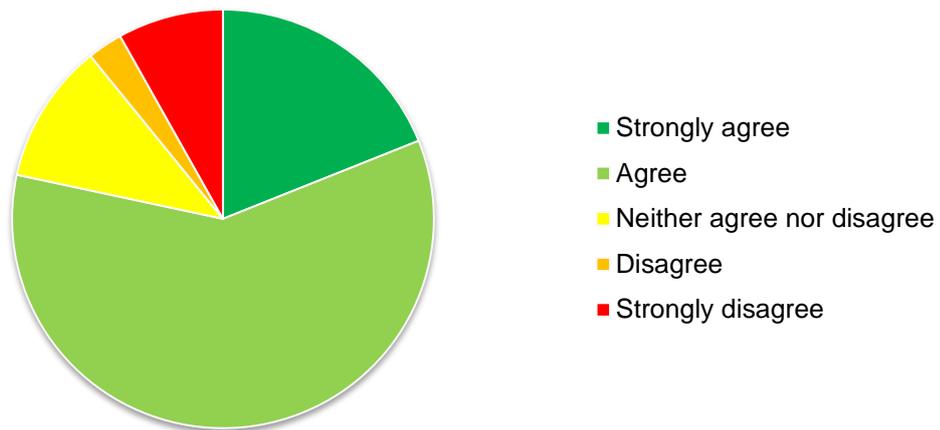
## 14. My information



*'I need to be able to understand the information you send me'*

*'Can the Council come up with more Easy Read leaflets about things like Safeguarding and staying safe?'*

## 15. Do you agree or disagree that the action points are a good way forward to improve support for people with a learning disability living on the Isle of Wight?



People were then asked **'If you could add just one more recommendation or action point to one or more of the sections what would it be?'**

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*'Publish data on where you are now and where you hope to be.'*

*'A named ASC worker would be beneficial as they would have a clear understanding of an individual's needs and the history'*

*'Empower people with learning disabilities and any other disabilities, support workers and carers with easy access to support and advice'*

*'Listen to what works with the individual'*

*'Make everything much more personal'*

*'I expect there may be some things I could agree with but by and large I have little faith that many suggestions will be carried out.'*

The most frequently recurring theme was that while the aspirations outlined in the strategy were positive, respondents were very sceptical that the transformation work would take place.

Finally, people were given an opportunity to **make any further comments on the draft strategy**.

*'It's a good plan and way forward, I hope the services enable it to happen and there is the funding to do this.'*

*'I hope that if the strategy is agreed that it does make a difference but I am not fully confident that this will be the case'*

*'I found the Draft to be very interesting. It looks to be a positive step forward.'*

*'It's good to see better health support for this client group'*

*'Stick to putting people and carers views first rather than dogmatically pursuing set targets'*

*'Why should we believe this will happen? Too many broken promises already'*

*'Actions speak louder than words..... ask us in a year.'*

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## Conclusion

In conclusion, the majority of individuals who were consulted agreed with the content of *Living Well with a Learning Disability on the Isle of Wight*. The average rate of 'agree' and 'strongly agree' with the longer survey questions was 74%. Negative comments were received; however, these were in the majority relating to current services and scepticism regarding implementation, rather than about the content of the strategy. Nevertheless, these will be valuable in informing the action plan.

There were some helpful suggestions throughout the development of and consultation on the strategy which will feed into the action plan. Particularly worth noting is people with learning disabilities' trepidation regarding the action point for employment, 'My job'. It is important to manage the message that while the aim is to make employment more accessible for people with a learning disability, ensuring people's personal choice would always remain priority.

Speaking to younger people with a learning disability re-enforced the message that it is necessary to explore new methods of accessibility, such as Widgit and video.

The Isle of Wight has approximately 600 people accessing Learning Disability Services. During the consultation period, over 100 of these people shared their views on the strategy. To support a wider consultation, self-advocacy groups, day opportunity and residential providers, healthcare providers and other statutory organisations also worked with the people they support to provide feedback. The Isle of Wight College Pathways programme and St. George's School facilitated consultation with a younger group of people with a learning disability than had previously been consulted with. It is therefore felt that the feedback received is comprehensive.

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## Recommendations

The recommendations are as follows;

- That following inclusion of specific suggested changes, the strategy be approved and launched
- A comprehensive action plan is coproduced and monitored through the Learning Disability Transformation Task and Finish Group, which meets monthly and includes members who are parents, carers, and people with a learning disability and/or Autism
- The action plan is published and widely circulated, and progress is regularly communicated in an accessible format – probably newsletter and video – with frequency to be agreed. The newsletter will be coproduced with the Learning Disability Partnership Group.
- The strategy is for a three year period, and reviewed and refreshed after 18 months.