

APPG ON DOWN SYNDROME

Inaugural meeting Wednesday May 12th 15.30 - 16.15 Via Zoom

In attendance

Dr Lisa Cameron	Ruth Cadbury	Nicola Enoch
Matt Western	James Daly	Ken Ross
Nick Fletcher	Mark Logan	Siobhan Baillie
Seema Malhotra	Virendra Sharma	Flick Drummond (represented)
Stephen Morgan	Ruth Jones	Lord Shinkwin
Gareth Thomas	Stephen Morgan	Stephen Timms
Marion Fellows	Douglas Chapman	Lord Alton
Lord Touhig	Baroness Smith	

Apologies

Elliot Colbourn

Feryal Clark

The meeting commenced with introductions and welcome from Nicola Enoch (NE) of the Down Syndrome Policy Group, advising all that the meeting was being recorded.

NE advised that both Dr Lisa Cameron and Matt Western had put themselves forward for the roles of Co Chairs. This was approved by all present. NE preceded to confirm those who had nominated themselves for the position of Vice Chairs Ruth Cadbury, Feryal Clark, Eliot Colburn, Seema Malhotra & Virendra Sharma. James Daly, Nick Fletcher and Mark Logan put themselves forward.

Roles duly elected during the meeting were;

Officers

Co Chairs	Dr Lisa Cameron MP, SNP (registered contact) Matt Western MP, Labour
Vice Chairs	Ruth Cadbury MP, Labour Feryal Clark MP, Labour Elliot Colbourn, Conservative James Daly, Conservative Nick Fletcher, Conservative Mark Logan, Conservative Seema Malhotra, Labour Virendra Sharma, Labour

Lisa Cameron (LC) confirmed that the roles had been duly elected, confirming no objections had been raised and thanked everyone for attending.

LC explained that there would be an introduction from the Secretariat followed by a video from the trustees with Down syndrome followed by discussion around the topics of discussion proposed. LC handed over to Ken Ross (KR) and NE from the Down Syndrome Policy Group (DSPG).

KR thanked LC and all for attending and recognising the need to help promote those with Down syndrome. KR went on to explain the framework of how the Down Syndrome Policy Group had been formed, a group of individuals who each run their own separate charities and within that group, all specialise in different areas. KR explained the overarching areas of focus would be for those with Down syndrome to be recognised in the same vein as Autistic and Deaf individuals as a separate group.

LC asked whether the aim of the group was to put together a Down Syndrome Act?

KR stated that if we could enshrine the support in an Act that would be amazing. The intention is to have the framework in place to support individuals and their families through life. The DSPG would love to help this group and provide as much support as needed. KR added, all the trustees specialise in certain areas, and have a wealth of experience who are here as a resource to support the APPG.

KR introduced the video and the trustees who want to talk about their experiences and how they wish the APPG to consider working.

<https://www.youtube.com/watch?v=-zL0naw24a0&t=2s>

NE began the summary of the four proposed key areas, the first being maternity care. NE explained the high numbers of expectant mothers who are given little choice in terms of screening and of those 90% will terminate, often due to the societal and medical influences. A report published by Positive about Down syndrome in October 2019, shared the experience of 1,410 women and substantiated the evidence of discrimination in maternity care. There is undue pressure for screening, letters issued still use the word 'risk', an expectation to terminate despite no medical reasons. NE raised concerns due to lack of care path for those who choose to continue, required as babies more likely to be preterm and higher incidence of still birth.

LC highlighted that people should be given the opportunity to speak with someone who is able to provide information which would ensure they are able to make an informed decision.

KR discussed the proposal on Education and gave a brief introduction into the Portsmouth Down syndrome association, currently working with over 100 establishments and training across the country but focusing on the specific learning profile of those with Down syndrome which when understood can allow education in mainstream schools. Preventing segregation and carrying through to employment.

LC drew people's attention to the time and thanked those who were having to leave.

NE provided a summary in terms of Health Care & Research. On average those with Down syndrome die 28 years earlier due to a lack of understanding in health care, resulting in poor health outcomes. Lack of physio and speech therapy, which if introduced at an earlier stage would have a much better impact on the individual. NE highlighted that currently £5.33 per individual/per year is spent on research into Down syndrome.

Siobhan Baille (SB) introduced herself and raised a question in terms of the gap from childhood to adulthood of care and support, explaining her nephew, who is 18, struggles to get consistent support as some areas do and some don't support those over the age of 18. SB asked whether this was something that could be considered in the programme of work.

NE agreed, confirming there is a void in those areas.

KR provided a summary of the current issues for those with Down syndrome in terms of employment with currently only 6% in the workplace.

Providing specific examples of those trustees within the video and their experiences in the workplace, mostly negative.

Meg Hillier (MH) very pleased group is being re-established. Meg explained she chairs the Public Accounts Committee (PAC), have done work in health care and people with disabilities, flagging that aware of life outcomes for people with LD phenomenally bad compared with the general population. Sadly, not much time to devote to this group, committee also often looks at special education needs and beneficial for the secretariat to liaise in advance of hearings to submit evidence which would help to shape the work in the issues addressed by the PAC.

NE confirmed this was something the DSPG would be happy to assist with.

Lord Alton (LA) congratulated the formation of the group and reinforced the topic of employment. LA detailed a performance previously held in the Speaker's House with the actor Tommy Jessop and whether this was something that could possibly be arranged again. LA explained that this was a topic close to his family's hearts.

KR advised that Tommy Jessop and DSPG Trustee Beth Pickard feature in short film Innocence and advised would forward link: https://www.youtube.com/watch?v=Rih_GMIjaWI

Baroness Smith (BS) provided a brief introduction to her background and her support for those with Down syndrome.

LC took the opportunity to introduce her Co-Chair Matt Western (MW)

MW thanked the attendees from the DSPG for their detailed presentations, the video from the trustees and the four key areas which he felt provided a great agenda.

LC welcomed those in the group to speak.

Douglas Chapman (DC) firstly thanked all for their hard work in forming the group. Specifically in relation to the four key areas proposed, speaking as the dad of a young man with Down syndrome DC highlighted that currently there is a gap in support from school age transitioning to college and then again into employment. DC suggested that more support in terms of helping

the families prepare their children for college and then into employment. There is nothing in terms of pre-planning or preparing families for what the future might hold.

LC stated that this group would be led by those who have Down Syndrome and they're going to be instructing the parliamentarians.

Stephen Timms (ST) advised that there is an ongoing enquiry of the Work and Pension Select Committee into the disability employment gap. ST reinforced it would be an opportune moment to raise any particular points when the Minister hears evidence next Wednesday.

KR confirmed he had information readily available which he would email directly to ST.

LC confirmed next steps in drawing together parliamentary questions which will be sent to peers and MPs to enable the issue to gain prominence across both houses. LC set out intention to hold the annual debate, previously held in 2020 and which will continue to be an annual occurrence to raise Down syndrome awareness. LC sought confirmation of Co-Chair MW that there was nothing further to raise. MW confirmed nothing further to raise.

LC finished by confirming that wherever possible those with Down syndrome should be involved in the meetings so they can lead on the work and collaboration.

LC thanked all for coming and closed the meeting.