

Cross-Party Group on Learning Disability



Minutes of the meeting

Where: Scottish Parliament/Zoom

Date: 8 March 2023

Time: 1:00 - 2:30pm

**Produced by ENABLE Scotland, Cross-Party
Group Secretariat**



People who were there

Paul O'Kane MSP - Convener

Oliver Mundell MSP

Heather Gilchrist - ENABLE Scotland

Richard Baker - ENABLE Scotland

Ali Petrie - ENABLE Scotland

Gary Airnes - ENABLE Scotland

Cameron Smith - SCLD

Tony Bowman - SCLD

Aaron Hume - The Assembly

Maggie Wilson - People First

James McNabb - People First

Caroline Kingston - People First

Lisa Weylandt - People First

Sonya Bewsher - The Assembly

Sandy Cruickshank - The Assembly

Jenny Miller - PAMIS

Donna Coakley - PAMIS

Mark McDonald - Scottish Autism

Gayle Forsyth - Action Group



People who were there

Arun Chopra - Mental Welfare Commission

Sally Cavers - Inspiring Scotland

Catherine Dempsey - National Involvement Organisation

Fiona Dawson - National Involvement Organisation

Michael Connolly - National Involvement Organisation

Lynnette Linton - National Involvement Organisation

Matthew James - Royal College Psychiatrists

Ewan Hamilton -

Jill Fotheringham - ILF

Leeane Clark -

Susan Bell - University of Dundee



People who were there on Zoom

Charlie McMillan - SCLD

Andrew Miller SCLD

Alastair

Andy Central Advocacy Partners

Fiona

Gillian Callander - NHS

John G

Mark

Michelle Pearson

Sally

Scottish Independence Advocacy Alliance

Tony

William Rae - The Assembly

Douglas McConachie - NHS Lothian

If you are aware of any missing information, please contact us:
cpg@enable.org.uk

We know that not all names were captured at the meeting and apologise for any missing information.

We also ask if you join on Zoom, could you please put your full name and organisation.



**People Who could not make it
to the meeting:**

MSPs:

Gillian Mackay

Stephanie Callaghan

Members

Alan Bingham

Anna Hooker

Peter Scott

Jana Devillers

Lynnette Linton



1. Welcome and apologies

Paul O'Kane MSP welcomed everyone to the meeting and noted apologies made.



2. Minutes and Matters Arising from last meeting

The minutes from the last meeting in November were approved.



3. Update from The Scottish Government

Jacqueline Campbell from the Scottish Government came along to provide an update on the Learning Disability, Autism and Neurodiversity Bill.



The Scottish Government had done lots of scoping work.

This is where they ran events with different organisations and had conversations with people with a learning disability.

The report from the Government's scoping work was published in February 2023.





Jacqueline said that although it is early, the scoping work was useful to highlight the issues people would like to see addressed.



Some of the key issues highlighted were:

- People feel like they are invisible
- Issues around housing
- Issues around mental health



The next steps for the Scottish Government has been setting up 3 panels:



Lived Experience panel - this panel has people with learning disabilities on it.



Stakeholder Panel - this panel has of representatives from different organisations



Professional Panel - this panel has people who work within the public sector and third sector



The Scottish Government had over 260 applications from people to be on the panels.



On the lived experience panel they have 21 people in total on it.



However, they do not have as many people with learning disabilities on that panel as they would like.



The 3 panels will go through all the things they want in the consultation paper.



A consultation is where the Scottish Government set out what they think should be in the Bill and will get feedback from people and organisations.



There are lots of things that can be covered in the Bill.



Jacqueline said that we often talk about learning disabilities and autism but are there other things that can be included.

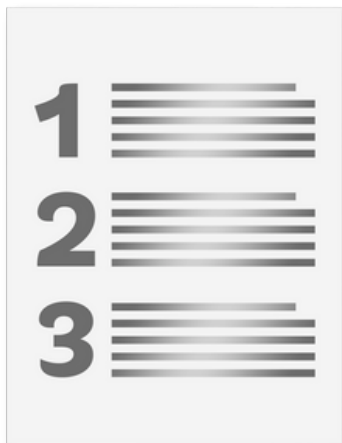
This could include things like:

- ADHD
- Foetal Alcohol Syndrome



The consultation will also need to set out what a commissioner would do.

It would also ask people whether there should be a commissioner.



Jacqueline pointed out that there is lots going on just now:

- The creation of a National Care Service
- Lots of work around mental health legislation



Jacqueline said that before the consultation is published these are all things that the Scottish Government will need to consider.

4. Discussion on the update

Aaron Hume said that they thought the Scottish Government would update on the Scottish Mental Health Law Review.



They also said that the application process for the lived experience panel was not fair.



Jacqueline said that they tried to not make it too difficult.





The Scottish Government wanted to make sure they weren't just asking organisations to put people forward.

The Scottish Government thought it would be fairer to have a more open process.



Sandy Cruickshank asked how the Scottish Government would include people who are non-verbal?



Jacqueline said that the Scottish Government want to get more non-verbal people involved.



They said it would be great if we could design something that would make it more inclusive and easier with the people we work with.



Mark McDonald from Scottish Autism said that from speaking to people involved, there are challenges to accessing the meetings.

He asked if the meetings could be turned into smaller groups?



Jacqueline said that everyone who has come along has said they are able to communicate on the meetings.

She said there will be opportunities to have smaller groups.



5. ENABLE Scotland's Learning Disability, Autism and Neurodiversity Update.

Heather Gilchrist from ENABLE Scotland provided an update on the LDAN Bill.



Heather said that since the last CPG meeting in November lots has been happening.

ENABLE Scotland's members have been busy:

- Completing surveys
- Hosting receptions
- Talking to MSPs
- Attending important political events





Heather said that the Bill should have new laws on supported decision making and advocacy.



It should have these laws to make the legal system fair and accessible to people with learning disabilities.



Heather said that ENABLE Scotland have a survey that is out at the moment.



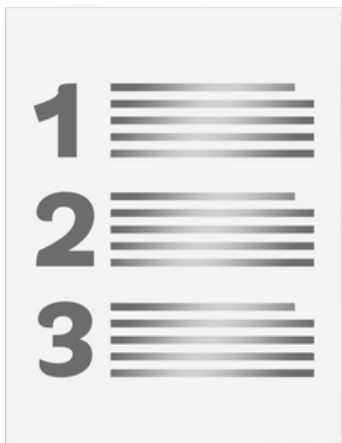
The aim of the survey is to hear what people think the main priorities of the Bill should be.



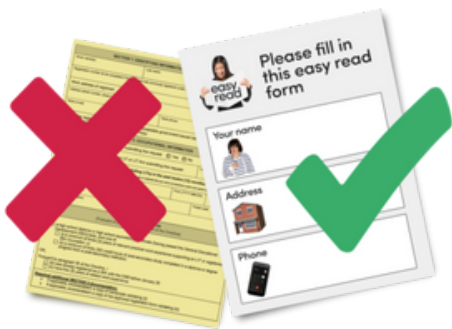
ENABLE will publish their report on the survey in May 2023.



The last part of Heathers update was on the lived experience panel that the Scottish Government have set up.



The panel is about the Learning Disability, Autism and Neurodiversity Bill.

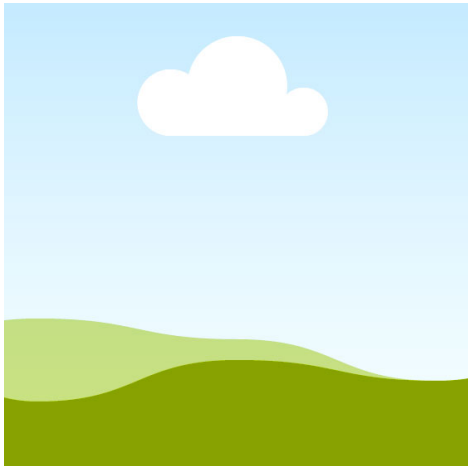


The first meeting has taken place to talk about what the Bill can and cannot do.

6. Discussion on ENABLE Scotland's Update



Jacqueline Campbell was asked why they didn't have as many people with a learning disability on the panel?



Jacqueline Campbell said there were different reasons why recruitment had been difficult.



Gayle Forsyth from the Action Group asked why people who the Action group supported hadn't been able to get on the panel?



Aaron asked what Jacqueline's teams process was with shortlisting people for the panel?



Oliver Mundell, MSP said that in the event of a change of minister in the future, it would be good for the CPG to write to the new minister about the commitment to the Bill.



Paul O'kane agreed that this would be a good action point.



David Stewart from Fed Cap said that we need to be asking what next and how do we make sure what people are asking for happens.



It was said that there is still a lot of difficulty for people with learning disabilities getting employment.



The person who asked this question wanted to know how the Bill would tackle this?



Paul O'kane asked if they think it is important that the Bill protects peoples rights in employment?



He asked if we have someone like a commissioner in the bill could this be something they investigate?



Someone said that many people with learning disabilities struggle with the interview process.



When people mention they have a learning disabilities a lot of employers might not feel they have the time or patience for them.



Paul said it shows the importance of the consultation process



Jacqueline Campbell says the Scottish Government knows there are different views about whether there should be a Commissioner or Commission.



**People First
(Scotland)**



4. People first's update on Supported Decision Making.

People First Chairperson Maggie Wilson and Support Worker Lisa Weylandt spoke on supported decision making.



Maggie said they are sharing the information as a result of discussions and work that has taken place in their self-advocacy groups over many years.



The Scottish Mental Health Law Review

Recommendations also talk about supported-decision making.

Maggie said that People First will describe supported decision making as a system of supported decision-making that would be a whole life approach.



She said that this means it should be available to everybody, all of the time.



Maggie had asked Lisa Weylandt to assist her with the presentation.

She said that as an organisation People First have always been worried about the level of decision-making that exists in the lives of many of their members.



Lisa said that the Adults with Incapacity Act has led to a huge number of adults with learning disabilities having their legal capacity removed under guardianship.



Legal Capacity is the right of a person to make decisions in law.



Lisa said that People First have raised these issues with the Scottish Government.



They also talked about these issues with the Office of the Public Guardian and the Mental Welfare Commission.



Maggie Wilson said that in 2014 the United Nations Committee on the Rights of Persons with Disabilities published comment number 1 about Article 12 of the Convention.



Maggie said that this is about equal recognition before the law.



She said that the committee has said that no person should have their legal capacity removed because of their mental capacity.



People First have campaigned a lot about removing learning disability from mental health law.

As well as from the definition of mental disorder.



Lisa said that this is because having a mental disorder allows a person with learning disabilities right to make decisions removed under the Adults with Incapacity Act.



Maggie said in 2016 and 2017 that People First members designed and carried out research to find out if decision-making matters for adults with learning disabilities in Scotland.

.



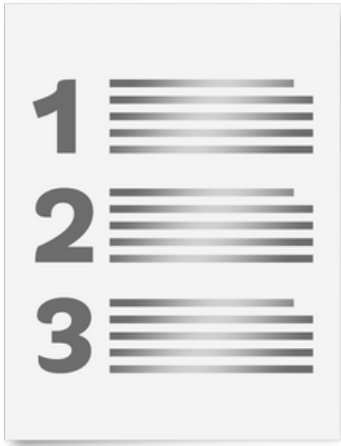
They asked people if it was important to them to make decisions.



Some people said yes, because then I feel I am being listened to.



Others said when people make decisions for you, you feel powerless.



Lisa said that People First wrote a Framework for supported decision making.

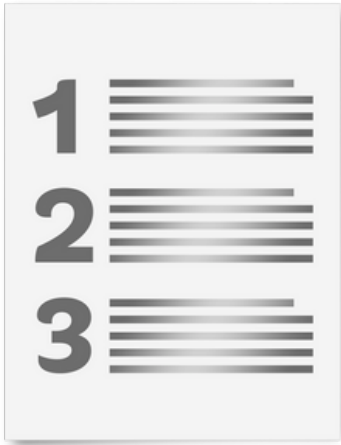
This framework is based on Comment 1 about Article 12 of the United Nations Convention on the Rights of Persons with Disabilities.



She said that they know that no system is perfect.



But they want to see a Scotland where people with learning disabilities are seen as equal human beings with rights.



Maggie and Lisa said that their framework for supported decision making talks about 3 different levels of support:



1. Decisions we make ourselves with support and information from our chosen supporter.
2. Supporter decisions where we express our will and preference and our supporter helps us to make our decision.
3. Interpreted decisions.



Maggie said that some people have suggested that interpreted decisions are not any different from substitute decisions.

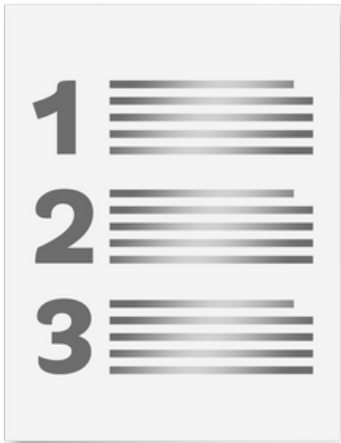
People think it is the same as making the decision for someone.



Maggie said they disagree since substitute decisions are mostly based on what is believed to be in the person's best interests.



Supported decision making is based on the person's will and preference as well as rights.



Lisa said that in their Framework for supported decision-making they have also put together a list of steps that we think are part of supporting decision making.

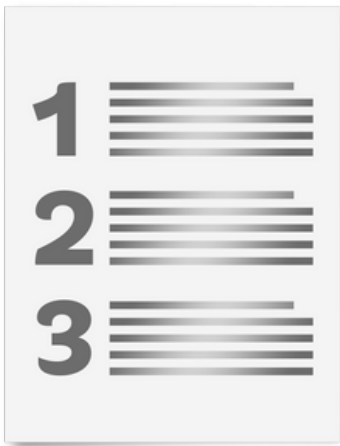


They include:

- Allowing the person to choose their supporter.
- Being provided with information in a way that is accessible to them.
- Having the chance and time to think about their decisions.
- Ask people for other advice
- Be able to change their mind.



Maggie said that they have also written about principles for supported decision making.



This includes making sure at every step that the decision is being made by the person themselves or their will and preference.



Maggie says that it also says that people with learning disabilities should be allowed to make mistakes and change their mind.



Lisa said that People First have also thought about the challenges too.



In their groups and in their framework they have spoken about undue influence

Undue influence is when someone tries to pressure someone into a decision that would work best for them.

Not the person they are supporting.



Lisa said that they have also spoken about the risk of harm.



Maggie said that a system of supported decision making needs to be created alongside change in how the law views people with learning disabilities and treats them.



She said it can only work if people have support that makes sure they can live full and meaningful lives.



It can only work if time and money are invested in changing how society views us and the opportunities people with learning disabilities have.



People First think that the Learning Disability, Autism and Neurodiversity Bill presents an opportunity to create supported decision making in the way they have described.



Maggie finished by saying that the presentation shared at the Cross Party Group was just a small part of the work we have done around supported decision making.



Paul thanked Maggie and Lisa for their presentation on supported decision making.



He said that at our next CPG meeting we can have a discussion about supported decision making with regards to the Scottish Mental Health Law Review.



Richard Baker discussed we did not get the opportunity to discuss what should be talked about at future meetings.

He said people were welcome to email about any ideas for future topics.



Paul thanked everyone for coming and said he looked forward to seeing everyone in June at the next meeting.



As a reminder the next meeting will be on Wednesday the 28th of June at Scottish Parliament in the Fleming Room.

Do you have any questions?



We hope you found these minutes helpful.



If you have any questions about this update you can contact ENABLE Scotland



You can email ENABLE Scotland at:

cpg@enable.org.uk

**Produced by ENABLE Scotland
Cross-Party Group Secretariat**