

**Minutes for the All-Party Parliamentary Group on Down Syndrome (APPGDS)
Inaugural Meeting: Tuesday 8th October 2024
Room S, Portcullis House 2pm**

Present:

Members

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

Noah Law MP (Lab)
Amanda Martin MP (Lab)
Lord Kevin Shinkwin (Cons)
Graham Stuart (Cons)
Lord Don Touhig (Lab)

Jack Abbott MP (Lab)
Mike Amesbury MP (Lab)
Lewis Cocking MP (Cons)

Other

David Goss Political (Deputy Political Secretary, Rishi Sunak)
Anna Robinson (Chief of 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

Fionn Crombie Angus (Chair) Florence Garrett (Officer)
Ed Daly (Officer) Jonathan Angus (NDSPAG PA)

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**

<p>1.0 Preliminaries Andrew Cooper Co-Chair (AC) welcomed all present to the inaugural meeting of the All-Party Parliamentary Group on Down Syndrome</p> <p>1.1 Apologies: Chris Evans MP, Dame Karen Bradley MP, Baroness Sheila Hollins, Abtisam Mohammed MP, Helen Morgan MP, Jack Rankin MP</p> <p>2.0 Election of Officers 2.1 Damian Hinds MP, Chair 2.2 Andrew Cooper MP, Co-Chair 2.3 Baroness Sheila Hollins, Officer 2.4 Jack Abbott MP, Officer</p>	

All candidates were elected unanimously.

RR to formerly register the group and officers with the Parliamentary Groups Register. A full list of members will be uploaded to the APPGDS website in due course. <https://appg-ds.org/>

Lord Don Touhig requested that the current chairs DH and AC compose a letter to Sir Liam Fox, thanking him for his previous chairmanship and for his unwavering commitment to the Down Syndrome Act. Unanimously supported.

DH/AC

3.0 Brief History of APPG on Down Syndrome

Rachael Ross MBE (RR) NDSPG, delivered a brief history on the APPGDS.

- First APPGDS was chaired by Virendra Sharma but disbanded in 2015.
- The National Down Syndrome Policy Group (NDSPG) collaborated with Members of Parliament (MPs) and Peers to re-establish itself in response to persistent challenges in provision, opportunities, and outcomes for individuals with Down syndrome and learning disabilities.
- The inaugural meeting of the re-established group took place on May 12, 2021. Initially, the group was chaired by Dr. Lisa Cameron, followed by Sir Liam Fox. This initiative highlights the ongoing commitment to addressing and improving the societal and governmental support structures for those with Down syndrome, ensuring they receive the necessary resources and opportunities for a better quality of life.
- The APPGDS and NDSPG has made some important achievements in a very short space of time, most notably the historic world-first Down Syndrome Act (production of guidance ongoing), and our successful bid to the Star Chamber for Down syndrome to be added to the annual school census as a separate category which has numerous benefits, as a starting point knowing how many children with DS are in schools and where they are in a mainstream or special education setting.
- Request that current APPGDS back new education guidelines as previously agreed by the previous APPGDS. To be presented at next meeting.
- The NDSPG looks forward to continuing working with the APPGDS in positive partnership.

4.0 Introduction to the National Down Syndrome Policy Group (NDSPG)

Ken Ross OBE (KR) NDSPG and RR delivered a brief history of the NDSPG.

The community recognised the need for a stronger advocacy voice for individuals with Down syndrome (DS) to collaborate effectively with lawmakers. In response, eight leading Down syndrome organisations, along with key advocates who have DS, united to establish the National Down Syndrome Policy Group in 2021. This coalition has very quickly made significant strides in advocating for policies that benefit the Down syndrome community.

- The NDSPG's first action was to reform the APPG on Down Syndrome with support from peers and MPs in May 2021.
- The group collaborated with Sir Liam Fox, and drafted the initial Bill for the Down Syndrome Act, supporting its successful passage through Parliament

with robust cross-party backing. Additionally, the group produced a report effectively advocating for the inclusion of Down syndrome as a distinct category in the annual school census, an achievement that would not have been possible without the dedicated support of Sir Liam and the APPGDS's concerted efforts.

- The NDSPG is backed by 120+ Down Syndrome organisations and has the support of Mencap. It conducts both virtual and in-person consultations and symposiums to gather insights from the community, which directly inform their initiatives. These include in-person roundtables at Downing Street with Minister Caulfield and consultations in Westminster and Leeds that engage individuals, families, and professionals in meaningful discussions.
- We collaborate closely with the National Down Syndrome Policy Advisory Group, which consists of over 120+ representatives from organisations across all four UK countries. These representatives meet regularly to provide valuable insights and feedback that directly inform their work and that of the NDSPG.
- We assembled an expert panel consisting of more than 40 leading specialists in Down syndrome to develop a comprehensive report. This report offers key recommendations for the education chapter of the Down Syndrome Act Guidance, aimed at enhancing educational practices and outcomes for individuals with Down syndrome.
- The group organised a symposium in November 2023 in collaboration with NHS England, Integrated Care Board (ICB) Leads for Down Syndrome, the Department of Health and Social Care, and Secretary of State Victoria Atkins. This event focused on the new roles and implementation of guidance, and also highlighted good practices in the field of Down syndrome care and management.

5.0 Introduction to the National Down Syndrome Policy Advisory Group

A presentation on the role of the Advisory Group was delivered by Fionn Crombie Angus, the group's chairperson, alongside Florence Garrett and Ed Daly, two of the group's officers. The group convenes regularly and selects various members to represent them at key events, including meetings of the All-Party Parliamentary Group on Down Syndrome. **Please see a copy of their report – Attachment 1.** The representatives additionally encouraged members to explore ways to provide opportunities for the advisory group members, such as facilitating work experience or collaborative projects. They also suggested that members of the All-Party Parliamentary Group on Down Syndrome (APPGDS) could engage more directly by visiting or working with local charities in their constituencies.

Lord Touhig, Andrew Cooper and members thanked Florence, Ed and Fionn for their presentation.

6.0 Progress report on the Down Syndrome Act Guidance

RR and KR provided an update on the status of the Down Syndrome Act Guidance from the Department of Health and Social Care (DHSC). Currently, work on the guidance is paused as the DHSC awaits instructions from the Minister to approve the existing draft format and proceed with further development. Additionally, a financial review is expected. The guidance chapters vary in their stages of completion, with the housing section requiring the most work. Currently, there is no established timeline for completion. The group raised that previous

ALL

<p>communications sent to the Minister by the community (and some MPs) had either gone unanswered or received only generic responses. This lack of substantive feedback has raised concerns within the community.</p> <p>The group noted that concerns about delays had been raised prior to the election in May by Sir Liam Fox on behalf of the APPGDS, leading to a meeting with the previous Minister Caulfield ‘as a matter of urgency’, where reassurances were provided. However, it has now been 30 months since the enactment of the Down Syndrome Act, and the guidance remains unpublished. In response, the group has proposed sending a letter to the new Minister to express these concerns. The letter will request an update on the guidance, a definitive timeline, confirmation of their ongoing commitment, and assurances regarding Down syndrome-specific content and provisions. Members also offered to speak with the Minister in person should the opportunity arise.</p> <p>7. Any Other Business</p> <p>Members invited the National Down Syndrome Policy Group and Advisory Group to provide questions for MPs to raise in the HOC and the HOL or with relevant parties.</p> <p>8. Adjournment</p> <p>AC thanked everyone for attending, and the meeting was adjourned.</p> <p>Please save the dates of the next meeting of the APPGDS:</p> <ul style="list-style-type: none"> • Tuesday 19th November 2024 at 2.00pm (Room S, PCH) <p>Attachment 1 can be found below.</p> <p>Minutes prepared by RR, NDSPG (Secretariat to the APPGDS)</p>	<p>DH, AC, ALL</p> <p>NDSPG/AG</p>
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Attachment 1



National Down Syndrome Policy Advisory Group report to the All-Party Parliamentary Group on Down Syndrome Presentation

Fionn:

Thank you for inviting us to speak to you today. We are three Officers of the Policy Advisory Group, and we would like to introduce each other to you.

Ed:

This is Florence Garrett, who lives in Twickenham, works at four jobs and swims competitively. She'll soon move into her own flat.

Florence:

And this is Fionn Crombie Angus, our Chair, who lives in Galway, & runs a social enterprise with his father. He's just completed a research internship with Harvard Law School.

Fionn:

And this is Ed Daly, who lives in Leek, near Stoke-on-Trent. He works as a park ranger, and recently won a BBC Make A Difference Award. Thank you to Ed's MP, Karen Bradley, for joining this APPG. Ed will tell you about our group.

Ed:

Thanks Fionn. Yes, I'm going to tell you a bit about the Advisory Group and our achievements so far.

We're a group run by, and for, adults with Down syndrome who exist to inform policy on matters that impact our lives. We're the first such group in the UK and probably in the world.

We now have sixty active members and another sixty affiliates, in all four countries of the UK.

Our members are mostly young adults, who are interested in helping to change policy, but we also have members who are older. Some are quite talkative, others rarely speak a word, but we all have our opinions and experiences, and the Advisory Group works to assure that everyone is heard.

We were formed at the end of 2021 by 5 founding officers, with Down syndrome, of the National Down Syndrome Policy Group, the NDSPG.

We work alongside the NDSPG, and together we have achieved amazing things.

We have participated in every step of the Down Syndrome Act 2022,

- from lobbying for its passage as a Bill through parliament;
- to facilitating at meetings, in person and online, with civil servants - so that dozens of people with Down syndrome participated in the Call for Evidence and helped inform the Department for Health in writing the Act's guidance;
- to meeting with Minister Caulfield at 10 Downing Street to discuss issues important to us;

- to speaking to ICB executive leads on Down syndrome in readiness for the implementation of the Act - to make it meaningful and powerful; and
- to being a stakeholder in the Department of Health's pre-consultation on its draft guidance - helping to make the guidance DS specific and aspirational.

We are growing fast. From frequent online meetings, to ad hoc gatherings, and to establishing local policy groups across the UK, 9 so far. These local groups meet to discuss actions specific to their areas, but are informed by our shared knowledge on a national and international scale.

Now you'll hear Florence

Florence:

Thanks Ed. Hello everyone. I'm Florence and as Ed said, I live in Twickenham but am soon to move to Whitton but my MP will still be Munira Wilson.

I'm going to talk briefly about our upcoming Summit and our role within the National Down Syndrome Policy Group and this APPG group.

On the 8th November we are holding our first Summit in London. The event will be held at the offices of our sponsors A and O Sherman. We expect to have 100 delegates, 60% of whom have Down syndrome. As Ed said just now, some of our members speak a lot and some less so. Some prefer to listen and some to watch, we have different needs and different ways of operating. Our Summit will have multiple ways of engaging with all our delegates regardless of their needs and abilities. It will be a fully accessible event with facilitators to ensure this.

We think this will be the largest policy-focused Down syndrome gathering in the world, and we are planning to hold it annually.

Following the Summit, we will change our name from the National Down Syndrome Advisory Group to the National Down Syndrome Policy Network, thereby emphasising our focus on policy.

Originally, we were established as the Advisory Group working with the National Down Syndrome Policy Group, guiding and advising towards a more inclusive and fairer future. And we do plan to continue to advise. However, we are prepared and indeed want to take action ourselves.

We pledge to come to all of your meetings and keep you informed of our journey. When you come, and we really hope you will, to national events hosted by the NDSPG, such as World Down Syndrome Day in March, we will be there, providing you with opportunities to share in the lives of your constituents with Down syndrome. We will celebrate with you in person, and through social media.

Over to you Fionn!

Fionn:

Our plan is to form an Executive Committee that supports and co-ordinates Local Groups who meet face-to-face to work with government on local issues important to people with DS.

We need resources to get our word out to citizens everywhere, so they are informed and can engage about the Down Syndrome Act.

Please keep us in mind. Perhaps there is an opportunity to lend a hand in your constituency office. You may want to participate in our campaign to promote the DS Act to the general public once the guidance is finally published.

Our goal is to have at least one Group in every ICB region, working hand-in-hand with local government. We will need your help to establish relationships. Having you meet with the group themselves would lend a powerful message to local authorities that you will be our ally going forward.

Thank you for setting aside time in your meeting to hear our thoughts. We are really looking forward to working with you.



