

Scottish Parliament Cross Party Group on Disability
Wednesday 7th February 2017
Mary Fairfax Sommerville Room (CR1)
The Scottish Parliament

12.30pm-2.30pm

In Attendance:

Jeremy Balfour MSP (Convenor), Stuart McMillan MSP (Vice-Convenor), Julia Shillitto (Jeremy Balfour's Office), Katie Mackie (Jeremy Balfour's Office), Rhona McGrath (Jeremy Balfour's Office), Michael McMahon (Secretary – DAS), Natalie Frankish (Genetic Alliance UK), Salena Begley (Family Fund), John Miller (Action Duchenne), Mike Harrison (SATA), Rebecca Scarlett (Lead Scotland), Alan McGinley (Arthritis Care), Carolynne Hunter, Ann Henderson (Elaine Smith MSPs Office), James O'Malley (Arthritis Research UK), Margaret Anslow (STUC DWC), John Ballantine (SATA), Stephanie Sanchez (Parent/Carer), Rebecca Pender (Parent/Carer), Michelle Robertson (Community Brokerage Network), Janet Thornton (PA) Ben Bradbury (Capability Scotland), Carolyn Scott (SCOVI), Maggie Chapman (SCOVI), Richard Baker (Royal Blind), Seonaid Cooke (TalkTime Scotland), Jenny Miller PAMIS) Susan Walls (Contact), Maggie Ellis (PhoneAbility) Kenneth Fleming (SCLD),

Apologies:

Jackie Baillie MSP, Alexander Stewart MSP, Linz Connell (SIAA), Caitlin Brown (Quarriers), Amanda Burns (Quarriers) Peter Carruthers (South Edinburgh Amenities Group), Rachel Le Noan (DS Scotland) Terry Robison (Describe Online)

Introduction

The Convenor welcomed members and explained that the proposed speakers from CoSLA on SDS and ILIS on Employability had submitted apologies at short notice and that alternatives had not been possible to arrange. He sought agreement that these topics would be re-arranged for future meetings if possible. This was agreed.

Social Security (Scotland) Bill

The Convenor gave an update on the progress of the Social Security Bill and began by outlining the Bill's structure and passage through Parliament so far. He advised that the Stage 2 amendment phase would be completed by the end of March 2018 with the Stage 3 debate likely to be in May. He reported that the Scottish Government had accepted an amendment on providing independent advocacy. There was cross party support for this but a debate still had to take place on the definition of who would be able to access this support. There was also agreement at the Social Security Committee on claimants automatically receiving advice in statute. A discussion followed in relation to areas such as the Bill's principles and capacity to deliver services.

Presentation

Rare Diseases

Natalie Frankish – Policy and Engagement Manager – Genetic Alliance UK

Natalie outlined the aims and structures of the charity which seeks to improve the lives of people with rare and genetic diseases.

She highlighted that such diseases affected 5 in 10,000 of the general population and explained what the charity hoped to obtain by awareness raising through Rare Diseases Day on Wednesday 28 February 2018.

The work of the CPG on Rare, Genetic and Undiagnosed Conditions was spotlighted.

A lengthy discussion followed the presentation which included topics such as the provision of education and support for children with rare diseases, understanding of rights and access to records, costs and coproduction.

The Convenor thanked Natalie for her presentation and for responding in such detail to members points and questions.

AOB

John Miller raised an issue in relation to wheelchair football and advised the CPG that the local authority concerned would not assist with increasing the speed of wheelchairs as others had done. Jeremy Balfour MSP agreed to take the issue up on his behalf.

The CPG Treasurer, Mike Harrison, reported that the CPGs funds had become depleted. After a short discussion it was agreed that member organisations and individuals be asked to contribute an annual fee of £25 to cover the costs of lunch at future meetings.

The meeting closed at 2.20pm