

**Minutes of the meeting of the  
Cross Party Group for Learning Disability  
Committee Room 3, Scottish Parliament  
Tuesday 23<sup>rd</sup> February 2016**

**People who were there**

Jackie Baillie MSP  
Joan McAlpine MSP



Jan Savage (ENABLE Scotland (Secretariat))  
Kayleigh Thorpe (ENABLE Scotland)  
Kayleigh Hirst (ENABLE Scotland)  
Sarah Wilkie (ENABLE Scotland)  
Colin McKay (Mental Welfare Commission Scotland)  
Chris Creegan (SCLD)  
Linda Allan (Scottish Government)  
Jess McPherson (Scottish Government)  
Penny Curtis (Scottish Government)  
Ruth Wilson (Scottish Government)  
Colin Menabney (ENABLE Glasgow)  
Rachel Le Noan (Downs Syndrome Scotland)  
Eleanor Brewster (Royal College of Psychiatrists)  
Neil Hendry (Camphill Scotland)  
Ewan Hamilton (Key Community Politics)  
James McNab (People First (Scotland))  
Rhona New (People First (Scotland))  
Caroline Gray (Quarriers)  
Iain Cuthertson (Quarriers)  
Florence McQuilter (Quarriers)

Sonya Bewsher (LDAS)  
Andrew Doyle MBE (LDAS)  
Ian Hood (LDAS)  
Layla Theiner (Disability Agenda Scotland (DAS))  
Helen Wright (Edinburgh Development Group)  
Frances McDonald (Edinburgh Development Group)  
Andy Williams (Central Advocacy Partners)  
Elizabeth Findlay (Central Advocacy Partners)  
Gloria Greganti (Ark Housing Association)  
Sue Tait (Ark Housing Association)  
Jenny Miller (PAMIS)  
Emma Soanes (Unity Enterprise)  
Christine Carlin (Mindroom)  
James Fletcher (ARC Scotland)  
Edward Fairweather (Gowrie Care)  
Sarah Buchan (Gowrie Care)  
Rachel Webb (Scottish Autism)  
Patricia Kearn (Speak Out Advocacy Project)  
Geraldine Herd (Speak Out Collective)  
Paul Lindsay (Speak Out Collective)  
Fiona Sinclair (Autism Rights)  
Gregor Sinclair (Autism Rights)

### **People who could not come and sent apologies**

Annabel Goldie MSP  
Ken McMahon (DCP Scotland)



## 1. Welcome

Jackie Baillie MSP welcomed everyone to the meeting.



## 2. Minutes of the last meeting on 16<sup>th</sup> June 2015

Jackie said Linda Allan from the Scottish Government had asked to change some words in the minutes.

She asked if everyone was happy with the changes. Everyone said yes.



Everyone said the rest of the minutes were correct.

Jackie said at a previous meeting Annabel Goldie had been nominated as Co-deputy Convener.

But there were not enough MSPs at that meeting to make this official.

Jackie said there were 2 MSPs here today so we could make it official.



Jackie nominated Annabel as Co-deputy Convener.

Joan McAlpine MSP supported the nomination.

Jackie said it was important to do this because Annabel had sent letters on behalf of the Cross Party Group.

So it was important to make sure the group were happy to have her acting on their behalf.

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

#### A new law about Mental Health

Jackie said the Cross Party Group had agreed that they wanted the Scottish Government to look at whether the Mental Health Law should cover people with learning disabilities.



The group agreed at the meeting in April that they would try to get the Government to look at this.

Jackie tried to change the law to say that the Scottish Government **had** to look at whether the law should cover people with learning disabilities.

There was a vote in Parliament on 24<sup>th</sup> June about the law.

MSPs voted not to change the law. So the law does not say the Scottish Government **have** to review it.

But even though it is not in the law, the Scottish Government have said they will still do a review.

This is good news. And a good result for the Cross Party Group.

## **Letters to transport providers**

Jackie said at the last meeting, the Cross Party Group agreed to send letters about issues with access to transport.

Jackie said when the group get any replies they will be emailed to Cross Party Group members.



Jackie said there is a Scottish Parliamentary Election in May.

After that the Cross Party Group will be reformed. There might be some new MSPs.

Jackie suggested that the group invites the new Transport Minister to a meeting to talk about transport issues.

Everyone said they were happy to do this.



## **Protecting the rights of people with learning disabilities**

Jackie said there was a story in the news recently about Winterbourne View.

Winterbourne View was a care home in England where people with learning disabilities were abused.



The news story said a report had been done about Winterbourne View.

The report recommended that the UK Government should have a Commissioner for people with learning disabilities.

A Commissioner is a person who would promote the rights of people who have learning disabilities.

Jackie said she thought this was an interesting idea.

She wondered if Scotland should have a Commissioner for people with learning disabilities too.

## 4. Mental Health Law

Jackie introduced Penny Curtis and Ruth Wilson.

Penny and Ruth are from the Scottish Government team who are working on the Mental Health Law.



Ruth said the Scottish Government wants to find out if the law should cover people who have learning disabilities or not.

The Scottish Government will ask lots of people what they think of the law. This is called a review.

They will make sure people with learning disabilities are included in the review.

Ruth said the Scottish Government are working with the Mental Welfare Commission and the Scottish Commission for Learning Disability on this review.

Colin McKay is from the Mental Welfare Commission. He talked a bit more about the work they are doing on this review.

Colin said lots of people have asked for the law to be changed in the past. But it hasn't happened yet because it's very complicated.

Colin said The Mental Welfare Commission want to find out what people want to achieve by changing the law.

They also want to find out how they can make sure everyone can have their say about the law.

Colin said they would like to do a survey for Cross Party Group members and other people who are interested in the law.

He called this survey a 'scoping exercise'.

They are also going to write some information to help people understand...

- what the law is used for just now
- how it affects people with learning disabilities
- what other countries say in their laws
- how laws about human rights affect the issue.

Colin said the Mental Welfare Commission will write a report for the Scottish Government.

The report will give the Government some suggestions for how to do the review.



Jackie asked when will the review of the law actually start?

Colin said they will write their plan over the spring time.

So after the election in May the new Scottish Government will look at the report and decide how they want to do the review and when it will start.

Ruth said when the Scottish Government have a timescale in place for the review they will tell the Cross Party Group.



Jackie asked if the Scottish Government has to finish the review by a certain time?

Ruth said the new mental health law was passed in August 2015.

The Scottish Government have to do the review within 3 years. So they have to do the review by August 2018.

Ian Hood is from Learning Disability Alliance Scotland (LDAS).

He asked how people with learning disabilities will be included in the review?

Colin said they are keen for everyone to take part in the review.



But they are not sure about the best way people with learning disabilities can take part. Because some parts of the law are complicated and hard to understand.

He said the Mental Welfare Commission will work with others to find out the best way for people with learning disabilities to take part.

Chris Creegan is from the Scottish Commission for Learning Disability (SLCD).

Chris said people with learning disabilities would be involved from the start of the work.

James McNab is from People First (Scotland).

He said People First (Scotland) have been campaigning for a long time to change the law.

He said People First (Scotland)'s campaigning wants to change the Law so that Learning Disability is not defined as a mental disorder.

Colin (Mental Welfare Commission) said People First have worked hard on this so far.

And they want People First (Scotland) to be involved both parts of the review.

Fiona Sinclair (Autism Rights) asked if the Cross Party Group will campaign for the law to be changed so it does not cover people with learning disabilities and autism?

Jan Savage said some people think the law should change. But other people think the law should not change.

So the Cross Party Group would not campaign for one thing or the other.

Jackie said the Cross Party Group want to be involved in all the work that is going on with the law.

She suggested it is put on the agenda for a meeting in autumn.

Jackie thanked Colin, Chris, Ruth and Penny for coming to the meeting.

## **5. Residential care**

Andrew Doyle is Chair of LDAS.

He said LDAS are worried that councils are developing residential care homes for people with learning disabilities.



Andrew said he used to live in residential care. He said people used to say he could not live a “normal” life. Andrew said he now lives in his own flat, he is married and has a job.

Andrew said even people with complex learning disabilities can live in the community and enjoy the same things as other people.

Andrew said most people with learning disabilities choose to live their own homes.

He said living in a residential care home is often people’s last choice.

Patricia Kearn is from Speak Out Advocacy South Lanarkshire.

She said more and more people with learning disabilities are being placed in care homes for older people.

She said councils do this because they don’t have enough money.

Colin Menabney is from ENABLE Glasgow.

He said not all care homes for people with learning disabilities are bad.



He said there are some smaller homes that work well.

Colin said there are 4 things that make group living work well:

1. People are close to their family and friends
2. Family and friends are involved in people’s support
3. People have a say about how the home should be run

4. People in the home use community doctors and dentists rather than having a doctor or dentist in the home.

James McNab told us about the work that People First (Scotland) did with Scotland Excel on procurement of care home places.

Patricia said smaller group homes can cost a lot of money to run.



She said she knew 4 people who used to live together in South Lanarkshire.

But the council didn't put enough money into their home.

The people have now been placed in a larger home for older adults. They do not get the support they need to get out and about.

Jackie said councils were going to have less money to spend. So this problem is likely to get worse.

Neil Hendry is Chief Executive of Camphill Scotland.

He said sometimes people think residential care is the opposite of living in the community. But it is not that black and white. There are lots of options in between.

He said it was important to look for examples of good practice in all types of care.

Linda Allan is from the Scottish Government's Keys to Life team.

She said lots of people with learning disabilities live independently. But some people can feel lonely.



She said the Keys to Life team will be working with Dr Anne MacDonald to look at where people live. Especially people who live far from home.

Linda said the keys to life team want to know if people are concerned about residential support.

They want to find out what works well for people. What works well for people in towns and cities as well as people who live in rural areas.

Linda Allan said if anyone has any evidence about people being moved to care homes for older people, please pass it on.

Florence McQuilter is from Quarriers.

She said she thinks people who have been in their homes for years should be allowed to stay in their own homes.

Jess said they think people should have choice and control. That is what is most important.



Elizabeth Findlay from Central Advocacy Partners said advocacy is also important.

She said some people do not have access to advocacy.



Jess said the Scottish Government agree that advocacy is important. Advocacy is one of the big issues in the Keys to Life.

Patricia Kearn said money for advocacy services is being cut. So some people who need advocacy don't get it.

Ian from LDAS thanks everyone for a good discussion about residential care.

He said LDAS think there is still space for small residential care settings that give people a good life.

Jackie suggested we invite Linda, Jess and Dr Anne McDonald to the next meeting to talk more about residential care.

Everyone said they were happy to do that.

Jackie and Joan had to leave the meeting at this point.

Jan Savage from ENABLE Scotland is the Secretariat for the Cross Party Group. She took over chairing the meeting.

She said the formal business of the Cross Party Group was now finished because the MSPs on the group had to leave.

But the group could carry on talking about the next issue.

## 6. Keys to Life

Jan said the Keys to Life team had written a report for the Cross Party Group about what they have been working on.

Linda Allan is from the Scottish Government's Keys to Life team.

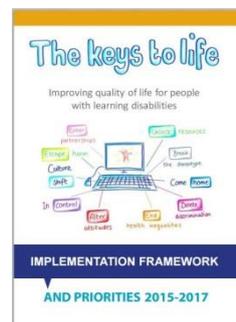
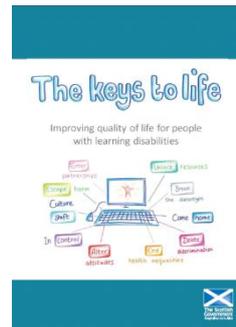
She said the Keys to Life is a plan for 10 years.

Last year the team wrote a new plan.

The plan was about what to work would happen during 2015-2017

Linda said the plan will help the Scottish Government to think about what they can achieve in 2 years.

Linda talked about some of the work the Keys to Life team are doing.



## Health information

Linda said the Scottish Government needs more information about the health of people with learning disabilities.



The Scottish Learning Disabilities Observatory was set up a year ago to work on this.

Linda said they are finding out information about people with learning disabilities going into hospitals.

She said this information would help the Scottish Government understand why people with learning disabilities don't live as long as other people. And help them understand how they can change this.

Jan said the Cross Party Group has not met anyone yet from the Scottish Learning Disabilities Observatory.

She said we could invite someone to come to a future Cross Party Group meeting.

## Health and fitness

Linda said lots of people with learning disabilities told the Scottish Government that eating healthy and being fit is important to them.



She said the Scottish Government have been finding out things that will help people with learning disabilities stay healthy.

Fiona Sinclair (Autism Rights) asked about the information Scottish Government has about health and life expectancy for people who have learning disabilities and autism.

Linda Allan said the Keys to Life team are working with the Scottish Learning Disability Observatory. This work will help get better information about the health of people who have learning disabilities.

Jan Savage suggested the Cross Party Group think about inviting someone from the Scottish Learning Disability Observatory to come to the Cross Party Group.

## Funding

Linda said the Scottish Government had awarded money to people to set up projects about:



- hate crime
- parenting
- being socially connected
- employment and
- complex care needs

She said the keys to life team are working with Active Scotland to think about how to make sport more accessible to people with learning disabilities.

Christine Carlin from Mindroom said she would like to know how much money had been awarded for these projects.

Jess said about £400,000 had been awarded for one year.

She said the Keys to Life website will have details of successful projects soon.

Linda said lots of people and organisations had applied for the money.

She said the Scottish Government are interested in the projects that did not get the money as well as the ones that did.

She said there are lots of good ideas out there for how to make life better for people who have learning disabilities.

## 7. Anything else?

### **People with learning disabilities and dementia**

Rachel Le Noan is from Down's Syndrome Scotland.

She said people with learning disabilities have a higher risk of getting dementia.

She said half of people who have Down's Syndrome will have dementia by the time they are 60.



She said people are meant to get a link worker when they are diagnosed with dementia.

But none of the people she works with have had a link worker.

She said link workers know about dementia.

But they don't know about Down's Syndrome.

She said some younger people with Down's Syndrome and dementia have been put into care homes for older people.

But the staff in care homes for older people are not trained to care for people with Down's Syndrome.

She said the Scottish Government's plan for dementia will be published in spring.

Down's Syndrome Scotland would like the plan to include information on people with learning disabilities and dementia.

She suggested the Cross Party Group invites the Scottish Government's dementia team to a meeting next year.

Jan said other organisations can support Down's Syndrome Scotland on this issue.

She said the Cross Party Group could think about it in the new session.

## **ENABLE Scotland campaign**

Kayleigh Thorpe is from ENABLE Scotland.

She said their latest campaign is about education for young people who have learning disabilities.



It is called **Included in the Main?!**

She said lots of young people with learning disabilities don't have the same opportunities as other young people to take part in school and other activities.

She said ENABLE Scotland is having a national conversation about all this. They want to know more about what school is like.

Kayleigh asked everyone to join in the conversation by putting messages on Facebook and Twitter.

People can also fill in surveys on the ENABLE Scotland website: [www.enable.org.uk/includedinthemain/](http://www.enable.org.uk/includedinthemain/)

There will be a survey for teachers coming soon.

She asked group members to pass on any stories they have about the experience of young people with learning disabilities in school.

## **Hate crime drama**

Florence McQuilter said Quarriers were putting on a drama about hate crime.



People with learning disabilities were acting in the drama.

It was on 29<sup>th</sup> February.

## Elections

Ian Hood said the Scottish Parliamentary elections are happening soon.



And there will be a referendum on whether the UK should stay part of the European Union soon.

He said LDAS had written Easy Read information about the election and the referendum.

You can get this from the LDAS website:

<http://www.ldascotland.org/>

## 8. Next meeting

Jan said the Scottish Parliamentary election is happening in May.

So today's meeting was the last Cross Party Group of the current parliament.

She said thank you to all the Cross Party Group members.

She said the Cross Party Group had achieved a lot this year.

Jan said after the election they would look at who the new MSPs are and ask some MSPs to join the Cross Party Group on learning disability.

## 8. Actions – things to do before the next meeting

Who	What to do
ENABLE Scotland	Send round any replies from transport providers to Cross Party Group members.
Everyone	Send evidence about people with learning disabilities being moved to care homes for older people to the Scottish Government
ENABLE Scotland	Invite Linda Allan, Jess McPherson and Dr Anne MacDonald to the next meeting to talk about her work.
Keys to Life team	Bring information about amounts of money that has been awarded to projects
ENABLE Scotland	To speak to new MSPs and ask them to join the Cross Party Group