

# Cross-Party Group on Disability AGM

Wednesday 11 June 2025 at 1pm-2.30pm

Minute

Present

MSPs

Jeremy Balfour MSP  
Pam Duncan-Glancy MSP

Invited guests

Amanda McCarren – Scottish Government  
Dr Mark Bevan – Family Fund  
Salena Begley MBE – Family Fund

Non-MSP Group Members

Julia Shillitto (Office of Jeremy Balfour MSP)  
Sam Barge (Office of Jeremy Balfour MSP)  
Eloise Richmond (Office of Pam Duncan-Glancy MSP)

Ian Buchanan  
Andrew Muir  
Alex Kellas  
Gordon Downie  
Jack Bradford  
Jenny Miller  
Joanne Devit  
Shaun Powell  
David Kerr  
Liz Kerr  
Jess Wade  
Maggie Ellis  
Charlotte Mitchell  
Karen Procek  
Lawrence Cowan  
Doug Ross  
Elle Tashdjian  
Dr Caroline Gould  
Julie Brown  
David Stewart  
Fiona Souter

Natalie Frankish  
Terry Robinson  
Mark Gaffney  
Rob Gowans  
Marianne Scobie  
Sue Bowen  
Joanne McGee  
Douglas Bryce

## Apologies

Alexander Stewart MSP

Hussein Patwa  
Nicoletta Primo  
Jill Pritchard  
Robin Wickes  
Donna Tomlin  
Lucy Mulvagh  
Celine Sinclair  
Joanna Zawadzka  
Antonella Valbonesi  
Alison Pendragon

## Agenda item 1

Welcome by Jeremy Balfour MSP.

### **AGM BUSINESS**

Minutes of the AGM meeting on 12 June 2024 approved as a correct record.

Appointment of office bearers were nominated as follows:-

Convener – Jeremy Balfour MSP  
Deputy Convener – Pam Duncan-Glancy MSP  
Treasurer – Mike Harrison  
Secretariat – Spinal Injuries Scotland – Ian Buchanan

Treasurer not present to give report – funds stand at £91.14.

Winner of Charity Draw to receive banking funds – PAMIS – changing places toilets.

Maggie Ellis said she expected any future in person meeting to have provision for refreshments funded by Jeremy.

No matters arising.

No Items of correspondence.

## **AOB – Maggie Ellis raised Accessible Toilets –**

Jeremy advised the Group that Maggie has met recently with Kaukab Stewart, Minister for Equalities who agreed to write to the Equalities and Human Rights Commission, (EHRC) in their role as the body responsible for overseeing the Equalities Act 2010, seeking information on work undertaken or yet to undertake on accessible toilets. There was no commitment made at that meeting to arrange a meeting for the CPG and the First Minister.

Maggie advised she attended a meeting of the Justice Committee in Westminster, yesterday with various important members of that Parliament who deal with Equalities, Maggie said we need to be very careful not to disallow meetings to happen

Maggie pressed for in-person meetings particularly for AGM meetings.

Dr Caroline Gould pressed for online meetings as she lives a considerable distance away on the Isle of Skye and is disabled and in a power-wheelchair.

Jeremy advised that for this session of Parliament the Group would continue with online meetings as this was the majority consensus.

## **AGM BUSINESS CLOSED**

## **Agenda item 2**

### **Meeting Proper**

Minute of 26 February 2025 were approved as a correct record after it was agreed the terminology to correct the minute from 'learning difficulties' to read 'annual health checks for those with 'learning disabilities.'

Karen Procek who raised this in the minute – it was her understanding that learning difficulties takes into account dyslexia. Where is learning disabilities? We're going into a lot more complex issues that people who will be going for the annual health checks. It applies to them.

It was noted for the Group that Marianne Scobie raised that within the disability movement in terms of the whole social model of disability, we are talking about people with learning disabilities, which does include people with diagnosed medical conditions, which cause them to have a 'learning difficulty'. Marianne thinks that's about medicalised and disabled people, and disabled people's issues.

New Members were approved:-

CAPS Advocacy – Alex Kellas

Spina Bifida Hydrocephalus Scotland – Lawrence Cowan

## **Agenda item 3**

Presentation by Policy Official – Amanda Mccarren, Learning Disability Policy Manager, Neurodivergence and Learning Disabilities Unit, Mental Health Directorate briefed the group on the implementation of annual health checks for those with learning disabilities.

**SLIDES will be circulated with the minutes.**

Currently the population with learning disabilities makes up around 0.5% of the whole population in Scotland.

In 2019, there were 23,584 adults known to local authorities across Scotland with learning disabilities.

People with learning disabilities die on average 20 years earlier than the general population from largely preventable diseases.

Adults with learning disabilities have poorer health and poorer access to health-care than other people.

Morbidity burden and multimorbidity is higher in the population with learning disabilities than in the general population.

People with learning disabilities are at higher risk of physical conditions associated with potentially avoidable mortality, such as:

- Diabetes
- Asthma
- Epilepsy
- Chest infections/aspiration
- Chronic constipation

People with learning disabilities are also at higher risk of mental ill-health with high rates of psychotropic prescribing observed. This emphasises the need for better prevention and tailored management of health conditions to reduce the risk

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Annual Health Checks were extensively piloted, evaluated and refined between 2000 and 2010, in advance of a national roll-out

In 2011 and 2012 a randomised controlled trial, using this tool, was conducted to investigate the clinical and cost-effectiveness of AHCs for adults with learning disabilities - a key finding of the RCT was that the AHC resulted in significant increases in health monitoring needs being met including detection of unmet clinical need

They have also been evidenced to be cost-effective, being both cheaper and more effective than standard care

NHS England Learning from Lives and Deaths People with a Learning Disability (LeDeR) 2021 report showed the likelihood of dying aged 18-49 years was 1.5 times

greater for people with learning disabilities who had not had an annual health check in the previous year.

#### Annual Health Checks – National Directions –

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#### **The annual Scottish Health Check is a targeted invitation and core routine activity available to anyone aged 16+ with a learning disability**

Implementation and Support from Boards include:-

National Implementation Group (NIG) with representation from all Board areas along with key Scottish Government officials and stakeholders. (meets monthly)

Data programme board feeding into the NIG to support data and reporting requirements of annual health checks. (meets quarterly)

Policy Leads from Scottish Government meet individually with NHS boards to support implementation as and when required

A commissioned programme of work with NES which includes a specific page on TURAS for annual health checks with education and resources to support practitioners in carrying out annual health checks

During the last national reporting period we saw an average of 40% of annual health checks carried out resulting in onward referrals with some Board areas seeing this at around 80%.

Some examples of onward referrals reported are;

- Occupational Therapy/Speech and Language
- Gynaecology
- Behavioural Support Team
- Screening Programmes
- Audiology
- Dental
- Falls Team
- Epilepsy
- Dietician

Related Benefits include:-

Improved data collection for people with learning benefits – see slides.

Positive impact stories include:-

Following discussion and advice at their annual health check and subsequent ongoing support, an individual lost over 4 stones in 5 months, and is now exercising, which has massively increased their confidence and ability to interact socially.

During delivery of a health check, a staff member discovered the adult was being financially exploited by a paid carer. Adult Protection referral resulted in immediate action being taken to improve the adult's circumstances.

An annual health check identified several red flag symptoms of breast cancer for someone not yet eligible for screening. An urgent GP appointment was made, and an urgent referral actioned by primary care for further investigations.

**Jeremy** thanked Amanda for her briefing and advised the Group that If you want to take political questions, we can take them and write to the new Minister.

**Mark Gaffney – Scottish Disability Sport** – wanted to highlight the role of physical activity as the second biggest driver after obesity in many studies and health inequality around about physical inactivity. We have a regional manager network that can receive referrals from allied health professionals. Can introduce individual to physical activity in a supported way.

**Amanda McCarren** – We have a national implementation group and that meets on a monthly basis – it would be good to invite you to promote a session in the future.

**Lawrence Cowan** – Regarding the 40% to 80% uptake levels at NHS, various different NHS boards - quite a big difference - Are they in the areas of lower uptake? Were there any kind of general themes that were the barriers that need to be overcome for that?

**Amanda McCarren** - The 40 to 80% was the uptake in referrals resulting from the health checks. There is differentiation in the uptake across all of the boards. Some boards have closer to 70% uptake. Issues include transport difficulties, how it might affect benefits, or medical/GP support already in place, or missing an appointment, we try to get information through lived experience to see how to improve on uptake.

**Marianne Scobie** wished to raise a concern around Disabled people with learning difficulties, who have additional protected characteristics or who are also disabled, people who have physical impairments and are you gathering data on them? Use of hoists for example, or difficulty in coming in for a smear test and ethnic or LGBT additional protected characteristics.

**Amanda McCarren** - We fund The Scottish Learning Disabilities Observatory (SLDO), who are based in Glasgow University and they carry out quite a lot of research projects.

We make reasonable adjustments - Reasonable adjustments in terms of people with physical needs, so having hoists for example and having access to clinics.

**Jeremy** left the meeting to Answer a Question in the Chamber and asked Julia to Chair the remainder of the Meeting. **Pam Duncan-Glancy MSP** also left to attend to business in the Chamber.

**Maggie Ellis** – raised two points - what happens to 'sensitive records', who holds them and how secure are they? People don't want to be part of a group of records which they have no control over and point two - paramedical professions there is in general a lack of actual training and ability of the majority of those staff, who are fully qualified to deal with the topics raised.

**Amanda McCarren** – Point 1 - in terms of the information in records, - all of the information regarding a health check and also the registers that we ask the health boards to create, are held within primary care, within general practice are within your GP medical records and stored that way. So no-one has access to that, apart from the usual people that would that would have access to your data/information. Only high level reporting coming back. The ability to control that is the same way they do for all the medical records within the GP process at the moment.

For point 2 Amanda asked if Maggie was referring to paramedics and ambulance technicians?

**Amanda MacCarren** - Scottish ambulance service are part of the implementation group and we also work closely with them on a regular basis in terms of how we can connect them into the work that we are doing, and we support the Education aspect. However, Paramedics don't carry out health checks – only registered medical practitioner or a registered nurse do. Can only comment on the nurses that people who are carrying out the annual health checks do receive the right amount of training and support.

**Julie Brown** - Firstly, what work has been done to support people with learning disabilities to register as having a learning disability with their GP? My sister-in-law has a learning disability and I'm her carer and I would need to facilitate that for her because she doesn't have the abilities because her learning disability.

**Amanda McCrren** - We're working hard on how learning disabilities is coded. Making sure that you're coded correctly. Working on that with GPs and we're creating some guidance that will be going out to all of the GPs across Scotland.

Working in line with what we ask in terms of the whole entire health check and how that's carried out.

**Julia Shillitto** – It was agreed Amanda McCarren would put her email in the Chat for Andrew Muir and Ellie TashDijan to email their questions direct to Amanda as the meeting had to move on to the second presentation as there was only 30 minutes left for the meeting. She agreed there was no problem to do this -

[Amanda.Mccarren@gov.scot](mailto:Amanda.Mccarren@gov.scot)

## Agenda item 4

Presentation Item 2 – Dr Mark Bevan from Family Fund - introduced Family Fund's *Cost of Caring 2025* research and launch of their report, focussing on the experiences of families in Scotland raising disabled or seriously ill children or young people on a low income. The research explores barriers experienced by parent carers seeking to access and sustain paid work, informing interacting areas of policy, including parent carer support, employability and child poverty.

### SLIDE PRESENTATION

The latest UK-wide research, with a particular focus on the experiences of families in Scotland, the report explores how families often encounter multiple, compounding disadvantages and barriers when trying to access and sustain paid work. It offers vital insights for policy makers and others working to improve support for parent carers — with the aim of enabling more families to increase their income and reduce the number of children growing up in poverty.

**Dr Bevan** – I am a research evaluation officer at Family Fund.

Family Fund is a grant making charity for families raising a disabled or seriously ill child on a low income.

The cost of caring reports the data is drawn from our December 2024 version of our long running family poll of families who use our services. We had over 2300 responses across the UK. The response in Scotland was 232 families.

The statistics and key findings for this presentation are all drawn from the families in Scotland.

In this presentation gives a very brief overview of some of the findings and the details of the full report will be given at the end of this talk.

Our findings suggest that for almost half of the families who responded making ends meet and getting all the essential goods they need is not possible.

45% of families reported that they are experiencing income insufficiency where their income is insufficient to meet their essential expenses.

As we know, one of the drivers of this situation is not just the cost of living rises that have affected everyone.

**A brief video clip of Norah's Story** was viewed by the group. She spoke about her daughter Jessica and their personal situation through lived experience with a non verbal child and all the complexities connected with her emotional well-being and how Universal Credit, made it hard financially, as both Norah and her partner used to work, but had to give up in order to care for their daughter.

**Mark** - Our research demonstrates that the additional costs of disability, both financial and emotional, must be properly recognised in the support available to families.

Policy must take into account that for many families, increasing paid work is not a viable solution to poverty.

Childcare and respite services must be available, affordable and tailored to children with complex needs.

The well-being of carers must be prioritised without this, families risk reaching crisis point with long term social and economic consequences.

Finally, I would like to thank all the parent carers who took time to respond to our survey and to share their views and experiences. Families are doing all they can, but they need support that reflects the complexity of their lives. We call upon policy makers, funders, support agencies and charities to continue to recognise the day-to-day realities faced by families.

And continue to work together to create a fair and sustainable future for families on a low income who are raising disabled and seriously ill children.

No family should have to choose between heating eating.

And caring for their child.

**Julia Shillitto** – Thanked Mark for his presentation and a Q&A followed.

QUESTIONS AND ANSWER SESSION FOLLOWED

**Maggie Ellis** - 93% of the population in Estonia have their own ID card, which means they can control everything about themselves, their education, their tax, their health. It's a good system and we could speak to them about this.

**Dr Mark Bevan** – agreed – If there's any opportunities for international policy learning, they should be welcomed here.

**Jenny Miller** – Had a case this week where a mum had been told that she had no right to have support for a child with really profound disabilities because that was her role as a mum to look after that child. Social work are being pushed into an untenable position but should any social worker be saying that to a parent. It can't be accepted that just because you are a mum you should be caring for your child to that degree.

**Dr Mark Bevan** – had a situation where one parent care has to give rescue baths to her daughter almost on a nightly basis. And when she reached out for support, she was told she wasn't eligible. If you are not in crisis. We're seeing in our own experiences any opportunities. Need to collaborate and work together to perhaps raise awareness of what it takes to be a carer as well as a parents.

**Salena Begley** – One of the challenges we have is that we no longer have the disabled children, young People's Advisory Group, which you know have a role in terms of advising the Scottish Government in relation to policies that impact on the lives of families raising disabled and seriously ill children, young people and most importantly disabled children, young people. Context within which parent carers are caring for disabled children and young people and carers more widely are caring. Tom Arthur MSP, Minister for Employment and Investment, did speak at the Care of Scotland conference on carers employment, fairly recently and seemed to be quite responsive to the challenge from carers. Carolyn Hunter is leading the way in that as she often does. Perhaps it's time that that we, are looked at as a cohort.

**Maggie Ellis** – Asked what training those on the call had on special training and how did they get that. An honest hands up for who thinks they've got any training appropriate would be interesting

**Julia Shillitto** - We're all working together and we have some experts in their fields here as well.

**Marianne Scobie** – We connect at GDA as well because we support disabled - Families, disabled young people and their parents. The situation is dire. Disabled parents of disabled children – need support in their own right as disabled people, never mind as parents of disabled children. And I get Maggie's points about Estonia and other countries, but until Scotland actually implements progressive taxation, I think we're not going to be able to afford a lot of the things that we actually want. And I think we

need, we need to have honest conversations about tax raising, property powers within Scotland.

**Dr Mark Bevan** – closed his Q&A session and recommended the group access the report to be able to get the details from the slides.

**Julia Shillitto** – Thanked Dr Bevan and Amanda McCarren for their presentations and for coming to the meeting.

**Maggie Ellis** – Asked if as a group we could share email contacts. Maggie had a list from previously from some members.

**Julia Shillitto** – said she would raise it again with the Convener.

**Marianne Scobie** – Asked if meetings could be held at another time, not over lunchtimes.

**Julia Shillitto** – said she would mention it to the Convener.

Meeting Closed.

Date of next meeting is scheduled for 1 October 2025.