Minutes for the All-Party Parliamentary Group on Down Syndrome (APPGDS)
Inaugural Meeting: Tuesday 19th November 2024
Room S, Portcullis House 2pm

Present:

Members

Damian Hinds MP (Cons, Chair)
Andrew Cooper MP (Lab, Co-Chair)
Dame Caroline Dinenage (Cons)
Jack Rankin
Baroness Sheila Hollins (Cross-party)
Lord Kevin Shinkwin (Cons)

Other

David Goss
(Political Principal Private Secretary to the Leader of HM Official Opposition)

Lucy Lee (Staff, Damian Hinds)

Representing the National Down Syndrome Policy Group (NDSPG) Secretariat for the APPGDS:

Rachael Ross MBE
Ken Ross OBE

Representing the National Down Syndrome Policy Advisory Group

Millie Prelogar

With virtual representations from the Cheshire Down Syndrome Group

Statement of purpose: To campaign for equal access and provision to ensure equality and promote respect at all stages of life for people with Down syndrome.

Notes of the Meeting	Action
1.Welcome and preliminaries **1.1** Welcome from presiding Chair, Damian Hinds Damian Hinds (DH) welcomed all present to meeting of the All-Party Parliamentary Group on Down Syndrome **1.2** Apologies: Jack Abbott MP, Lord David Alton, Dame Karen Bradley MP, Dame Meg Hillier MP, Rebecca Kirby MP, Jayne Kirkham MP, Amanda Martin MP, Abtisam Mohammed MP, Graham Stuart MP **2. Minutes** **2.1** Members approved the minutes from the group's inaugural meeting on 08.10.24. The minutes are filed on the APPGDS website https://appg-ds.org/ once approved.	

3. Actions update from previous meeting **3.1** Progress report on Down Syndrome Act Guidance **3.2** Minister Kinnock's response to the letter from Co-Chair Andrew cooper on behalf of the group	
Rachael Ross (RR) reported that the Department of Health and Social Care (DHSC) has confirmed they have now been given authority to proceed with the Down Syndrome Act Guidance after a significant pause. This was in direct response to the letter from the group's Co-chair Andrew Cooper (AC) to Minister Kinnock on behalf of the APPGDS dated 25.10.24 requesting an urgent update on the Guidance status. Minister Kinnock has since written to AC and the group to say Departmental officials have been asked 'to take forward the work to develop the Guidance as a priority'. The Minister said how pleased he is to hear about the group reconvening, and that he looks forward to drawing on the group's collective expertise.	
AC will write to thank the Minister for his response. DH will collaborate with the NDSPG to write a follow-up letter highlighting some additional points regarding the development of the guidance.	**AC** **DH, RR, KR**
3.3 Letter of thanks to APPGDS former Chair Damian confirmed he had written a letter of thanks to express gratitude to Sir Liam Fox the group's former Chair for his unwavering commitment and dedication to the Down Syndrome Act, improving policy and raising awareness.	
3.4 RR has formerly registered the group and officers with the Parliamentary Groups Register. A list of members has been uploaded to the APPGDS website https://appg-ds.org/.	
4. Ministerial Task Force **4.1** Ken Ross (KR) brought to the attention of the group a commitment previously made by former Secretary of State for Health and Social Care, Steve Barclay. He had agreed to establish a Cross-Party Ministerial Down Syndrome Act Guidance Task Force, the purpose of which was to facilitate collaboration among relevant departments to address and resolve structural barriers hindering the implementation of the Down Syndrome Act Guidance. However, this task force has not yet been established.	
DH will address this issue in his upcoming correspondence to the Minister, highlighting the need to expedite the formation of the task force as agreed with the previous Minister.	**DH, RR, KR**
5. Questions for Parliament In the previous APPGDS meeting, members had offered to ask questions in Parliament on behalf of members of the NDSPG Advisory Group (AG), consisting of over 160 adults with Down syndrome from Down Syndrome organisations from across the UK.	

The AG met to discuss some of the issues and challenges they face on a daily basis, and selected questions they would like to put to parliament.

One of the group's facilitators Millie was elected by the AG to represent them in person at the APPGDS and she opened with a presentation (see Attachment 1) before handing over to a video presentation led and complied by Cheshire Down Syndrome Group #IChooseBoard. The video featured a variety of individuals with differing abilities from regions across the UK including Scotland, Portsmouth, Bristol, Northwich, the Wirral, London, Midlands, Coventry, Lancs, Essex, West Midlands and Cornwall who were able to present their questions to MPs virtually via video. The group praised Millie's 'excellent' presentation along with praise for everybody who contributed.

It was subsequently decided that RR would assign one or two questions to each APPGDS member. These embers are asked to provide updates to the NDSPG AG upon receiving updates from Parliament.

ALL Members/RR

6. The Assisted Dying Bill

RR relayed concerns from individuals and groups in the community regarding the Assisted Dying Bill, and its potential consequences for vulnerable groups such as people with Down syndrome or people with a learning disability. She summarised:

Kim Leadbeater MP has proposed a Terminally Ill Adults (End of Life) Bill. Despite the intention to put this Bill to vote at the Second Reading on Friday 29th November, only eighteen days' notice has been given for the public to examine this information, while, for example, Parliamentary guidance states a constituent emailing their MP with concerns should allow 28 days for their communication to be processed.

Many medical professionals, along with the vast majority of disability charities and learning disability charities have voiced strong concerns regarding the bill's rapid introduction, its insufficient safeguards and the potential consequences it could pose to vulnerable people such as people with Down syndrome and learning disabilities. Many organisations including the NDSPG are working now with their members to publish their public statement warning of the risks of such a bill, but they are acutely aware they have insufficient time to properly consult with their members, experts and their MPs.

Proponents of the Bill claim the law will remain limited, and there is talk of 'robust safeguards', accompanied by reassurances that assisted dying is regulated by "the strictest safeguards in the world." This admission underscores the potential risks inherent in these laws. Such strict safeguards are necessary precisely because of the vulnerability to abuse but ensuring that a decision is free from external pressure is challenging. Evidence is widely available to show countries which began legalising assisted suicide in limited instances, in the space of a few years, have rapidly expanded their criterion to include circumstances that would initially have been unimaginable. Many have alerted the public to these realities. Canada is now allowing euthanasia for patients who cite poverty and housing uncertainty as their main reason and plans to allow assisted suicide for people with mental

health conditions; the state of Oregon in the USA has expanded the interpretation of 'terminal illness' to encompass non-terminal conditions like anorexia, diabetes, hernias and arthritis; and the Netherlands and Belgium have extended the practice to allow euthanasia for children and newborn babies. This trend is concerning, especially when considering potential pressures on the UK healthcare system and societal attitudes that may undervalue the lives of individuals with disabilities, potentially leading to justifications for assisted dying justified on the basis of intellectual disabilities alone. Frequently, the first to suffer from any oversight are those least capable of protecting their rights, especially individuals with learning disabilities. The disparities in healthcare for people with Down syndrome are well documented; individuals with learning disabilities are more likely to die around 20 years earlier than their peers, face higher risks of neglect and abuse, and are at least three times more likely to die in hospital from preventable or treatable conditions. Historical instances during the pandemic have most recently illustrated this vulnerability. Disabled individuals and their families faced undue pressure to refrain from seeking necessary medical care in efforts to conserve resources for others and were often denied life-saving healthcare. Individuals were also disproportionately subjected to Do Not Resuscitate (DNR) orders without proper justification or consent, and there were instances where families were coerced to consenting to these measures. This history underscores the critical importance of scrutinising the ethics of assisted dying legislation, ensuring thorough research and consultation are conducted before any laws are enacted. The hurried introduction of the Bill, coupled with insufficient research, consultation, and transparent and robust safeguarding measures, raises serious concerns about its impact on vulnerable populations, including individuals with learning disabilities. We urge the All-Party Parliamentary Group on Disability (APPGDS) to address these issues by writing to Parliament calling for an expanded debate and consultation, along with stronger assurances regarding safeguards, to protect all society members, particularly the most susceptible. DH and the group acknowledged that this is a sensitive subject, and a discussion followed. Baroness Hollins offered to share her peer-reviewed papers on the documented impact of similar legislation on people with learning disabilities: ***Disability, vulnerability and assisted death commentary -***Tuffrey-Wijne, Curfs, Finlay and Hollins ***Euthanasia and assisted suicide. An examination of nine relevant euthanasia cases in the Netherlands (2012–2016)*** - Tuffrey-Wijne, Curfs, Finlay and Hollins ***The Reality of Assisted Dying: Understanding the Issues***. This book is co-edited by Professor Hughes and Baroness Finlay published by the OUP. Please see attachments in email.	**RR, BSH**

The group decided to await the imminent results of the second reading of the Assisted Dying Bill on 29.11.24. Should the bill advance to the subsequent stage, a plan will be formulated to develop a strategy to express concerns in Parliament and raise scrutiny of the bill's safeguards. It was suggested that the NDSPG and APPGDS start preparations in advance. To be further discussed.	**DH, ALL, NDSPG**
7. Future meetings and closing remarks Adjournment	
Please save the dates for the next meeting of the APPGDS: - **Tuesday 14th January 2025 at 2.00pm-3pm (Room M, PCH)**	**ALL**
Attachment 1 can be found below. Minutes prepared by RR, NDSPG (Secretariat to the APPGDS) 	

Attachment 1

National
Down Syndrome
Policy Group
Advisory Network

By APPG Reporter 19.11.24 Millie Prelogar - 10 mins inc video clip

Introduction:
Hi everybody! My name is Millie Anna. I've just turned 20 years old, and I live in Windsor, Berkshire with my parents and dog Lola. I have a Saturday job at the National Trust in Runnymede AND I'm VERY lucky to be a student at the Royal Central School of Speech and Drama here in London because…I LOVE acting. People with DS don't often get to see people that look like them on TV or the big screen…I want to change that!
Also, I love advocacy because I want to help people with DS to live their best lives…that's why I'm an advisor for the National Down Syndrome Policy Group and… THAT'S why I'm here today.

Introduction of Advisory Group:
I am here to represent the members of the NDSPG Advisory Group.
Our AG is run by and for adults with Down syndrome and has been part of the Down syndrome Act and consultations from the beginning. We are passionate about having our voices and experiences reflected in the policies that affect our lives.
Our AG has a core membership of over 50 adults with DS and a further growing regional membership of over 100 members across the UK…over 160 in total now, and rising.
We began life in 2022 as a single online group of just a handful of adults with DS and now reach to a network of regional groups across England.

The APPG asked the AG for questions our members with DS would like asked in Parliament.
With this in mid our group have worked together to come up with questions about the things that matter to us.
Common themes that keep coming up from our members have been captured and put into the key questions on this handout.
(Please work in Governments new measures to get people into work - 5.1% will they take people w DS, we have an expectation to go into employment, we want meaningful and relevant work experience outside of college and external employment opportunities)

My own question, for example, is:
'My experience with Middle and Upper School was that the schools I went to let me

down because they didn't follow my Education and Health Care Plan (EHCP) and the borough said there are no consequences for schools if they don't follow the rules.
Will the DS Act Guidance include comprehensive checks and put in place a failure regime for schools that are not meeting the additional support needs of students with SEN as outlined in their EHCP OR using their SEN government support on non-SEN related stuff?' Shouldn't that money going to schools for SEN from the government be ring-fenced for students with SEN?
But I am one voice of many, in this video you will hear some questions from our members in Cheshire and beyond:

<Video link by Cheshire DS Group plays>

So you can see from our questions why it's so vitally important to have the Down Syndrome Act guidance written thoughtfully, utilizing the lived experience of people with Down syndrome. This legislation must reflect our contemporary experiences and eliminate the many current barriers to our success to be meaningful and robust - we need you to help get this crafted and published, will you support us? We look forward to hearing our questions asked in Parliament and continuing to work together to make sure the DS Act delivers the envisioned support people like me with DS truly need. We're counting on you! Success in delivering this guidance will enable us to live the fulfilled, happy and independent lives we all envision and strive for the best we can. Thank you very much and I will be available after this meeting for any questions.

Thank you.

End

National
Down Syndrome
Policy Group
CHANGING THE NARRATIVE