

**Minutes of the meeting of the
Cross Party Group on Learning Disability
Committee Room 1, Scottish Parliament
Tuesday 11 September 2018, 1pm – 2:30pm**

People who were there

Jackie Baillie MSP (Convener)*
Joan McAlpine MSP (Deputy Convener)*
Jeremy Balfour MSP*
Lorne Berkley (SCLD)*
Sonya Bewsher (LDAS)
Gillian Callander (RCSLT)*
David Campbell (ENABLE Scotland)
Nathan Cork (People First)
Sandy Cruickshank (LDAS)
Jana de Villiers (Royal College of Psychiatrists)
Sally Ann Elfverson (ENABLE Glasgow)
Ewan Hamilton (LDAS)*
Neil Henery (Camphill Scotland)*
Bronach Hughes (Scottish Government)
Shirley Hyman (ENABLE Scotland ACE)
Sharon Irvine (Cornerstone)
Kirsty Kennedy (ENABLE Scotland ACE)
Maureen Martin (EDG)
Robert McGeachy (Camphill Scotland)
Frank McKillop (ENABLE Scotland)
James McNab (People First)*
Colin Menabney (ENABLE Glasgow)*
Jenny Miller (PAMIS)*
Kate Morris (ENABLE Scotland)



Graeme Morrison (Healthcare Improvement Scotland)
Rhona Neil (People First)
Alison Roy (Equal Futures)
Marion Smith (Get2gether)
Kayleigh Thorpe (ENABLE Scotland)*
James Watt (Empower Glasgow- Unity Enterprise)
Bianca Wood (People First)

*= Voting Member

People who could not come and sent apologies

Eleanor Brewster (Royal College of Psychiatrists)
Sam Cairns (North Lanarkshire Advocacy)
Lorraine Mackenzie (Carer)
Michael McEwan (ERDA)
Christine Riddoch (Garvald West Linton)
Evelyn Shields (North Lanarkshire Advocacy)
Donna-Marie Speir (Values Into Action Scotland)
Diane Willis (Glasgow University Nursing and Healthcare)



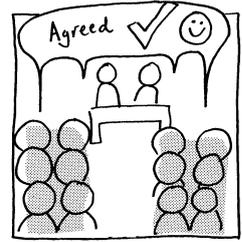
1. Welcome

Jackie Baillie MSP welcomed everyone to the meeting and noted the apologies above.



Jackie asked everyone present to remember to speak in accessible language so that everyone is able to follow the discussion. She asked members to let us know if they don't understand something so that it can be explained more clearly.

Minutes of last meeting and matters arising



- **Mental Health law review**

- Andrew Rome, the Chair of the Independent

Review of the place of learning disability and autism in the Mental Health (Care and Treatment) (Scotland) Act 2003, addressed the last meeting of the CPG. He agreed to come back to the group with an update next year. He also agreed that notes from meetings of the review's advisory groups will be published on their webpages, and we have had an update that the website should be set up to do this before the end of this year.

- **Where people live**

- The Scottish Government's new Programme for Government last week included a commitment to increase the number of accessible homes that are being built.
- At our meeting last September, Dr Anne MacDonald from the Scottish Government's Keys to Life team spoke about the housing needs of people who have complex learning disabilities and who are not able to live where they want to because of the availability of housing that meets their needs. Her report was due for publication this August, but we have had an update that it should be published soon.

- Jackie asked if members of the Cross Party Group would like an update on this report once it has been published at a future Cross Party Group meeting, and members agreed they would like this.

- **Access and support into employment**

- Jackie said that the Scottish Government had a consultation on targets for employment of people who have disabilities in the public sector. This consultation is now closed, and we are looking forward to seeing what the Government recommends as a result.

- Jackie said that at the Cross Party Group meeting in February, Maura Lynch from the Scottish Commission on Learning Disability (SCLD) spoke about their Employment Task Group and hoped to give an update on their report at today's meeting. The report hasn't been published yet, but we have had an update that it should also be published soon. Members agreed they would like an update on this report when it is ready.

- **The Keys to Life**

- Jackie welcomed members of the Scottish Government's *Keys to Life* team who had joined us to listen to the discussion of today's issues. The Keys to Life team have

been running engagement events around Scotland over the last few weeks, and there is one more being held in Edinburgh on 3rd October. There will be an update at a future meeting.

- **Accessibility of Government consultations**

- Jackie said we agreed at the last meeting to raise the accessibility of Scottish Government consultations with the Cabinet Secretary for Communities, Social Security and Equalities, Angela Constance MSP. There was then a Cabinet reshuffle, so we will now raise this issue with the new Minister with responsibility for equalities, who is the Minister for Older People and Equalities, Christina McKelvie MSP.

2. AGM

Jackie said that to make sure that we follow Parliament's rules, the Cross Party Group must hold an Annual General Meeting (AGM) every year to elect office bearers.



Jackie asked Kayleigh Thorpe from ENABLE Scotland to chair the election of Convener.

- Jackie Baillie MSP was proposed as Convener by Jeremy Balfour MSP, seconded by Joan McAlpine MSP, and agreed.
- Joan McAlpine MSP was proposed as Deputy Convener by Jeremy Balfour MSP, seconded by Jackie Baillie MSP, and agreed.
- ENABLE Scotland was proposed as Secretariat by Jackie Baillie MSP, seconded by Joan McAlpine MSP, and agreed.
- Jackie noted that as the Group does not handle any money, there was no need to elect a Treasurer.
- Jackie confirmed that MSP membership of the Cross Party Group is:
 - Jackie Baillie MSP
 - Joan McAlpine MSP
 - Jeremy Balfour MSP
 - Alex Cole-Hamilton MSP
 - Alison Johnstone MSP
 - Oliver Mundell MSP
- Jackie asked if any organisation that wishes to be added to (or to withdraw from) the official membership of the Group could contact ENABLE Scotland afterwards.

- Jackie said that there are now stricter rules about holding and using people's contact details as a result of the new GDPR rules, so the CPG Secretariat may need to ask members to confirm that they are happy to stay on the mailing list.
- Jackie closed the AGM section of the meeting.

3. Loneliness and isolation and access to healthcare

Jackie introduced **Marion Smith** from get2gether and **Alison Roy** from Equal Futures to talk about the impact of loneliness on people who have learning disabilities, and their work to tackle loneliness.



Some of the key points made were:

- Loneliness is dangerous to a person's health. People who have learning disabilities are more likely to be lonely than the rest of society. One of the main reasons why people with learning disabilities are so lonely is because of fear.
- Get2gether run club nights across Edinburgh and Midlothian where people who have learning disabilities can be supported to go out, so that they can make real friends to spend time together with when they are not being supported.

- A lot of parents of people who have a learning disability are concerned about the long term future.
- Equal Futures have found that the more support a person has in their life, the harder it is for that person to have real friendships. Some people who get 24 hour support will say that their key staff member is their best friend.
- They provide security and reassurance for families by helping people to build friendships with people who aren't paid to be there, and also by helping them to plan ahead.
- One member was moving house in her 30s and Equal Futures supported her through this transition. She now has people she can turn to when she is in need.

Jackie introduced **Neil Henery** from **Camphill Scotland** who



spoke about their approach to tackling social isolation and loneliness.

Some of the key points made were:

- Camphill Scotland has 11 communities. This is a positive effort to create places where people can live together and have fulfilling lives.

- The Communities are organised in 3 ways; family life in households where people live together with house parents, meaningful work which helps people to find a sense of vocation and the chance to develop valued skills, and encouraging cultural and spiritual life through poems, plays and music.
- Camphill Scotland suggested actions for the Cross-Party Group including:
 - Asking the Scottish Government what steps the National Strategy to tackle social isolation will take to make sure that people who have learning disabilities can access cultural and leisure activities and initiatives.
 - Asking the Scottish Government how the National Strategy will support children and young people who have learning disabilities during their transition from child to adult services.
 - Asking the Scottish Government if the National Strategy will require Community Planning Partnerships to work with community bodies, including third sector organisations and people within local communities, to identify and progress specific actions and initiatives to tackle isolation and loneliness amongst people with disabilities.

- Asking the Scottish Government to update the National Performance Framework to include a strong focus on tackling social isolation and loneliness. They should ensure that local authorities, NHS Health Boards and other key agencies are all taking action in an integrated and joined up approach to tackle these issues.
- Asking the Scottish Government and the Care Inspectorate to investigate what care providers are doing to tackle social isolation and loneliness, and to add this to the Care Inspectorate's questionnaire for care inspection visits.
- Jackie introduced **David Campbell** from **ENABLE Scotland** to talk about his work in partnership with Macmillan Cancer Support to develop the *7 steps to equal healthcare* for patients who have a learning disability.



Some of the main points made were:

- ENABLE Scotland are working in partnership with Macmillan Cancer Support to try and find out more about the experiences of people who have learning disabilities in cancer diagnosis and treatment. The study has been broadened to find out the views

of staff and volunteers in cancer services about how best to support people who have learning disabilities.

- The project found that the issues are not just about cancer, but they are more about healthcare in general, ways of communicating with patients and the physical environment.
- They have developed the '*7 steps to equal healthcare*' which focuses on empowering people by telling them about the 7 steps. They should feel like they can raise their concerns and not to be scared to ask for something different.
- The *7 steps to equal healthcare* are:
 - 1. Imagine being me**
 - 2. Find out who and what matters to me**
 - 3. Listen to me**
 - 4. Give me the info I need, in the way I need it**
 - 5. Think about where we are**
 - 6. Work with others who are in my life**
 - 7. Giving treatment seems too difficult? Think again**
- There will be a seminar on 29th October in Glasgow to launch and discuss the new materials.

4. Questions and Discussion

Jackie thanked all the speakers for their presentations and asked if anyone had any questions or comments.

- James McNab (People First) said that People First held an event and a focus group where members highlighted the need for better accessible transport, employment of people who have learning disabilities, getting the right support, and the need for places in communities where people who have learning disabilities feel welcomed.
- Ken MacMahon (Division of Clinical Psychology) said that it is important for the NHS to communicate in an accessible way and in different formats.
- Bianca Wood (People First) said that it is not easy for people who have learning disabilities to go on the internet, so if you can't speak to someone, you become isolated.
- Colin Menabney (ENABLE Glasgow) said that communal living can be a positive choice when delivered properly. Loneliness can make people ill and the Scottish government should consider this. He said that communal living is not right for everyone but there aren't a lot of other options.

- Sally Ann Elfverson (ENABLE Glasgow) said that she used to go to a centre during the week and a Tuesday night group run by ENABLE. She said that since it has moved to a new venue, she is unable to go as it is further away and there aren't good transport links.
- Jenny Miller (PAMIS) said that it is important to work together and that it takes time to understand people's needs. When the right tests and assessments are not done, it people don't get the treatment they need.
- James Watt (Empower Glasgow) said that fear stops people going out into communities. The existing schemes in place to combat this like Keep Safe are good but they are not big enough. There is a need for something wider and more educational tools.
- Maureen Martin (EDG) said that there is a resource called '*What? Why? Children in Hospital*'. This is a website that explains the treatments people may have to go through. There is also a video of how treatments are completed, which helps children to understand what the treatment will be like. Something similar might be a good idea to help people who have learning disabilities.

- Jana de Villiers (RCP) said that mental health should be considered equal to physical health, and that learning disability nurses are core in providing care. The hospital environment for people receiving mental health treatment should be of an equal standard.
- Graeme Morrison (Healthcare Improvement Scotland) said that his organisation has been exploring people's experiences of cancer, as well as standards and indicators. Standards are being developed around cervical screening and access to services. This process has just started and they are interested to find out peoples experiences of cancer.
- David Campbell (ENABLE Scotland) said that learning disability teams should be more involved in hospital teams. He said that they encourage joint working, including staff within cancer services and other services to contact each other and not to be afraid to pick up the phone.
- James McNab (People First) said that accessible information is really important, but it is hardly ever available. Trying to find out when and where to go for appointments is sometimes very difficult. Getting support on the day when you have an appointment can also be difficult.

- Bianca Wood (People First) said that People First are working on a project in Clyde Gateway which will involve developing materials and delivering sessions to raise awareness of the screening arrangements for cervical, breast and bowel cancers.
- Bronach Hughes (Scottish Government) introduced herself to the group and explained that she is a part of the team working on social isolation and loneliness. She said the actions outlined sound good and that she has taken a note of them. She also thanked everyone for their responses to consultation.
- Jackie said that there is an opportunity presented with housing and changing housing models that may help to combat isolation.
- Sandy Cruikshank (LDAS) said that socially rented housing needs to be available and all housing needs to be affordable, as one of the main reasons for loneliness is because housing is allocated outside of people's communities.

Jackie said she would take forward the following actions:

- Ask the Cabinet Secretary for Communities and Local Government, Aileen Campbell MSP, what progress has been made since the consultation on *A Connected Scotland*, and

what measures are being proposed to tackle loneliness and isolation for people who have learning disabilities.

- Ask the Minister for Mental Health, Clare Haughey MSP, how the Keys to Life strategy will aim to tackle loneliness and isolation for people who have learning disabilities.

- Ask the Cabinet Secretary for Health and Sport, Jeanne Freeman MSP, what action is being taken to make healthcare services more accessible to people who have learning disabilities.

- Ask the Housing Minister, Kevin Stewart MSP, to confirm details of the governments plan to build more accessible and affordable housing in the socially rented sector.

- Ask the Minister for Older People and Equalities, Christina McKelvie MSP, about plans to make government consultations more accessible for people who have learning disabilities.

5. Plan for next year's meetings

Jackie said that the next meeting of the Cross Party Group is booked in for Tuesday 4th December at 1pm, and we have

previously agreed that the topic of the meeting will be social care.

Jackie said that we have asked Parliament for available dates for meetings in 2019.

Jackie said that the Cross Party Group could look to make a real change around social care next year, and can also ask the Keys to Life team to give an update on the work they are doing. The Group could also ask Andrew Rome to give us updates on the Mental Health Act review in early and late 2019.

Jana De Villiers (RCP) asked if the Cross Party Group could consider the issue of delayed discharges where community support packages had not been provided.

Jackie said that Alexander Warren is also ready to give us an update on his research on empathy in support work which he first presented to the CPG in 2016.

6. Anything else?

- Bianca Wood (People First Scotland) said People First Scotland has issued a statement on how possible changes to the law on neglect might affect



parents who have learning disabilities, and encouraged other members of the Cross Party Group to respond to the Scottish Government's consultation on Protecting Children.

- Marion Smith (Get2Gether) said that Get2Gether have completed research on self-determination, and the interim report is ready to share.
- Values Into Action Scotland are holding an event on *'Relationships, Sexuality and the battle against Loneliness'* on 12th September in Glasgow.

7. Close meeting

Jackie thanked everyone for taking part, and closed the meeting.