

Cross-Party Group on Learning Disability
Thursday, October 28, 2021
6 PM - 8 PM



Minutes of the meeting.



People who were there

Paul O’Kane MSP - Convener

Pam Duncan Glancy MSP

Oliver Mundell MSP

Jan Savage - ENABLE Scotland (Secretariat)

Jana De Villiers - Royal College of Psychiatrists

Colin Menabney - ENABLE Glasgow

Sandy Cruikshank – The Assembly

James McNab – People First Scotland

John Clark – The Assembly

Pat Graham - PAMIS

Emma Congreve - Fraser of Allander Institute

Norma Curran - VIAS

Lorraine Mackenzie - Parent

Tracey McFall – PIA (Partners in Advocacy)

Michele Munro – Partners for Inclusion

Faye Keogh - Turning Point Scotland

Catriona McDougall - People First

Andy Williams – Central Advocacy Partners

Peter Scott – Independent Living Fund Scotland

Maureen Martin – EDG
Emma Walker – Camphill Scotland
Joe Gough - Kaleidoscope
Andrew Millar - SCLD
John Dalrymple – Radical Visions
Andrew Wright - SMC
Jenny Millar - PAMIS
Aidan Reid – RCP psychologist
John Gallon – The Assembly
Kate Monahan
Sharon Irvine – Cornerstone
Mark Morris
Alan Bigham – NHS Health Improvement Scotland
Paddy Carstairs – ARC UK
Alice Sold – ARC Scotland
Rachel Hughes
Rodger Watt – Scottish Government
Amanda McCarren – Scottish Government
Gillian Callander
Marjorie Irving
Aimee MacLeod
Aaron Hume

Please note some names/ organisations may be missing from the attendees list.

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

For future meetings can all attendees please have their name and organisation displayed on-screen.

If you need help with this, please contact us or ask at the beginning of the meeting.



People who could not make it to the meeting:

MSPs:

1. Neil Gray MSP - Vice Convener
2. Jackie Baillie MSP
3. Gillian MacKay MSP

Group Members:

1. Eddie McConnell – Down's Syndrome Scotland
2. Lynette Linton (ARC Scotland)
3. Fiona Clarke
4. Nick Ward, National Autistic Society Scotland
5. Kenneth Fleming, SCLD
4. Diane Willis
5. Paul White, ECLAP

Welcome and Apologies



Paul O'Kane MSP welcomed everyone to the first formal CPG meeting of the session and noted the apologies above. He said he was honoured to be the Group's new Convener.

Minutes of last meeting Matters Arising



As it was the first CPG meeting of the session there were no matters arising. The Convener reminded everyone about the CPG Legacy report though, which can be accessed here:

[CPG Legacy Report](#)

National Care Service



**RADICAL
VISIONS**

John Dalrymple from Radical Visions spoke about the National Care Service wants to achieve. He talked about the changes it could make. He said that people cannot wait five years for change.

What the members talked about:



- Lorraine (parent/ carer) asked about better salaries for care workers. She felt that this is an issue that needs action sooner rather than later.



- James McNabb (People First Scotland) talked about the National Care Service Consultation being difficult for people to complete, and not enough time given.



- Jan Savage (ENABLE Scotland) asked for updates from the Scottish Government about progress that has been made on the Coming Home Report. She felt that this could not wait for five years.



- Sandy Cruikshank (the Assembly) talked about the scrapping of care charges. He felt that this should happen now.



- Rodger Watt (Team Leader for Learning Disability and Autism – Scottish Government) told the members that there would be ongoing consultation on the National Care Service using the extra accessible materials the Scottish Government has sent out.



- [A National Care Service for Scotland consultation: easy read - gov.scot \(www.gov.scot\)](http://www.gov.scot)

Actions:

Paul O’Kane will write to Kevin Stewart MSP.

Points to be raised:

- **Inaccessibility of the National Care Service consultation so far.**
- **We cannot wait 5 years for change.**
- **Issues around the Coming Home Report and what to do to support people who need complex care.**
- **Community-based solutions.**
- **Better pay for care staff.**
- **Scrapping care charges.**
- **Request Kevin Stewart to attend a cross party group meeting to talk more about the National Care Service.**

Pam Duncan-Glancy (MSP) offered support with the above points.



Day Services



Day Service for people who have a learning disability

*Discussion led by Emma Walker,
Camphill Scotland Director*

Emma talked about day services and that many of them have closed during the pandemic.

She said some people had their day service taken away without being asked what they thought about it.

She talked about how this has not been good for many people who need these services.

Emma thinks this is taking away the rights of people who have a learning disability.

She said there is a need to stop day services from being closed.

She said people should be told about the good support day services can give people.

Emma wants people to change the way they think about day services.





Camphill Scotland would like there to have a big meeting called a National Summit to talk about how Covid has affected disabled people.

Emma said she would like the meeting to be done in a creative way.



She thinks the big meeting should also involve unpaid carers and service providers.

Emma said Pam Duncan Glancy (MSP) and Jeremy Balfour (MSP) would be writing to the Minister in November to ask if the summit could be part of the Covid enquiry.



She asked the members of the Cross-Party Group on Learning Disability if they support this by adding their signature to the letter.

Emma has said if anyone would like to talk about day services they should contact her:

info@camphillscotland.org.uk

Members talked about:



Jan Savage (ENABLE Scotland) said we need to talk about how people spend their day and their lives as we move out of Covid.

She would like to see the National Summit talk about all options for how people spend their day.

She said some people love their day centres, and this is important.

But some other people have found that it is good to do other things near where they live.



Other people might like to do paid work instead.



Jenny Miller (PAMIS) spoke about a National Collaborative set up by NHS Healthcare Improvement Scotland.

This is a group of people who work across the Health and Social Care Partnerships in Scotland.



She said some people were worried that Collaborative were going to plan how to close all day centres, but this is not what they are doing.

They are looking at how people would like to spend their time after Covid.

They are talking to people about the support they will need.



John Gallen (the Assembly) thinks we should ask young people how they feel about services being taken away.

He said we need to open day services again.

Paul O’Kane (MSP) spoke about a question Jackie Baillie (MSP) had asked the Scottish Government about the re-opening of services.



He said for the next meeting he would find out more about this.

Allan Bigham from the iHub said the organisations they are working with have been very helpful.

He thanked organisations such as:

Pamis

ARC Scotland

People First

ENABLE Scotland

Camphill Blair Drummond



He said they have shared meaningful stories from the people they support.

These stories have helped Health and Social Care Partnerships understand the needs of people who have learning disability or autism.

He offered to come along to the next meeting of the CPG and tell members a bit more about the work of the National Collaborative



People First (Scotland)

James McNabb (People First Scotland) spoke about day services providing some support for some people.

He said other types of help are important too – like supporting people to go out at night.

He said giving people choice is the most important thing.



Colin Menabney (ENABLE Glasgow) spoke about the largely negative impact of closing day services in Glasgow and the need for people who have a disability to have a real say when this is being considered by a local authority.

Actions:

The Convenor will



- **Chase up work Jackie Baillie MSP had previously done on re-opening of day services**
- **Write to the Health and Social Care Support Committee to ask what they are doing to find out the effects of the pandemic on people who have a learning disability and how we re-think services.**
- **This could also be followed up with the Human Rights Committee or the Covid Committees.**
- **Invite NHS iHub project to speak at the next CPG meeting.**
- **Lodge a written question about national data on the status of day services and what closed over the pandemic.**



Towards Transformation plan

This session was hosted by:

Sandy Cruikshank

John Gallen

John Clark

Supported by Norma Curran.



The Assembly supports people who have a learning disability or Autism to be more involved with politics through meetings and workshops.

They have hosted lots of accessible events.

They have met with MSP's.

The Assembly would like to get bigger and is looking for more members.



They host a National Assembly Zoom meeting from 10.30-12pm every Friday.

There are also seminars every 2-3 weeks.

If you know of anyone who would like to attend, please contact Sonya Bewsher:

sonya@theassembly.scot



The members then spoke about the Scottish Government's Towards Transformation Plan.

This is a two-year plan which has been made to involve and support people who have a learning disability or Autism as we come out of Covid.



They feel the most important issue they want to work on is access to the right mental health services for children and adults.

The members feel that there needs to be better specialist services to support people.



Overall better training to all mental health staff would begin to address this.

Actions:

The Convenor will:



- Invite the **Scottish Government** to the next CPG meeting to ask what they are going to do about mental health services for people who have a learning disability or Autism.
- Organisations to spread the word about the Assembly and encourage people to join.
- sonya@theassembly.scot
- Send a formal written question to the **Scottish Government** about the waiting list times for access to specialist mental health and CAMHS services.
- **Oliver Mundell MSP** said that he would be happy to help with this.



UNIVERSITY of STRATHCLYDE
FRASER OF ALLANDER
INSTITUTE

The Value of Unpaid Care

Presentation from Rob Watts (pre-recorded presentation) and Emma Congreve, Fraser of Allander Institute.

The Fraser of Allander Institute are a group of people who find out information about how much money Scottish people earn and spend.

Rob Watts gave a presentation.

He said they have been doing research into what life is like for people who have a learning disability and their families.

Research has been done to find out how much money the Scottish Government saves when unpaid carers look after someone who has a learning disability.

An unpaid carer is usually a family member who looks after someone who has additional needs.



The research also looked at the amount of money unpaid carers have to live on and how families feel.



The findings show that life is not good for unpaid carers.

It gives us a clear picture of what life is like for them.



The research showed that having to care for someone who has additional needs made it very difficult to have a paid job outside the family home.

It also showed that if unpaid carers were paid the living wage for the hours they work, they would receive an average of £35,000 per year for personal care and £78,000 for total care.



(The living wage is the lowest hourly rate people should be paid in Scotland.)

There was concern about the amount of time unpaid carers spent on personal care.



Rob spoke about Frank's Law which gives people access to free personal care.

The replacement cost per year to taxpayers to provide paid staff members would be £55,000 for personal care and £114,000 for total care.

This information tells us that unpaid carers spend most of their time caring for their family members.

This makes it very difficult to be able to have time to work in a paid job to provide for their family.



This can leave families with very little money to live on.

This can make people feel lots of bad feelings like sad, worried and like they are on their own.



Rob also spoke about the same amount of care people received before the pandemic has not been returned.

He said there seems to be no plan in place for this to happen either.



He said that unpaid carers face an uncertain future.



Rob's presentation ended, and he handed over to Emma Congreve who was at the meeting to help answer questions.

Members talked about:

Maureen Martin (EDG) – EDG work to increase the rights of women as carers.



Women are not seen as being important.

Maureen believes unpaid women carers are losing the ability work and to save for their pensions.



This will lead to poverty in their later life.

Maureen believes this is very wrong and unfair but there is no sign it is going to change.



Sandy Cruikshank (The Assembly) said it's not always women who care for children.

Men also need to be protected as family carers.

He said prevention is better than cure before we head into crisis.

Jenny Millar (PAMIS) – written comment:

Useful and compelling research.



What if all that saved money was invested into services which would support family carers to get paid employment which would mean they could then contribute to the economy?

Catriona – (People First) - written comment:



Would be good to know if adults who have learning disabilities and are also unpaid carers for their children have been included in this research?

Emma Congreve (Fraser of Allander) answered the questions:

There was nobody in sample who had a learning disability.



This was not deliberate, just those who choose to take part did not have a learning disability.

Emma thought it would be very interesting piece of work to find out more about the lives of parents/ carers who also have a learning disability.



Emma agreed with Sandy that its not just women who are unpaid carers.

In this study, all the primary carers were women, but some male partners added their thoughts too.

Emma agreed with the points Maureen made about women's pensions





Emma said there is very little research available about learning disability in general.

She said Fraser of Allander were very pleased to do this research and shine light on it.

Emma finished by saying she was really glad to come along to this group.



She said if we need more research done then members could get in touch with the Fraser of Allander Institute. She said we try to bring funding in to research things that matter to you.

fraser@strath.ac.uk

Contact can be made directly or through ENABLE Scotland.

Jan.savage@enable.org.uk



Cross Party Group members thanked the Fraser of Allander team for their excellent research so far.

Jan Savage (ENABLE Scotland) said there was a question submitted prior to the meeting about the research.



Lorraine said it was worrying that such a lot continues to come down to data.

Public bodies use data to inform decisions, but there is not enough data available about people who have learning disabilities and their families. Why is this?



Could Cross Party Group urgently write to the Scottish Government about this?



It was noted that the Keys to Life strategy in 2013 had highlighted a lot of the issues still identified as challenges by the Fraser of Allander Institute in their research.



The Scottish Government recently published an independent report on the Scottish Autism strategy.

It was suggestion to the Convenor that a similar independent review takes place on Keys to Life strategy.

Based on FAI research we feel there is enough evidence to make this ask.

Members raised their hands or nodded to show they were in agreement with this idea.



Oliver Mundell indicated support too.

Actions:

The Convenor will:



Write to the Scottish Government to ask about the status of data collection about people who have a learning disability and their families in areas such as Education/ Social Care/ Health/poverty, housing, employment etc.



Present a motion on findings of Fraser of Allander and encourage debate on its findings so far.



Write a formal request for an independent review for the Keys to Life strategy regarding the impact for the last 10 years, aligned to the Independent Review of the Autism Strategy.



Anything else?

A member of ENABLE Scotland has asked the Cross Party Group to write to the Scottish Government about the Booster vaccination program.



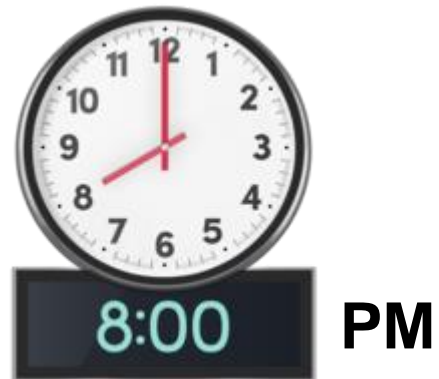
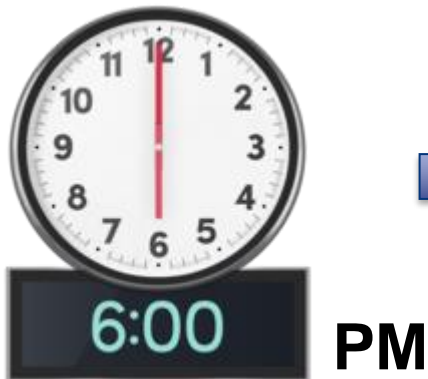
They would like to know how the Scottish Government are checking how many people who have a learning disability are getting the booster vaccinations.

They would also like to know what extra support is available for people who need it?

It was agreed that the Convenor would lodge a question with the Scottish Government about this.



**Date of next meeting:
Thursday 10th March
2022**



Zoom link:

Join Zoom Meeting:

[CPG Zoom link | March 10, 2022](#)

Meeting ID: 862 5710 3079

Passcode: 016610