

Minutes of the Cross-Party Group on Learning Disability

Zoom Session

Wednesday 16 December 2020, 1pm – 2:30pm

People who were there

Jackie Baillie MSP (Convener)*
Joan McAlpine MSP (Deputy Convener)*
Oliver Mundell MSP
Jan Savage (ENABLE Scotland)
Nicole Forsyth (ENABLE Scotland)
Paul O’Kane (ENABLE Scotland)
Derek Feeley
Frank McKillop (ENABLE Scotland)
Mike Casey (Garvald Edinburgh)
Jana De Villiers (The State Hospital)
Pat Graham (PAMIS)
Colin Menabney (ENABLE Glasgow)
Nick Ward (National Autistic Society Scotland)
Jenny Miller (PAMIS)
Andy Miller (SCLD)
Sam Cairns (North Lanarkshire Advocacy)
Anette Pyle (Scottish Government)
Sonya Bewsher (Values Into Action Scotland)
Sandy Cruickshank (Parent)
Pat Graham (PAMIS)
Alan Guild (PAMIS)
Kenneth Fleming (SCLD)
Emma Walker (Camphill Scotland)
Leanne Keegan (Community Integrated Care)
Lorraine MacKenzie (Parent carer)
Aiden Reid
Vikki Manson
Aaron Wallaker



Jason Henderson (National Autistic Society Scotland)
Alison Taylor
Andy Foreman
Andy Williams (Central Advocacy)
Arron Ashton (Scottish Government)
Caroline Kingston (People First Scotland)
Clare White
Craig McEwen
Graeme Roy
Louise Scott (Scottish Government)
Malaika
Maureen (EDG)
Mike Warwick
Paddy Carstairs (ARC Scotland)
Rob Watts
Sharon Irvine (Cornerstone)

People who could not come and sent apologies

Jeremy Balfour MSP
Ewan Hamilton (Values Into Action Scotland)
Alina Mykytyshun
Sally Ann Elfverson (ENABLE Glasgow)
Mark Kolek
Michelle Kerr
Miriam Brown
Angela Henderson
Andy Williams (CPP Parents Network)
Gillian Smith (SLDO)
James Cap (Parents Network)
Laura Ferguson
Catherine Dempsey (ARC Scotland)
Stuart Wardall
Tracey McFall (Partners in Advocacy)
Veronica Gibson
Frances Macdonald (Edinburgh Development Group)
Rob Holland (National Autistic Society Scotland)



Lynnette Linton (ARC Scotland)
Arun Chopra (Mental Welfare Commission)
Franck David (People First Scotland)
Karin Heber (SASW, Scottish Association of Social Work)
Emma Reilly (The Huntercombe Group)
Shona Cardle (Glasgow Children's Hospital Charity)
Sarah McClarey (Salvesen Mindroom Centre)
Brendan Nisbet (Scottish Government)
Adam Wilson (Families Outside)
Alice Squire (ARC Scotland NIN)
Roger Watt (Scottish Government)
Keith Lynch (People First Scotland)
Paul White (ELCAP)
Gillian Barclay (Scottish Government)
Brenda Bradley (North Lanarkshire Advocacy)
Marian McDonald (Garvald West Lothian)
Susan Weir (Parent)
Christine McEvoy (Parents group)
Christopher McKinlay (PAMIS)
Tom Ritchie (Teens Plus)
Simon Webster (Independent Review of the Mental Health Act)
Andrew Strong (The ALLIANCE)
Paul Surgenor (Pagoda PR on behalf of British Psychological Society)
Kelly Cunningham (ELCAP)
Ewelina Rydzewska (SLDO)
Andy Rome (Independent Review of the Mental Health Act)
Marjorie Irving (The Usual Place)
Douglas McConachie (British Psychological Society)
Steve Robertson (People First Scotland)
Vivien Jayne (Down's Syndrome Scotland)
Catriona Petrie (North Lanarkshire Advocacy)
Chris O'Shea (Royal College of Psychiatrists)
Sarah Moreland (Mindroom)
Michael McEwan (ERDA)
Maureen Martin (Edinburgh Development Group)

Melanie Lowe (Scottish Government)
Nick Hobbs (Children and Young People's Commissioner Scotland)
Andrew Fraser (Royal College of Psychiatrists)
Norma Curran (Values Into Action Scotland)
Gillian Callander (RCSLT)
Alex Cole-Hamilton MSP
Alison Johnstone MSP
Mark McDonald MSP
Sharon Horne-Jenkins (NHS)
Faye Keogh (Turning Point Scotland)
Robert McGeachy (Camphill Scotland)
Colin McKay (Mental Welfare Commission)
Alison Roy (Equal Futures)

1 Welcome

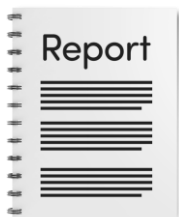


Jackie Baillie MSP welcomed everyone to the CPG meeting, noting that the meeting would be recorded and asked anyone who did not want to be recorded to switch off their camera. Jackie noted the apologies above.

2 Presentation and discussion with Derek Feely around Independent Review of Adult Social Care



Derek is chairing the independent review as part of the programme for government, which is due by the end of January 2021. The aim of the Review is to recommend improvements to adult social care in Scotland in terms of outcomes achieved by people who need social care support. Derek said the Review is taking a human rights-based approach.



The Review is beginning to see value in having a more national approach and is looking at what a national care service should do. This is being informed by people who receive social care, their families and carers. The Review will also look at how that system should be funded and regulated and continuously engage people.

Derek said that individuals and providers should be part of the commissioning process. He also said that unpaid carers are the cornerstone of the system and that there

will be investment in the social care workforce, working with the Fair Work Convention.

Joan McAlpine MSP added feedback around the national care review of older people and the behaviour of the private sector. She said that the third sector and unpaid carers have told them that local authorities have let people with learning disabilities down.

Joan has a motion in Parliament about this and the loss of day services and the failure to replace them with any meaningful social care packages. It was mentioned that people should receive individual assessments rather than by their provider as these assessments can be cost driven.



Derek added that there has not been investment in local implementation and a national care service should create local capacity for improvements. He said that ENABLE Scotland should be able to help with this process and it needs to be nationally directed. Derek said that the diversity of provision in Scotland can be a strength, but we need to enable collaboration. This can be done through the commissioning process.

Derek is confident the Review has spoken with the right people and has gained a strong view on the needs, rights

and preferences of people. He welcomed the Group to send further thoughts or questions.



3. Matters Arising

- **Independent Living Fund (ILF) Scotland**

Jackie said the response to the resumption of ILF has been circulated with everyone and Joe Fitzpatrick said that the ILF is due to meet with Derek's Review of Adult Social Care.

Paul introduced Linda from ILF who updated on ILF's CEO, Peter Scott's meeting with the Review in October. Peter presented a paper to the Review giving options on how ILF can contribute towards the Review. Peter has since provided Derek with further information on how ILF can be repositioned to help with any national scheme. This topic will be added to the next meeting as a matter arising for further updates.



- **Care Home Visiting**

Jackie said that the Government has produced new guidance which has been circulated to the CPG. This guidance is still not working for everyone and Jackie added that there is a related issue from PAMIS about people with learning disabilities being supported by paid carers in hospital.



Jackie introduced Pat who said that social work Fife will not fund people in hospital with a disability as it is the responsibility of the NHS, meaning that individuals would not have one to one support if admitted to hospital.

Pat updated on an ongoing complaint with NHS Fife and the ombudsman, who replied on 9th October saying that a multi-agency approach should apply, and joint emergency contingency plan should be drawn up to ensure needs are met. The Mental Welfare Commission is pursuing the issue with Fife HSCP. Jean Freeman MSP endorsed all points and stated that social care support will be needed, and carers will be able to provide that support in hospital. This is a legal matter and there may be complexities but there should be no delays.

- **Testing for Care Staff**

This issue was raised in Parliament and Joan updated on the announcement of those being tested would begin mid-January. Joan has written a lot of letters to Government and raised research being done around people with learning disabilities being 6x more likely to die from Covid-19. Joan hopes that third sector organisations and charities are also making the case to Government and she will be asking when care workers are going to start being vaccinated next week.





- **Mortality Rate**

Annette said that she has a statement prepared by the Scottish Learning Disability Observatory on Covid-19 work in terms of the death data. Work is ongoing as Covid-19 has led to excessive deaths in the learning disability population in Scotland. Data has been made available to the Observatory researchers and is being analysed and will be shared with Scottish Government and made available immediately following disclosure and quality checking.

Joan said that she was told the data would be published in September and that Public Health England has already published this data. Annette said they have different processes, so we have to set up our own data analysis in Scotland.

The CPG agreed to follow up with the Scottish Government to ensure that the data is published as soon as possible.

- **Keys to Life**

A document was circulated around which explained that the Scottish Government is working with COSLA on a recovery and transformation plan in response to Covid-19. This plan will be the next version of the Keys to Life.

A draft is with the Minister for Health and will be discussed at COSLA.

This was shared with stakeholders at a joint meeting with Keys to Life and Autism strategy stakeholders.



A joint plan is being looked at because whilst everyone is different, when we look at the issues which impact on people's lives, there are common high-level themes that are important to people with learning disabilities and also autistic people.

Feedback so far is that health and mental health are high on the agenda, and there is acceptance that people are not starting from the same place of equality and restrictions have had a serious impact on mental health. The pandemic has deskilled people in lots of ways, with more anxiety, isolation, and digital exclusion.

Annette said we must tackle isolation and inclusion. Services must be built back and be person-centred. The pandemic has also had an impact on education for pupils and on employment.

Anette welcomed any feedback from members of the CPG following the meeting.

- **Commissioner for people who have a learning disability**

Jan updated that ENABLE Scotland is working to set up a leadership group of people with learning disabilities, working with organisations in the autistic community to build a consensus for a reason for the commissioner. Jan said that they spoke at the SNP party conference and highlighted persistent challenges in human rights over the years, despite good policy intentions. Jan added that the fact there is still no access to data on mortality rates, is further evidence that something needs to change.

Jan told the Group that we will hear evidence from the Fraser of Allander Institute on why this population is invisible when it comes to public policy and decision making. She said that this needs leadership to change.

A campaign will be launched in the new year. This will ask for a commitment from every political party to create a stronger function that stands up for the human rights of people who have a learning disability and autistic people too.

Jan said the cross-party group supported this campaign idea at a previous meeting. She said that some people had different ideas about how it should work, but she hoped that everyone could agree that we need change.



Jan apologised for her audio connection as it was poor.



4. Fraser of Allander Institute

Professor Graeme Roy introduced research he has been working on with colleague Rob Watts around the relationship between people with learning disabilities in Scotland and economic outcomes for them and their families.

Rob said that the research centres on people's focus on core agendas in Scottish policy making and lack of understanding of the challenges faced by people with learning disabilities.

The research aims to understand the key issues faced by adults with learning disabilities from a policy wide economy level. Rob said that Keys to Life sets out a whole person approach, which needs to mean whole Government approach.



The research so far has found that strategies mostly talk about the need to overcome disability inequalities but not learning disability. Barriers faced by people with learning disabilities are not discussed outside of learning disability strategies.

A webinar was held for people with learning disabilities to share issues that are important to them. People said that support services, inconsistent provision impact by Covid-19, housing, social security, employment, and devolution of key benefits were key issues for them.

Rob said that we need to change peoples' attitudes towards learning disability. He added that learning disability is rarely mentioned across Government.

Rob will be working on the research until September and hopefully beyond. Graeme will remain involved too even though he is moving to another university.

Graeme asked the Group to reach out to them to help inform the research.

5. Local Area Coordination

Nicole Forsyth presented slides on what LAC is and what it means in Scotland. She said that there are LAC services in 13 local authority areas across Scotland.

Ralph Broad, from Inclusive Neighbourhoods added that LAC is for people of all ages and backgrounds. It is about a whole community approach and reducing the need for dependency services.



Ralph said that LAC enhances the voice of those usually excluded. He added that LAC is about natural support of a community instead of waiting on a crisis before intervening.

Ralph was involved in a Scotland meeting where 13 areas expressed interest in transitioning to this approach.

Ralph spoke about the opportunity for more investment in LAC services in more communities across Scotland as we plan to move out of the pandemic.

Jackie said that the Keys to Life had originally had a commitment in it to look at the role of LAC services across Scotland. She suggested that Parliamentary Questions could be asked about the progress of this commitment. She asked that information provided by Ralph be shared with the Group. Joan McAlpine and Oliver Mundell indicated that they would have a follow up meeting to pursue.



6. Any other business

Emma from Camphill Scotland raised the issue of reopening of day services. She is concerned that the pandemic was used to advance previous agendas to cut budgets. This is impacting hugely on day services.

Emma said that day services provide meaningful work opportunities as people with learning disabilities work with and for the community. This allows people to create connections.

Emma added that they have received 18 cancellations and 17 potential terminations of contract and 62 services are still closed. There are 97 families who are desperate.

Emma asked if the Group could pull together a survey for other service providers. She also welcomed Joan's motion and asked that everyone contacts their parliamentarians.



Choice

James said that people who have a learning disability have the right to say no to the vaccine.

Jackie thanked James and said that it was important to share different views.

People First Scotland have seen an opportunity to introduce a pilot programme and Jackie asked Caroline to share.

