

Minutes of the CPG on Disability and AGM Minutes

16 September 2020 at 1pm

Virtual – Zoom

Attendees:-

Jeremy Balfour	MSP
Stuart McMillan	MSP
Julia Shillitto	Secretariat
Katie Mackie	Office of Jeremy Balfour MSP
Mike Harrison	Treasurer
Stephanie Fraser	Cerebral Palsy Scotland
Kenryck Lloyd Jones	CSP
Alison Keir	RCOT
Kim Hartley Kean	RCSLT
Ross Barrow	COP
Katherine Byrne	CHSS
John Ballantine	Edinburgh Access Panel
Rae Cahill	Action on Hearing Loss
Tina Yu	Sense Scotland
Cate Vallis	RNIB
Jock Encombe	The EC Partnership
Keith Park	MS Society
Aidan Reid	RSPSYCH
Jana Devilliers	RSPSYCH
Gavin MacLeod	Scottish Disability Sport
Alison Skillin	OTADCC
Shabaz Khan	SACU
Maggie Ellis	EKTG and WSA
Sarah Russell	Headway
Patricia Hewitt	Adult Carer
Donna Tomlin	Contact Scotland
Colin Millar	SPAEN
Catriona Burness	RNIB
Colette McDiarmid	MND Scotland
Nada Shawa	EaRN
Kayleigh Miller-Lambie	GIRFEC - SG
George Allan	SPPN
Laura Smith	Children's Health Scotland
Pat Duffy	STUC Disabled Workers Committee/GMB
Fiona Souter	PAMIS
Mark Kelvin	Disability Snowsport UK
Maureen McAllister	Versus Arthritis
Salena Begley	Family Fund
Terry Robinson	Individual

Denis Shovlin

Scottish Churches Disability Group

Apologies:-

Miles Briggs MSP	Scottish Parliament
Dr Lisa Cameron MP	Westminster Parliament
Hazel Kelly	RNIB
Janis McDonald	Deaf Scotland
John Miller	Action Duchenne
Hussein Patwa	Individual
Gillian Sefton	SACU
Claire Mooney	Individual
Tony Slaven	STUC Disabled Worker's Committee / UNISON)
Anne-Marie Barry	Guide Dogs

1. Jeremy Balfour MSP opened the meeting at 1pm, and welcomed everyone.

2. AGM business:-

- The minutes of the meeting of 18 September 2019 were approved as a correct record.

Appointment of Office Bearers:

The office bearers were reconfirmed:

- Jeremy Balfour MSP as Convenor – Proposed by Mike Harrison and seconded by Stuart McMillan MSP
- Stuart McMillan MSP as Deputy Convenor – Proposed by Jeremy Balfour MSP and seconded by Stephanie Fraser
- Office of Jeremy Balfour MSP as Secretariat with a review after the election.
- Mike Harrison as Treasurer – Proposed by Stephanie Fraser and seconded by Nada Shawa

The other MSP members were also reconfirmed:

- George Adam MSP
- Jackie Baillie MSP
- Alex Cole-Hamilton MSP
- John Mason MSP

- Pauline McNeill MSP
- Anas Sarwar MSP
- Colin Smyth MSP
- Alexander Stewart MSP

The following non MSP individual and organisation members were reconfirmed or added to the list:

Non MSP Individuals:

- Paul Cockburn
- Aurora Constantin
- Patricia Hewitt
- Michael McEwan
- Janice Connelly
- Carolyn Hunter
- John Sutherland MBE
- Hazel Kelly
- Wilma McLean
- Claire Mooney
- Emma Pauley
- Rebecca Pender
- Yvonne Stevenson-Robb

Organisations:

- Office of Jeremy Balfour MSP - secretary
- Scottish Accessible Transport Alliance, (SATA) – treasurer
- Action Duchenne
- Action on Hearing Loss
- ASD Fife Community Hub
- Capability Scotland
- Carers West Lothian
- Cerebral Palsy Scotland
- Children’s Health Scotland
- Disability Equality Scotland
- Down’s Syndrome Scotland
- Dyslexia Scotland
- EKTG
- Equality & Rights Network
- Glasgow Centre for Inclusive Living (GCIL)
- Glasgow Children’s Hospital Charity
- Glasgow Disability Alliance (GDA)
- Go Upstream
- Guide Dogs Scotland
- Headway
- Inclusion Scotland
- Lead Scotland
- Leonard Cheshire
- Motor Neurone Disease Scotland (MND)

- MS Society
- Multiple Sclerosis Therapy Centre Lothian
- PASDA
- PhoneAbility
- Quarriers
- Remploy
- Renfrewshire Access Panel
- RNIB Scotland
- Royal War Blind and Scottish War Blinded
- Scottish Auto Cycle Union (SACU)
- Scottish Churches Disability Group (SCDG)
- Scottish Commission for Learning Disability (SCLD)
- Scottish Council on Visual Impairment (SCOVl)
- Scottish Disability Sport
- Scottish Personal Assistant Employers Network (SPAEN)
- South Edinburgh Amenities Group (SEAG)
- Scout Scotland
- Sense Scotland
- Skills Development Scotland
- STUC Disabled Workers' Committee
- Talk Time Edinburgh
- Turning Point Scotland
- UK Owner Trained Assistance Dogs Campaign for Change (OTADCC)
- Versus Arthritis
- West Dunbartonshire Access Panel

Treasurers Report:-

- Spent £500 last year, there is still £91 in funds. Jeremy said as the meetings are happening virtually we will look at the £91 again in the future.

Action: - Jeremy Balfour MSP will complete and submit the necessary paperwork to the Scottish Parliament.

AOB:-

Maggie Ellis - EKTG and WSA, informed the group that there has been further action regarding accessible toilets to be 'accessible'. The North Highland Council are ignoring the Equalities Act and keeping them locked. Westminster MPs also taking up issue. Help needed to complain about lack of equality.

Conclusion of the AGM

The minutes of the meeting of 17 June 2020 were approved and noted as the meeting was not quorate.

The group formally approved 2 organisations as members of the CPG on Disability:

- Children's Health Scotland - Dr Laura Smith
- UK Owner Trained Assistance Dogs Campaign for Change, (OTADCC) – Alison Skillin

Jeremy welcomed Stephanie Fraser from Cerebral Palsy Scotland to the meeting and the panel of speakers. The CPG meeting was led by Stephanie Fraser from Cerebral Palsy Scotland and theme of the CPG was the rehabilitation of patients post COVID-19 and the provision of services.

A panel of Speakers participated in a Question and Answer Session:

- Stephanie Fraser – Cerebral Palsy Scotland
- Kim Hartley Kean – Royal College of Speech & Language Therapists
- Alison Keir – Royal College of Occupational Therapy
- Kenryck Lloyd Jones – Chartered Society of Physiotherapy
- Ross Barrow – The College of Podiatry

Stephanie Fraser thanked the group for the opportunity to make a presentation, as Chief Executive of Cerebral Palsy Scotland.

Stephanie provided background of CP Scotland and made a slide presentation –

Bobath Scotland changed their legal name and rebranded as Cerebral Palsy Scotland from 1st April 2020. CP is the most common physical disability in children.

Experience since March has been similar to all of us. The Centre closed in Glasgow from 23rd March and those with CP were left vulnerable. Ability of individuals to assess vulnerability was difficult. CP helped with assessments and CP specific advice with weekly zoom group support, and a weekly update summarising guidance and how it affected people with CP. 30% identified as being shielded.

What was the impact of restrictions on CP? There was a Survey monkey consultation in May. (The findings on first survey on slide. Inability to get assessments, lack of respite care such as help from elderly parents etc.) Following this, the reopening the centre was very important at Phase 3, and the centre re-opened from week commencing 13 July 2020.

Only 8% of people with CP were put on shielding list but many more chose to shield. Whole families needing to shield adding to sense of isolation. People not feeling confident about making decisions re shielding. Confusing. Who to go to for information? Some asked consultants, GPs, therapists. Some wanted to be on list as it helped with online shopping but did not understand isolation of being on list.

Commented [SF1]: It is a neurological condition, but epilepsy is more common – so I've re-worded to be accurate.

Following the lifting of lockdown, many not able to access pre-covid care package. Some didn't want people in their homes - risk of catching covid

Healthcare. Many not able to access healthcare other than online or by phone. Access to physio and pain issues big challenge. Equipment issues and access to mental health care. Shocking that 17% not been able to speak to anyone. Left to get on with it. System needs to be better. Pressure on family life. Families of kids with CP struggling to cope, as often they are the sole carer. Physical, emotional, home schooling siblings. Grandparents not able to help due to shielding etc. Adults have had to move back with elderly parents. Carers often not able to come into home. People struggling.

Schools – so important schools more than just education. Families can access respite support, therapy input. 79% sent kids back to school but many still feel school not safe. Again how do you assess risk despite risk of covid for kids.

Some schools unable to accommodate child. Kids with additional needs being put in "too difficult" group. Waiting to hear.

Access to specialist services should resume as should community services. Evidence of physical and mental health decline. Mid-September and level of care at pre Covid levels still not restored.

Within remobilisation of services there is potential for a triaging role for 3rd sector organisations. – increasing evidence that people turning to 3rd sector during the pandemic. CPS Looking to supply post covid support. Who needs to be sign posted where? How do people reconnect with other statutory and community services? Organisations facing increased demand for services at a time when opportunities to raise funds for organisations etc. have been hugely reduced meaning that organisational resilience could not be more perilous.

Shielding Policy Team good communication but what happens now? What are the implications of local lockdowns? Stephanie thanked the group for the opportunity to present and lead the meeting and asked please do get in contact if there is anything you would like to know more about: info@cpscot.org.uk

Kim Hartley Kean – RCSLT – Thanked the group for the opportunity to speak. RCSLT represents 1,600 speech and language therapists. SLTS work for people of all ages with eating, drinking, swallowing and / or speech, language and communication difficulties. Stephanie's comments reflect concerns of Speech and Language Therapists.

Alison Keir – RCOT – 3,500 OT's work with people of all ages, across all sectors, schools, homes, health, social care and 3rd sector, helping regain or to have skills that are important in life. Occupation deprivation. OT's help with loss of occupation. Right for rehabilitation for everyone. Should not have to wait for this intervention.

Kenryck Lloyd Jones – CSP - Very concerned with slow pace of return of services. Written to Health Boards. Number of people suffer from loss of services due to covid

but not because they had covid. If there is a second wave services should remain open.

Ross Barrow – COP – 1,000 podiatrists in Scotland. Very keen to promote and engage.

Jeremy Balfour MSP - directed a question to Kim Hartley Kean – Lockdown has increased waiting lists, once normal caseload picks up how do we get to a point where we get numbers under control. How do we catch up as some of the most vulnerable are left behind. How will this work? Danger we never catch up.

Kim Hartley Kean – Children and Young people need speech and language therapy services at universal (all children), targeted (children who are at risk of having poor outcomes) and specialist levels (children who have an identified need which can benefit from direct SLT).

Capacity of SLT services pre and post lockdown to deliver services has been extremely challenged. Demand for SLT is much greater post lockdown. RCSLT and SLT Children and Young People Service leaders have written to John Swinney MSP, Deputy First Minister and Cabinet Secretary for Education and Skills about catch up for children and young people who had missed out on services during the pandemic. Parents and colleagues in education need support too. There is as it stands still no requirement for schools to work with therapist. There is no guidance or clarity re PPE for visiting services to schools. Multi agency approach in schools is still not there yet and there are ongoing SLT funding issues. It is also not clear whether the Pupil Equity Funding (significantly increased for schools to “catch up”), will reach SLT services. There are additional cuts in SLT funding in some local authority areas; there is no guidance on access to AHP services for Local Authorities for children with additional support needs.

Kenryck Lloyd Jones - capacity, planning and priorities. We need shift to happen. Community services stretched before Covid. Facing consequences of not providing services. Now facing consequences of pandemic and backlog plus normal caseload. Government needs to plan and action required with funding.

Stephanie Fraser – If there is a 2nd Lockdown – the 3rd sector has a role to play. Triaging – 3rd sector can be the one to refer up. Essential services should not be locked down if there is another wave. Third sector can help statutory services share the burden but need funding. Rehab services were already stretched pre-covid, even worse now. 3rd Sector can help with this.

Alison Keir – There is a tsunami of need for rehabilitation. Rehab a problem before Covid, huge problem now. People who have had Covid medically better but far from normal. Greater need for rehab than ever has been.

Maureen McAllister – Those working from home – MSK support.

Kenryck Lloyd Jones – MSK services capacity not available to meet demand. Services are resuming too slowly.

Maggie Ellis – Need for digital services. Example of Estonian being in UK and having medical records on a phone. There is no such system in Scotland but SG may have it in place in 2024.

Kim Hartley Kean - We do need better digital services. Members of Primary care clinical professional group asking for sharing of records. GDPR issues but these can be overcome. Although digital is good for many I caution that there are mixed messages re digital care. Digital doesn't work for everyone or is preferred by everyone. Digital by default not good for everyone as explained by Stephanie.

Kenryck Lloyd Jones - Difference between virtual services and use of digitised patient records. (which would help everyone). Virtual services not always appropriate

Alison Keir - Grampian facebook page for all to access – everyone the same. Digital better attendance rate and kids can set their own goals. Need to look at blended opportunities.

Katherine Byrne - Rehab framework – a missed opportunity?

Stephanie Fraser - Yes. Difficult to see what service providers should do differently because of framework. May be a right to rehab in theory but not everyone can access this. Rehab can be a difficult term, for example for disabilities that are degenerative. You cannot put additional needs on a strained system unless additional funding in place

Kim Hartley Kean – The rehabilitation framework needs to be backed by funding. Need a strategy for AHP services and money behind it. We need a Right to rehab. Good if group could consider questions on right to rehab framework capacity and funding. Consider raising a Question with the Parliament about the “right to rehab” and where the Government sees the money coming from.

George Allan – Scottish Post Polio network – rehab has been a problem for a long time. One door approach is not happening. Need for PPS co-ordination, Specialists, Doctors and professionals coming together. For a referral usually have to go back to a GP.

Kenryck Lloyd Jones - should be no need to go back to GP to get a physio appointment. Rehab service and community services right for service users and NHS. Need to shift balance of care from acute to community services, so that patients require shorter stays if they do need to go to hospital and have a better quality of life.

Panel Summing Up:-

Ross Barrow - Framework - missed opportunity inclusive framework must have all professionals. Access – not all services are back up and running. Where do they go next, back to GP? Onus shouldn't be on the patient should to get a GP referral. Digital – risk assessment required. Is it appropriate for service user? Opportunity to improve links between clinician, digitally.

Kenryck Lloyd Jones – It is taking longer to get an appointment however, your referral comes into the system. This shouldn't be the case.

Alison Keir – Framework gives us a document about rehabilitation which we have not had before and we are in a different situation than previously. Social deterrents of health have a huge impact. Very much about how we can work in that type of approach and move away from healthcare being about medical issues.

Kim Hartley Kean - would like to request CPG look to get whole team (included in GIRFEC) given access to schools. No clear guidance at the moment. Needs to be some more central guidance as schools under pressure. Kids have a lot of catching up to do.

Stephanie Fraser - what is backing for rehab framework? Need to look at services in the round. There are community services that keep people well, such as gyms, parks, supported centres and these need to be considered within the rehab context too. Need to look at risk and risk assessment. At moment, feels like professionals are assessing why they can't help people. How do we enable families, service providers to assess their own risk more accurately so that they can weigh up the risk of covid vs staying well and healthy? Current guidance not helping with this.

Jeremy Balfour MSP thanked the panel for their contribution.

AOB – There was no further business and the meeting closed at 2.30pm.

The date of the next CPG on Disability is 9 December at 1pm.