Minutes for the All-Party Parliamentary Group on Down Syndrome (APPGDS)
General Meeting: Tuesday 14th January 2024
Room M, Portcullis House 1.30pm – 3pm

Present:

Members

Damian Hinds MP (Cons, Chair)
Andrew Cooper MP (Lab, Co-Chair)

Lord David Alton
Carla Lockhart MP
Graham Stuart MP
Perran Moon MP

Other

David Goss
(Political Principal Private Secretary to the Leader of HM Official Opposition)
Lucy Lee (Staff, Damian Hinds)
Neil Smith (Staff, Andrew Cooper)
Anna Robinson (Staff, Jack Rankin)

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

Community Guest

Tommy Jessop (actor and advocate)

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:
Dame Caroline Dinenage, Abtisam Mohamed MP, Lord Shinkwin

2. Minutes
2.1 Members approved the minutes from the group's previous meeting on 19.11.24. The minutes are filed on the APPGDS website https://appg-ds.org/ once approved.

3. Actions update from previous meeting
3.1 Update on member questions to Parliament

At the previous meeting, members of various support groups from across the UK including the Cheshire Group, Cornwall Group and the National Down Syndrome Policy Group made a presentation to APPGDS members to ask questions in parliament on their behalf about a range of topics and concerns that impact them including further education, early intervention, employment and work experience. Around half have received official responses and these have been passed on to the relevant individuals and groups who have thanked members for their support. Rachael Ross (RR) to follow up on the outstanding replies. Some members highlighted that they had submitted questions but were waiting for a response.	**RR**
DH suggested that the group should invite the Careers and Enterprise Company to present at a future APPGDS. Millie Prelogar stated she liked the idea of a discussion so we can identify any knowledge gaps.	**DH, RR to discuss**
Lord Alton (LDA) suggested that Baroness Sherlock (Department of Work and Pensions) would be a valuable contributor as she is very knowledgeable in the field of employment and benefits. She also answered Lord Alton's question from the Advisory Group about support in the workplace. Could a meeting be explored with Baroness Hollins, Baroness Sherlock and Baroness Merron? Could Baroness Sherlock be invited to a future APPGDS?	**DH, RR to discuss** **BSH**
3.2 Letter to Minister Kinnock from APPGDS Damian Hinds (DH) announced that he received a reply from Minister Kinnock that day concerning the most recent APPGDS letter which again detailed persistent concerns about the Down Syndrome Act Guidance and requested a meeting. Unfortunately, the response still failed to address the key guidance concerns and request to meet. This sentiment was echoed by others at the meeting, who confirmed receiving a similar generic response. Despite efforts from Ministers, MPs, and the APPGDS, successful communication remains elusive. (continued below, item 4). Perran Moon (PM) shared that Minister Kinnock had attended a meeting of the APPG on Autism, and an option might be to invite the minister to a future APPGDS (to be reviewed after we receive a response to the APPGDS further communications).	**Awaiting response**
4. Progress report on the Down Syndrome Act guidance At the group's previous meeting in November, it was confirmed that civil servants had finally been given the green light by Minister Kinnock 'to take forward the work to develop the Guidance as a priority' after being on hold for several months during and after the election. The Minister said he 'looks forward to drawing on the group's expertise'. This was in direct response to the letter in October from Co-chair Andrew Cooper (AC) and the APPGDS calling for an update. Since this response, further letters have been to express concerns about the guidance. It was reported that the Department of Health and Social Care (DHSC) issued draft guidance before Christmas to key stakeholders to review over the Christmas period. Civil servants have acknowledged that the Guidance is not complete and requires further refinement, but they want to be transparent and keep stakeholders updated with progress. However, despite former ministerial assurances and commitments, the guidance still fails to address longstanding concerns. Notably, no cross-departmental ministerial task force has been established to tackle significant structural barriers such as the adverse effects of benefits on employment or the	

delays in social care assessments, which impede access to residential college placements and employment opportunities. This task force was anticipated to facilitate the implementation and effectiveness of the guidance, aligning with earlier ministerial pledges. Again, could any meetings with Baroness Hollins, Baroness Sherlock and Baroness Merron provide advice about the structural barriers to consider when implementing the Down Syndrome Act guidance?	**DH**
Given that the consultation on the draft publication guidance grows increasingly imminent, a meeting with the Minister is now critical.	
The group elected to draft a further letter to Minister Kinnock, expressing gratitude for his response but strongly emphasising the continued critical concerns with the guidance. They will urge him to refrain from publishing the draft guidance until a meeting with the APPGDS and NDSPG has occurred. There is growing unease in the community, and several DS organisations will also be writing to the Minister once again to highlight concerns. Members agreed the situation is very unsatisfactory, especially in light that the guidance has been in development for nearly 3 years.	**DH, AC, RR, PM, LDA, GS**
AC reported that he had made contact with Minister Kinnock's Principal Parliamentary Secretary, Ashely Dalton MP (DHSC PPS) who had offered meet with the APPGDS. It was agreed this would be a good idea. AC to make contact asap to arrange a suitable date and highlight in advance a list of the group's key concerns and to request that the minister does not proceed with publication until he has spoken with the APPGDS. DH and PM to attend also.	**AC**
Members explored additional actions to raise concerns about the guidance in parliament. All members should apply to the ballot for a Westminster Hall debate and members could also apply for an adjournment debate. It was suggested that Baroness Hollins should be contacted for support and advice in the House of Lords.	**All**
5. The Assisted Dying Bill (ADB) **5.1 Speech from Tommy Jessop (actor and advocate) on behalf of the National Down Syndrome Policy Advisory Group (see attachment)** Tommy raised concerns about the impact of the Assisted Dying Bill on vulnerable people and people with Down syndrome and learning disabilities on behalf of the NDSPAG, a collection of 160+ adults with DS from across the UK. It was explained that it had taken Tommy a lot of courage to present at the APPGDS as the topic of assisted dying was understandably very upsetting for him, but that he wanted to come to speak out as so many of his peers were unable to do that. The group unanimously thanked and praised Tommy for sharing his concerns	
It was highlighted the bill is being rushed though without adequate consultation time for both the public and professionals. Those the bill impacts most, like people with Down syndrome, have been excluded from the process and from giving evidence, and there are no accessible resources.	
The group largely agreed that it is impossible to give permanent assurances on safeguarding and limited scope, and this has been evidenced in every other country where they have adopted similar legislation, and where the scope has rapidly expanded within the space of a few years. Canada for example, expanded eligibility from 'terminal illnesses' in 2016 to include non-life-threatening conditions by 2021.	

35% of those who died by medical assistance reporting being motivated by being a "perceived burden on family, friends or caregivers". In the Netherlands, the scope also rapidly widened, leading to the euthanasia of 40 individuals with autism or learning disabilities between 2020-2021. RR reminded the group about the peer reviewed evidence links from Baroness Hollins and her colleagues which had been previously circulated. Her colleague Professor Irene Tuffrey-Wijne has provided evidence to Parliament in 2023 regarding assisted dying and its implications for individuals with learning disabilities and would like to be considered to give evidence again.	**RR**
Lord Alton (LDA) said there was a meeting that day at the House of Lords with campaigner Liz Carr and Baroness Tammy Gray Thomson to discuss the ADB concerns. He went onto to say that looking at experience overseas, there was a recent case in Canada regarding a war veteran who was encouraged to look at assisted suicide rather than consider accepting the stair lift for which he had applied. The ADB committee is convening their first committee meeting on 21st January and will meet twice a week going forwards. It was agreed that a representation from the APPGDS to include Tommy, MPs/peers and representatives from the NDSPG would request a slot to give evidence at the committee. Evidence from people with DS must be considered. DH will make enquiries and contact Danny Kruger MP who is on the committee.	**DH, RR**
Members emphasised that issues of mental capacity and coercion are crucial. DH said the group will ask the committee for clarification how the proposed legislation will consider Mental Capacity Act and how the bill addresses the needs of individuals with learning disabilities. They also sought assurances into the safeguards in place to prevent manipulation and the potential risks of medical professionals and judges approving decisions without a thorough understanding of an individual's capacity. RR stated that it is widely acknowledged that mental capacity is very difficult to assess and can fluctuate depending on circumstance. People with LD are more susceptible to coercion, particularly when communication may be impacted, and stressed Mental Health Act recommendations on capacity leave room for interpretation and wiggle-room, and can often be contradictory, and therefore do not provide watertight protection. Ken Ross (KR) also reminded the group how safeguarding failed people with DS during the pandemic, when illegal Do Not Resuscitate Notices were placed on people with LD without their consent or that of their families, and treatment was withheld.	**RR, DH, AC**
The group will write to the committee asking for clarification around safeguarding vulnerable people/people with LD/mental capacity. RR to provide background on the Mental Health Act and capacity/cohesion.	**DH, RR**
It was suggested that the group contact Baroness Hollins to ask for her support and advice as this is an area where she has experience and expertise.	**RR**
The group will consider additional ways to share their concerns.	
6. Down Syndrome Awareness Week (17th-21st March) Advocate Millie Prelogar addressed the group to explain what it is to have Down syndrome, the significance of the date for World Down Syndrome Day on 21.3 (3 copies of chromosome 21), and why the awareness week is so important. People	

with Down syndrome need the opportunity to realise their potential. Millie asked members to support their plans for WDSW (more information will follow). She went on to invite APPGDS members to the inaugural NDSPG Advisory Group summit which is billed to promote self-advocacy and engagement. The members all congratulated Millie and agreed that they would help publicise the summit, which is being held on Thursday 27th March at A&O Shearman (11am-2pm). The AG should personally invite their local MP to attend.	**Save the date/ALL**
DH would like the group to support a wider parliamentary debate about DS in March, and members will apply for this. Wait for further instruction from DH. **7. APPGDS Membership** The group thought it would be helpful to increase numbers for the APPDS. Millie suggested the current members invite some of their colleagues who may have a vested interest. The members present said they were there either because they had staff member with a child with Down syndrome, or because they had been invited to join by one of their constituents. Graeme Stuart (GS) suggested that constituents in the advisory group make an appointment with their MP at their surgery and continue to invite them to join the APPGDS. DH proposed a drop in event. LDA suggested securing a Speaker's House Event. DH suggested that individuals should seek coverage from local press explaining how and why their member of Parliament has signed up for the All-Party Parliamentary Group on Down syndrome. The group will explore suggestions. **8. Any other business** **7. Future meetings and closing remarks** Adjournment **Please save the dates for the next meeting of the APPGDS:** • **13:45-15:00 on 25th March in Room N, PCH** Attachment 1 can be found below. Minutes prepared by RR, NDSPG (Secretariat to the APPGDS)  	**DH (ALL)** **DH, ALL, RR, KR**

Attachment 1

My Thoughts on Assisted Dying by Tommy Jessop, Actor and Advocate

- I do feel very sorry for the people who are suffering,
- but
- we are all scared and frightened by assisted dying.
- **Please keep us safe**.

- Some people say they speak for us.
  But do they really know how we feel?
- We might be pressured into asking people to help us die.
- I find, if you are being pressured or rushed,
  it really is difficult to say no.
  We might not understand what is really happening.
- We don't want that to happen to us.

- Some people are already pressured to have abortions when
  they are going to have a baby with Down syndrome.
- This is the same as assisted dying.
- **How would you feel** about people targeting people like you for abortion
  because they don't want you in the world?
- **This has scarred me for life.**

- People must feel our lives are not worth living.
- They are wrong. We love our lives.

- BUT
- They might target us for assisted dying?
- In my Panorama film 'Will the NHS Care For Me'
  I found some healthcare staff don't think our lives are worth living.
  This has led to poor health care and even people dying.

- The same thing could happen to us with assisted dying.
  They might think our lives are not worth living.
- It really frightens and upset us.

- I think it is a terrible idea letting people choose when to end their life.
- We should help them to live pain free.

- Please keep us safe
- **Please vote NO to assisted dying**.