

**Minutes of the meeting of the
Cross Party Group for Learning Disability
Committee Room 3, Scottish Parliament
Tuesday 21st December 2016**

People who were there

Jackie Baillie MSP
Joan McAlpine MSP
Jeremy Balfour MSP
Johann Lamont MSP
Pauline McDonald, Scottish Government
Susan Brodie, Scottish Government
Jan Savage, ENABLE Scotland*
Kayleigh Thorpe, ENABLE Scotland*
Chris Creegan, SCLD*
Jenny Miller, PAMIS*
Angela Henderson, SLDO
Gillian Allan, Edg Sco
Prof Mandy Loucks, Families Outside
James McNab, People First Scotland*
Rhona Neil, People First Scotland
Layla Theiner, DAS*
Neil Henery, Camphill Scotland*
Fiona Sinclair, Autism Rights
Caitlin Isbister, Quarriers*
Florence McQuilter, Quarriers*
Caroline, Quarriers*
Donna Nicholson, LDAS*



John Clarke, LDAS*
Shiela Finlayson, LDAS*
Particia Kearns, Speak Out Advocacy Group*
Sally Elfverson, ENABLE Glasgow*
Colin Menabney, ENABLE Glasgow*
Madge Clark, Speak Out*
Kathleen Gilgunn, Speak Out*
G H, Speak Out*
Elizabeth, Turning Point Scotland
Aileen Reid, Turning Point Scotland
Darren Fyfe, Turning Point Scotland
Rab Muir, Turning Point Scotland
Loretta Galloway, Unity Enterprise

*= Voting Member

People who could not come and sent apologies

Alex Cole-Hamilton MSP
Alison Johnstone MSP
Oliver Mundell MSP
Lorraine MacKenzie, LDMACK
Faye Keogh, Turning Point Scotland
Ewan Hamilton, Key Community Support Politics Group
Dr Alison Clark, BPS DCP-Scotland
Peter Jung, Turning Point Scotland
Brid, Arc Scotland



1. Welcome

Jackie Baillie MSP welcomed everyone to the meeting.



Jackie welcomed Joan McAlpine MSP, Jeremy Balfour MSP and Johann Lamont MSP.



Jackie said Oliver Mundell MSP wants to join the Cross Party Group.

He will come to our next meeting.



2. Minutes of the last meeting on 21st September 2016

Jackie asked if everyone agreed with the minutes.

Everyone said the minutes were correct.

3. Matters arising – things that came out of the last meeting

Mental Health Act Review

At the last meeting everyone agreed Jackie should contact Maureen Watt MSP, Minister for Mental Health, to ask for an update on this.



Jackie said she had asked a question in parliament about this.

The Scottish Government will answer this question in January.

ACTION: ENABLE Scotland will update the Cross Party Group in January when the Scottish Government answers Jackie's question in Parliament.

4. Scottish Learning Disability Observatory

At the last Cross Party Group the Keys to Life Team told us about research being done by the Scottish Learning Disability Observatory.



Everyone agreed to invite the Scottish Learning Disability Observatory to the Cross Party Group to talk about their work.

Angela Henderson is from the Scottish Learning Disability Observatory.

Jackie welcomed her to the meeting and invited her to give the group an update.

Angela said the Scottish Learning Disability Observatory looks at lots of information. This includes information that is already collected by other organisations. For example information collected by the Scottish Government or the NHS.



They want find the information about people who have learning disabilities in all that information.

This will help them to find out what information they don't know about people who have learning disabilities.

Angela said the Scottish Learning Disability Observatory is doing lots of work on health.

They have looked at people who have multi-morbidity. This means people who have two or more long-term health conditions.

They wanted to know how many people who have learning disabilities have two or more long-term health conditions.

She said they found out that people who have learning disabilities are more likely to have two or more long-term health conditions than people who do not have learning disabilities.



She said they looked at information from GPs. But this only covers some conditions.

She said they looked at the health of lots of people who have learning disabilities. She said people who have learning disabilities had 11 health conditions on average. She said that the number of people who have learning disabilities with two or more long-term health conditions was high at all ages. For people who do not have learning disabilities, this got higher when people got older.

Angela said this information is very important. This will help make health-care pathways better. Just now health-care pathways usually look at one health condition on its own.

Angela said there are lots of ways to find out more about the Scottish Learning Disability Observatory

She said you can:

- Look on their website.

There are easy read videos on the [website](#).

She said people can look at information about learning disabilities in their area.

- Get their newsletter.
- Go to an event

She said there will be a conference every year.

Joan McAlpine MSP asked if the Scottish Learning Disability Observatory is looking at specific conditions. For example Down's Syndrome.

Angela said the Scottish Learning Disability Observatory does look at specific conditions like Down's syndrome.

She said the Scottish Government and NHS have a project called SPIRE. This is changing the way GPs write down information about their patients.

Angela thinks the SPIRE project will help to get better information from GPs about people who have learning disabilities.

Jan Savage (ENABLE Scotland) asked how the information will make things better. How can it be used to help health and

social care joint integration boards to make things better for people who have learning disabilities? Health and social care joint integration boards make decisions about health and social care for each local area.

Angela said people can look at the information about people who have learning disabilities in their area. This should help people plan to make things better for people who have learning disabilities.

She said they are thinking about how to support health and social care joint integration boards to use the information to make decisions.

Jackie thanked Angela for coming to the meeting and said that we would invite her back next year for another update.

6. Social Care Charges

At the last cross party group we agreed social care is a big issue for us to talk about.

Lots of people are worried about social care charging.

Johann Lamont MSP talked about her work on social care charging.

Johann said there has been a long campaign about social care charges called Scotland Against the Care Tax. Lots of members of the Cross Party Group are part of the campaign.

Johann said this is a human rights issue.



Johann said disabled people are more likely to be living in poverty.

She said she had heard about people limiting their own access to social care because of the charges.

She said money collected from older and disabled people for social care had gone up much more than other things. This is called the rate of inflation. She said it had gone up by four times the rate of inflation.

She said how local authorities get enough money to do everything is a big question. But we don't say education is really expensive so some people need to pay for it.

Johann talked about her debate on social care charging in the Scottish Parliament. She said MSPs from all of the political parties want to fix the unfairness of social care charging.

She said there is a strong argument for making social care free for everyone.

To do that the Scottish Parliament would need to make a law about this.

Johann talked about Siobhan McMahon's work to try to make a new law about this last year. This is called writing a Bill.

She said Siobhan McMahon's Bill did not go through because there was not enough time before the elections.

Johann said if she tries to write a new Bill it might not work. It will need the Scottish Government to write down how it will be paid for. This is called a financial memorandum.

She said it is better to work together with all the political parties to fix things.

Johann thinks it will be a better idea to talk to people about stopping social care charges and getting lots of support for this. She said this could be done by having a consultation.

Donna Nicholson (LDAS) told us about a campaign in Dumfries and Galloway. She said in in Dumfries and Galloway there has been a big increase in charges.

The local campaign wants to end care charges. It might take some time for that to happen. To make things better just now there is an idea to increase the income disregard threshold. This is the amount of money people can have before they are charged for their care.

There is an idea to make this the same as the amount of money people can have before they pay tax.

Caroline (Quarriers) said it is important to listen to people about this.

Johann Lamont MSP said the different rules for charging can be very hard to understand.

She said because Local Councils have not been able to raise the money they need in other ways they have increased social care charging.

Joan McAlpine MSP said that all parties should work together on this. It wouldn't be helpful to campaign against the Government. Everyone should work together.

Jackie Baillie said that the Cross Party Group can help to build support for this. She said if members want to tell Johann Lamont MSP about their experience they could send this to ENABLE Scotland.

Members can send their evidence of social care charging to ENABLE Scotland at CPG@enable.org.uk

Madge Clark asked if money for social care could be ring-fenced. This means it is only allowed to be spent on social care. She said it is not clear what councils are spending on social care.

Johann Lamont MSP said if we agree that this is a human rights issue, the money needed just has to be made available to pay for this.

Jackie said we could write to Cabinet Secretary to find out more about the plans for feasibility study. We could say the feasibility study should look at how we can end social care charging for all disabled people. Jackie asked if the Cross Party Group agreed with this plan.

Everyone agreed.

Joan McAlpine MSP said this affects carers too. We should speak to the Cross Party Group on Carers.

Colin (ENABLE Glasgow) said everyone could collect examples of social care charging problems. These are called case studies. It means writing down everyone's story about social care charging.

Jan (ENABLE Scotland) said everyone can send these case studies to the secretariat (ENABLE Scotland).

Jackie said we can think about if we need to do any Freedom of Information Requests (FOI). Or if we need to ask any questions in parliament.

ACTION: Everyone should collect stories about social care charging. These can be sent to ENABLE Scotland. ENABLE Scotland will share the stories from Cross Party Group members with Johann Lamont MSP

Madge Clark said Self Directed Support should be investigated. We should find out if it has made things better or worse for people.

Fiona Sinclair (Autism Rights) said there is unmet need. We need to look at where the money is going.

Donna Nicholson (LDAS) said Sheila (LDAS) is worried about losing overnight support. These are sometimes called sleepovers.

Jenny Miller (PAMIS) said that a family had been told if their package of care is over a certain amount they would be offered residential care.

Florence (Quarriers) said support shouldn't be cut.

Chris Creegan (SCLD) said Audit Scotland did a report on Self Directed Support. They will be doing another report in 2017.

Jackie said this was a good introduction because Audit Scotland is speaking next.

6. Social Care

Antony Clark is from Audit Scotland.

Audit Scotland checks that public money is spent properly.

Antony told us about their report on social care in Scotland.

He said it is about all social care. Not just social care for people who have learning disabilities. He said 34 people who have learning disabilities had taken part in the research.



He told us about the big problems for social care:

- More people need social care. This is called Demographic pressure.
- Pressure from changes in the law. For example Self Directed Support or the Carers (Scotland) Act.
- There are problems finding and keeping good staff. This is called recruitment and retention. He said Brexit might make this worse.
- Councils have less money. The money councils have to spend has gone down by 17% since 2010. This is called their budget.

He told us about how Councils are trying to cope:

- Reducing and tightening eligibility criteria.

This means people are only getting support when they have very high needs.

He said this did not fit with preventative spend. This means supporting people early so their needs don't get worse.

- Contracting other providers to deliver social care services.

Lots of councils are looking at getting more services for less money.

Anthony said we need to think about if it is possible to drive down costs anymore without making the quality of support worse.

- Reducing out of area placements by having in-house services for people with complex needs

Anthony talked about the risks if things don't change:

- Low pay and high staff turnover will make quality worse.
- Social care service providers will close down
- Stop moves towards prevention

Anthony talked about some things that could make things better:

- Make commissioning better

This is when service providers are asked to deliver social care on behalf of the Council.

He said this should look at different ways to design or deliver social care services.

He said social care providers should be involved in this.

- Improve elected member leadership

He said Local Councillors don't always know about the quality of services. They don't get reports on this.

He said they should know more about what is happening with social care services in their local area.

Anthony said Audit Scotland is going to do another report on Self Directed Support.

Jackie (Convenor) told us she had to leave at this point. There was a debate happening in the Parliament.

This was the end of the Cross Party Group meeting.

Jackie asked Jan Savage (ENABLE Scotland) to chair the next session.

Members stayed to ask Anthony some questions and talk about plans for our next meetings.

James McNab (People First) said our members are part of group meeting Audit Scotland in January. We are looking at whether people are getting all 4 SDS options.

He said some people are struggling to get a support package to meet their needs.

Jan (ENABLE Scotland) asked when the next report on Self Directed Support would be.

Anthony said the next report would be in summer next year (2017).

Fiona (Autism Rights) said there are not enough standards. My friend's son's budget is 75% admin 25% on support. You can't do an FOI on a charity.

Anthony (Audit Scotland) said that the Care Inspectorate would be better to answer that. But there was more work to be done on looking at quality of services and value for money.

Donna (LDAS) said there is a survey about Self Directed Support.

A member said she got support but she did not know what Self Directed Support was.

Jenny (PAMIS) told member there is a consultation about the new Health and Social Care Standards. This is on the Scottish Government's website.

Madge Clark asked if Audit Scotland would investigate why young people who have learning disabilities are being placed in elderly care homes.

Chris (SCLD) said they will be talking to Scottish Care about inappropriate care placements next year (2017).

Jan (ENABLE Scotland) said the Cabinet Secretary for Finance promised an extra £107 million in the Scottish Budget for 2017-

18. He said this would be given to Integration Authorities, to “ensure improved outcomes in social care”

Jan asked the Cross Party Group if we could ask Jackie Baillie MSP to find out more about this money.

Everyone agreed we should ask Jackie to do this.

7. Empathy training for Support Workers

Gillian and Alexander from the Edinburgh Development Group spoke about their work on empathy in support work at the last meeting.



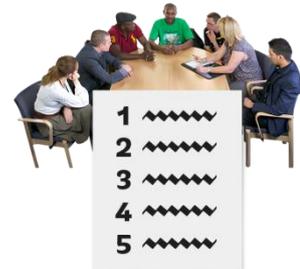
Alexander said he couldn't come to this meeting. Everyone agreed Gillian and Alexander can update us at one of our next meetings.

8. Work plan for the Cross Party Group

Jan Savage spoke about plans for the Cross Party Group.

At our last meeting we chose four big things people wanted to talk about at our meetings this year.

Today we talked about one of these: Social care and care charging.



We agreed to ask for volunteers to help decide who we could invite to speak and what we actions we should take. Jan asked who would like to volunteer to help plan for each of the big things we want to talk about.

These are:

- Social Security and jobs
- Residential care and living options
- Education, including bullying, and sex and relationships.

James (People First) said People First would like to help plan the meetings on all of these things. He said People First talk about hate crime not bullying.

Sally (ENABLE Glasgow) said she would like to speak about her work on hate crime.

Colin (ENABLE Glasgow) said ENABLE Glasgow would like to help plan the meeting on Residential care and living options.

Florence (Quarriers) said Quarriers has done a lot of work on hate crime. We would like to be part of planning a meeting on hate crime.

Fiona (Autism Rights) said it will be too much to try to talk about education and hate crime in one meeting.

Jan (ENABLE Scotland) said we might want to have a separate meeting on hate crime. But bullying is a big problem in schools.

Jan asked if everyone agreed with the plan to have a joint meeting on social security and jobs with the Cross Party Group on Disability?

Everyone Agreed with this plan.

9. Anything Else?

Fiona (Scottish Autism) asked what is happening with mental health law review?

Chris Creegan (SCLD) said they have sent their report to Scottish Government a few weeks ago. The Minister will decide when the report is made public.

Jan (ENABLE Scotland) said we had talked about this earlier in the meeting. Jackie told us she had asked a question in parliament about this.

The Scottish Government will answer this question in January.

We agreed that ENABLE Scotland will update the Cross Party Group when the Scottish Government answers Jackie's question in Parliament.

Kayleigh (ENABLE Scotland) told the Cross Party Group about ENABLE Scotland campaign on education.

#IncludED in the Main?! is ENABLE Scotland's campaign about schools.

ENABLE Scotland has spoken to lots of people to find out what they think about school.

We talked to:

- young people who have learning disabilities
- teachers and school staff
- parents and carers of young people who have learning disabilities

More than 800 people filled in surveys about school.

Lots of young people who have learning disabilities said they feel lonely at their school.

They said they had been **bullied**.

And didn't have any friends.

Some young people said they **miss out on school trips**.

Some young people said they don't get to play games or sports.

Many young people said they don't get the right support in school.

Lots of teachers are worried about not having the right support to help young people who have learning disabilities.

Most school staff said they **don't get enough training** to help young people who have learning disabilities.

Lots of school staff said there are not enough expert teachers.

These are sometimes called Additional Support for Learning Teachers.

Parents and carers feel worried.

They feel like they don't have anyone to talk to about their worries about school.

They feel like they have to argue to get the right support for their child at school

Lots of parents and carers told us their child had been sent home from school a lot.

They think this is because their child is not getting the right support at school.

This means that some young people who have learning disabilities are missing out on their education.

ENABLE Scotland's report says the changes that should happen to make schools better for young people who have learning disabilities.

Kayleigh said we can find ENABLE Scotland's report on their [website](#).

Actions

- ENABLE Scotland will speak to the Cross Party Group on Disability about a joint meeting on social security and jobs.
- ENABLE Scotland will ask Jackie Baillie MSP to find out more about the £107 million in the Scottish Budget for 2017-18 that the Cabinet Secretary for finance said would be given to Integration Authorities, to “ensure improved outcomes in social care”
- Everyone should collect **stories about social care charging**. These are called case studies.
Members can send their evidence of social care charging to ENABLE Scotland at CPG@enable.org.uk
ENABLE Scotland will share the stories from Cross Party Group members with Johann Lomont MSP
- Write to the Cabinet Secretary to find out more about the plans for **feasibility study on social care charging**. The letter will say the feasibility study should look at how we can end social care charging for all disabled people.
- ENABLE Scotland will update the Cross Party Group when the Scottish Government answers Jackie’s question in Parliament on the Mental Health Law Review.
- Planning meetings about the agendas for future CPG’s.