

**Minutes for the All-Party Parliamentary Group on Down Syndrome (APPGDS)
General Meeting: Tuesday 27th January 2026
Room M, Portcullis House 1.30pm – 3pm**

Present:

Members:

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

Lord David Alton (Crossbencher)
Baroness Sheila Hollins (Crossbencher)

Jen Craft MP (Lab)
Lord Kevin Shinkwin (Cons)

Other:

Rachel Cary, Staff - Carla Lockhart MP (DUP)
Thomas Kelly, Staff - Sam Rushworth MP (Lab)
Lucy Lee, Staff - Damian Hinds MP (Cons)

Vincent Masterson, Staff - Graham Stuart MP (Cons)
Neil Smith, Staff - Andrew Cooper MP (Lab)
Rosie, Staff - Paul Waugh MP (Lab)

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

Florence Garrett, Chair, NDSPG

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, Andrew Cooper (AC)

AC welcomed all present to the meeting of the All-Party Parliamentary Group on Down Syndrome

1.2 Apologies:

Lee Baron, Lorraine Beaver, Aphra Brandreth, Lord Kerr, Baroness Rosa Monckton, Jack Rankin

2. Minutes

2.1 Members approved the AGM minutes from the group's previous meeting on Monday 20th October 2025. The minutes are filed on the APPGDS website <https://appgds.org/minutes/> once approved.

2.2 Rachael Ross (RR) reported AGM Minutes and records have been filed as required with the Register Office.

3. Down Syndrome Act and Draft Guidance Consultation (FG)

Update: The Department of Health and Social Care has now published the draft Down Syndrome Act Guidance and opened a public consultation on 5 November 2026. The original deadline for responses was set for 28 January 2026, despite requests from all key stakeholders for a 16-week consultation period. The deadline was subsequently extended by 2 months to 30 March to allow British Sign Language resources to be included to ensure Deaf people can fully participate in the consultation process.

3.1 National Down Syndrome Advisory Group Feedback on the Consultation Process:

Florence Garrett, Chair of the National Down Syndrome Advisory Group, told members that NDSAG and other Down syndrome organisations across England, including those in Manchester, Cornwall, Cheshire, Lancashire, London, Portsmouth, Warwickshire and the Wirral, are hosting large in-person and/or virtual consultation events. These are designed to ensure the government hears from as many people with Down syndrome as possible in response to the draft consultation.

FG said members welcomed the long-awaited publication of the draft and the extension to the response deadline. However, she noted that the 44-page Easy Read version remains too lengthy and that the response process is challenging to navigate. To address this, the group produced enhanced Easy Read packs and shared them with other organisations. The packs were organised into themes, such as health, and education, allowing participants to focus on one area at a time, improving accessibility and making gaps easier to identify. FG emphasised that significant gaps remain. These key issues have already been raised many times with ministers and civil servants, and the group continues to urge them to listen to organisations and to people with lived experience.

AC thanked FG for the update and said he is looking forward to attending the Cheshire Group's consultation event. Members thanked FG for sharing the group's work and insights with them.

- **See FG's report at the end of the minutes – Attachment 1**

3.2 Continued concerns over the guidance

RR reported that the Down syndrome community, including experts, professionals, organisations and individuals, continues to have widespread concerns about the content of the draft guidance. The NDSPG has been contacted by numerous individuals and groups seeking the support of the APPGDS. While there is strong appreciation that the draft guidance has finally been published for consultation, many key recommendations made consistently over recent years, and previously endorsed by ministers, have largely been omitted, and a number of errors remain. Responses are restricted to a 200-word limit for feedback in each section of the consultation, and many groups and professionals have expressed frustration, feeling the consultation is just a tick box exercise and will be futile as the DHSC continues not to take their input into account.

Key omissions include Down syndrome-specific training. Although referenced briefly in the introduction, this requirement should be embedded throughout every section - health, education, social care and beyond. Anyone regularly working with a person with Down syndrome should have an appropriate level of condition-specific training. This would align with the tiered training approach recommended for autism. While

individuals with Down syndrome have unique needs, they also share a distinct profile of health, learning, behavioural and communication characteristics. Down syndrome-specific training is therefore essential to achieving good outcomes and preventing avoidable mistakes. Its importance must be clearly emphasised.

Other areas requiring greater emphasis include the importance of regular speech and language therapy from birth through adulthood, the role of early intervention, further education, and addressing diagnostic overshadowing to ensure that the specific health and developmental needs of people with Down syndrome are accurately recognised and met. These were all key areas raised repeatedly during the drafting process by experts and organisations but are not properly reflected in the guidance.

Factual inaccuracies relating to learning disability and SEND have been included, despite being highlighted before the draft guidance was published.

The guidance currently states that “most” children and young people with Down syndrome have a learning disability or are “likely” to require SEN support. This is factually incorrect. All (100%) individuals with Down syndrome have a learning disability, experience speech and language difficulties, have visual acuity issues and require an Education, Health and Care Plan (EHCP), alongside some level of ongoing support. These inaccuracies are not minor: they shape expectations, influence decision-making, and risk delayed or reduced provision. Beginning from an inaccurate baseline fundamentally undermines the purpose of statutory guidance.

A range of stakeholders including individuals, organisations, experts, MPs, and Sir Liam Fox, the bill’s sponsor have all written to Minister Zahir Ahmed to raise their concerns. To date, all have received only a generic response from DHSC, and Sir Liam Fox is still awaiting a reply. See Liam’s subsequent article in The Times – https://www.thetimes.com/uk/politics/article/downs-syndrome-law-crqhg1vpr?gaa_at=eafs&gaa_n=AWETSqf58ewfzBVk29DMUDwJbCOyKAXlu62V5zjNEM1q2edwzbJlVx4d_zubFuvQMgM%3D&gaa_ts=699c4908&gaa_sig=s9I42cuosPclvxqrEcfOqQS-hubMJapuQfJ5PdrWldt_dCif6W5EOITsPsogUSD1oglybFrJ52Jkxw7X0HFmjQ%3D%3D

3.3 Actions

BSH noted that personnel changes within the DHSC may have affected outcomes. Jen Craft (JC) suggested raising the issues with the Cabinet Office, particularly given the imminent publication of the White Paper on education. FG asked whether the concerns could be directed to Minister Timms. RR explained that she had previously spoken to him and he was aware of the issues, though this was some time ago. Lord David Alton (LDA) proposed that the absence of Down syndrome-specific interventions could potentially be challenged under the Equalities Act, and that Minister Timms could be approached to address this and raise it in the house.

Baroness Hollins (BSH) said the government has a duty to make reasonable adjustments. She recommended contacting Paula McGowan to explore whether Down syndrome-specific training modules could be added to the existing Oliver McGowan training programme; BSH and RR will follow up on this with Paula. RR also asked whether it might be possible to request a meeting with Minister Zahir Ahmed to outline concerns before time runs out. JC suggested waiting until after the consultation to write to the Minister, and DH proposed drafting the letter in advance, so it is ready to send. AC offered to attempt contact with Minister Ahmed to see if he would be willing to meet. Recommendations for NDSPG to rally support groups and professionals, encouraging

?

BSH
RR

them to write to their MPs, asking them to raise the issues and write to the minister on their behalf to raise issues/request meeting and to consider another “open letter” signed by groups and professionals.

DH
AC
NDSPG

4. Assisted Dying Bill (ADB) Update

AC reported that a second meeting had been held with Lord Falconer and Kim Leadbeater, sponsors of the ADB, alongside APPGDS Chairs AC and DH, and RR and KR representing the NDSPG. AC described the meeting as positive. RR expressed thanks to AC for facilitating the meeting.

KR reported that the discussion focused on ongoing concerns regarding the adequacy of the bill’s safeguards and the wording used, questioning whether they provide meaningful protection for individuals with Down syndrome, learning disabilities, and other vulnerable groups. Lord Falconer and Kim Leadbeater expressed the view that the wording was sufficiently robust and that the safeguards were among the strongest internationally, but they welcomed any legal opinions suggesting otherwise. Kim Leadbeater also requested further information on the processes followed when a person with a learning disability receives a terminal diagnosis.

The group emphasised the need for specialist training at every stage, particularly as many people with Down syndrome are outliving their parents, leaving professionals to make critical decisions. RR highlighted that the latest LeDeR Report continues to demonstrate persistent failures in care for people with learning disabilities and noted that people with LD were specifically targeted with Do Not Resuscitate notices during the pandemic. This makes individuals with DS and LD particularly vulnerable when decisions are made by professionals lacking specialist expertise, understanding of communication profiles, or knowledge of best practice. BSH added that all vulnerable groups are at risk, sharing her recent personal experiences.

KR said the group also requested that assisted dying should never be suggested to someone with LD and that every stage of these interactions should be recorded for people with DS, LD, and other vulnerable groups. Kim Leadbeater expressed reservations about whether this would be appropriate or acceptable. DH noted that similar recording procedures are standard in the justice system, and RR added that such recordings provide an additional layer of protection for both patients and staff when the stakes are high. Baroness Hollins emphasised that it is the Lords’ responsibility to make the legislation as safe as possible. She noted that in Switzerland, end-of-life conversations are filmed at all stages, and this has been a successful procedure. BSH suggested contacting Irene Tuffrey-Wijne, Professor of Intellectual Disability and Palliative Care. RR noted she had previously emailed Irene but had not received a response, possibly due to her being on leave.

RR also highlighted that peer-reviewed research by Tuffrey-Wijne, Hollins, Curfs, and Finlay on assisted dying, mental capacity, and the impact of legislation on people with LD has previously been circulated to APPGDS members and formed part of the NDSPG and APPGDS evidence presented to the ADB Committee. Key references include:

Tuffrey-Wijne, I., Curfs, L.M.G., Hollins, S. And Finlay, I. (2023). Euthanasia and physician-assisted suicide in people with intellectual disabilities and/or autism spectrum disorders: investigation of 39 Dutch case reports (2012-2021). BJPsych Open 9, e87, 1–8. <https://www.cambridge.org/core/journals/bjpsych-open/article/euthanasia-and-physician-assisted-suicide-in-people-with-intellectual-disabilities-and-or-autism->

[spectrum-disorders-investigation-of-39-dutch-case-reports-20122021/93B38EAE616E0A6C378BE308C87253A2#](https://doi.org/10.1111/jppi.12307)

Tuffrey-Wijne, I., Curfs, L., Finlay, L. And Hollins, S. (2019). "Because of his intellectual disability, he couldn't cope". *Is Euthanasia the answer? Journal of Policy and Practice in Intellectual Disabilities* 2: 113-116. <https://doi.org/10.1111/jppi.12307>

Tuffrey-Wijne I., Curfs L., Finlay I., Hollins S. (2018) *Euthanasia and assisted suicide for people with an intellectual disability and/or autism spectrum disorder: an examination of nine relevant euthanasia cases in the Netherlands (2012–2016)*. *BMC Medical Ethics*, <http://rdcu.be/lpaC>

BSH requested that the minutes from the meeting with Lord Falconer and Kim Leadbeater be shared, expressing concern about the ongoing impact of discussions on assisted dying for people with LD and other vulnerable groups.

LL, NS

RR will follow up with ADB legal opinions questioning the robustness of the Assisted Dying Bill safeguards and provide examples of end-of-life care procedures when someone with a learning disability receives a terminal diagnosis.

RR

5. School Census Update

Correspondence with DfE

AC said he wrote to DfE asking for an update on progress with overcoming the initial issues of the inclusion of Down syndrome as a separate category in the school census, and had received a reply from Georgia Gould, Minister for School Standards. RR said last year's census data about DS had to be withdrawn as it was inaccurate. The DfE withdrew the data immediately after the NDSPG raised concerns about significant inaccuracies in data collected. The DfE put this down to the new system and said they would work to overcome the issues in this year's census. The DfE response states that to support improved reporting of Down syndrome, they have:

- Held workshops with LAs, discussing the introduction of Down syndrome as a primary type of need in the collection, issues with collection, and ideas for improving quality;
- Added automated checks to the data collection in relation to the Down syndrome primary type of need. These checks will flag low or no uses of the Down syndrome code during the data collection process, meaning LAs are prompted at an early stage to check their data for accuracy, allowing them to resolve any errors ahead of the data submission date;
- Offered 1-2-1 support with LA data leads, making assistance more available for those who are unclear on how to record Down syndrome within the data collections.

The initial request/plan from the NDSPG and APPGDS was that the data included a binary yes/no question, but they said that they rejected the idea of considering recording Down syndrome with a binary yes/no. They expect data quality improvements due to the factors noted above (clarified guidance, increased familiarity with the code set and review of existing EHC plans) in the upcoming data collections of SEN2 and school census. The department will undertake data quality assurance once the data becomes available for the latest year, ahead of their next publications, and will transparently communicate on data quality in the publications.

They invite further thoughts from the APPGDS for progressing this.

- **The full response can be seen at the end of these minutes – see Attachment 2**

accountability there has been and continues to be? BSH said incidents like these are widespread and cited personal experiences.

7. NDSPG and AG Integrated Care Board (ICB) Research Report

The Down Syndrome Act 2022 rules a separate executive lead for Down syndrome for people of all ages is required by law. NHS England statutory guidance requires ICBs to publicly list the roles and the individuals filling them in the name of good governance practice and transparency. This report identifies widespread non-compliance by Integrated Care Boards (ICBs) with statutory duties to appoint and publicise named executive leads for people with Down syndrome. Just two out of forty-two ICBs were fully compliant, whilst no ICB website provided either Easy Read materials or contact details for any named ICB

leads, severely limiting the ability of individuals and families to access support. This report also provides specific recommendations from the National Down Syndrome Policy Group and its Advisory Group (comprised of adults with Down syndrome) to improve ICB compliance, transparency, and accessibility.

The completed report will be circulated to APPGDS members for comments. Chairs to circulate to Ministers and DHSC. Report will be circulated to ICBs.

8. Invitation to NDSAG Summit

FG invited APPGDS members to attend the NDSAG London Summit generously hosted by A&O Shearman during Down Syndrome Awareness Week on 19.03.26 from 11am. Please see the invitation attached and email advisory.group@ndspg.org for more information. Organised for people with Down syndrome by people with Down syndrome the day will feature celebrations of the Advisory Group's work, Discussions on Human Rights and the Down Syndrome Act Guidance, dancing and entertainment & awards.

- **Please see invitation attached.**

9. Any other business

Future meetings and closing remarks

Adjournment

Please save the dates for the next meeting of the APPGDS:

- **13:00-14:30 on 12th May in Room M, PCH**

Minutes prepared by RR, NDSPG (Secretariat to the APPGDS)

**DH
RR
ALL**

ALL

Attachment 1: Report from Florence Garrett on the NDSAG Sown Syndrome Act Guidance Consultation work



Guidance Consultation Report 27th January 2026



Since the government opened their consultation on the Down Syndrome Act draft guidance in November, the Advisory Group have been looking at how to respond.



We were really pleased that the government had made easy reads of both the draft guidance and the consultation.

We are also glad that the deadline was extended to 30th March.

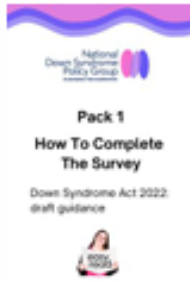


But, there was a lot information in the 44 pages of the easy read version of the draft guidance.

Many of us found it hard to remember it all.



This made completing the 37 pages of easy read consultation information and questions quite difficult.



To help make the consultation more accessible we worked with the NDSPG to create 10 enhanced easy read packs of each theme in the draft guidance consultation.



This made the process much better as each pack contains:

- A theme from the draft guidance
- The matching consultation questions
- A reminder of what we said before in other consultations
- Areas where there might be gaps



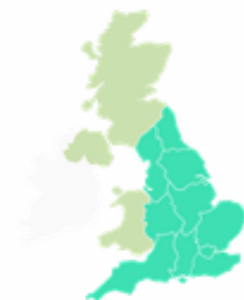
This makes the process more accessible to us as we can do one pack at a time and we don't have to do all of the questions at once.

And because the deadline is now March, we have enough time to think about our answers.



The enhanced packs worked really well at our Advisory Group online meeting for adults with Down syndrome.

They are also being used at our growing series of consultation events:



- Cornwall
- Central London
- Cheshire
- Lancashire
- Manchester
- Wirral

Attachment 2: Response Regarding the School Census from Minister for School Standards



Department for Education

2025-0041649

Georgia Gould OBE MP
Minister for School Standards

Andrew Cooper MP
By email: andrew.cooper.mp@parliament.uk

Your ref: AC08725

29 December 2025

Dear Andrew,

Thank you for your correspondence of 5 November, addressed to the Secretary of State, regarding the introduction of Down syndrome as a distinct category within the annual school census. I am replying as the minister responsible for this policy area.

Thank you for sharing the APPG's thoughts and offering strengthening challenge to the department's data collection methods. Reference is made in the letter to previous correspondence with the department regarding the collection of information about children and young people with Down syndrome. The correspondence highlighted feedback from local authorities (LAs) on the SEN2 data collection, indicating that some data recorders saw Down syndrome as a medical need rather than a special educational need, and that the data item's newness was likely the biggest contributors to the low data quality. To support improved reporting of Down syndrome, we have:

- Held workshops with LAs, discussing the introduction of Down syndrome as a primary type of need in the collection, issues with collection, and ideas for improving quality;
- Added automated checks to the data collection in relation to the Down syndrome primary type of need. These checks will flag low or no uses of the Down syndrome code during the data collection process, meaning LAs are prompted at an early stage to check their data for accuracy, allowing them to resolve any errors ahead of the data submission date;
- Offered 1-2-1 support with LA data leads, making assistance more available for those who are unclear on how to record Down syndrome within the data collections.

The department, together with the data governance board (which involves sector representatives), considered recording Down syndrome with a binary yes/no question. However, it was ultimately decided to record as a type of need in order to be consistent with the way that information on autistic spectrum disorder is collected, rather than develop a new data field.

We believe a key reason for the low data quality is that last year was the first collection of data on Down syndrome in both the school census and SEN2. It is common for newly introduced data items to be underreported in their first year, and this typically improves over time as data collectors become familiar with the changes.

For an example of this with a different data item, please see the department's Schools, Pupils and their Characteristics publication, accessible via the GOV.UK website at: [tinyurl.com/3N7KKAN9](https://www.gov.uk/government/publications/schools-pupils-and-their-characteristics), where we include a section on young carers. This information was collected in the school census for the first time in the 2022 to 2023 academic year, and we saw an increase from 38,983 young carers identified in the first year of collection, to 64,475 in the latest year (2024 to 2025). We believe that this increase is likely due to the new data item becoming established within the collection rather than a true increase in young carers.

Additionally, reviews of an Education, Health and Care (EHC) plan are typically only held once a year. Given the code for Down syndrome was introduced for the first time last year, many plans were likely reviewed before the new code's implementation. Therefore, we anticipate an increase in the use of the code as more recent reviews of plans for children and young people with Down syndrome take place.

We expect data quality improvements due to the factors noted above (clarified guidance, increased familiarity with the codeset and review of existing EHC plans) in the upcoming data collections of SEN2 and school census. The department will undertake data quality assurance once the data becomes available for the latest year, ahead of our next publications, and will transparently communicate on data quality in the publications. This quality-assurance will include year-on-year checks at LA level to assess changes in code usage, as well as comparisons of returned figures against external data sources.

Additionally, to deliver our SEND reforms, we will carry out a programme of work as part of a new SEND data strategy that will seek to improve data across the system. This includes assessing the data needs of decision-makers so they have robust data and insights to inform their choices. I would welcome any further thoughts on progressing this.

Thank you for writing. I hope that this response is useful for you and the APPG.

Yours,

A handwritten signature in black ink that reads "Georgia Gould". The signature is written in a cursive, flowing style.

Georgia Gould OBE MP
Minister for School Standards

Attachment 3: Response to Neil Duncan-Jordan MP from Siobhan Harrington, CEO, University Hospital Trust Dorset in regard to Adrian Poulter case.

Thank you for your letter dated 2nd December regarding safeguarding procedures for people with learning disabilities and the sad case of Adrian Poulter. I want to acknowledge the sensitivity of this matter and the concerns raised by the National Down Syndrome Policy Group.

We would like to reiterate our deepest condolences to Adrian's family and recognise the profound distress caused by the circumstances surrounding his death. Please be assured that we take these issues extremely seriously and remain fully committed to learning and implementing meaningful improvements.

Following Adrian's death in 2021, a Serious Incident Investigation was undertaken. This review identified several areas for improvement, alongside additional workstreams that have since been implemented. Key actions include:

- **Enhanced Medical Review Pathway:** A standard operating procedure (SOP) for requesting medical opinions and reviews for patients admitted to Orthopaedic and Surgical specialties has been established. This applies to urgent and non-urgent cases, both in and out of hours.
- **Nasogastric Tube Management Training:** Orthopaedic wards have received training on the management of nasogastric tubes. Theoretical training is available via our e-learning platform, complemented by practical support.
- **Nutrition Support Team (NST) Access:** An inpatient electronic referral system enables ward teams to request support, advice, or assessment from the NST. A dedicated team member is available Monday–Friday, 8am–4pm.
- **Oliver McGowan Training Compliance:** All staff now receive Oliver McGowan training. UHD is working closely with Dorset colleagues to deliver this essential programme. Compliance for Part 1 training currently stands at 92.7% across all staff roles. We have recruited additional trainers and experts with lived experience to support delivery of Part 2 training, enabling up to four training days per month for 30 colleagues per session.
- **System-Wide Alert Mechanism:** We have introduced an alert system to flag patients requiring reasonable adjustments and ensure multidisciplinary oversight. Upon admission, wards refer patients to our Learning Disability and Autism (LDA) Practitioners, who add a flag to the patient record and monitor locations via a Business Intelligence report, enabling proactive support for patients and families.
- **Family and Carer Involvement:** Protocols have been strengthened to ensure families and carers are actively involved in care planning and decision-making. We are also early adopters of Martha's Rule/Call for Concern.
- **Specialist Practitioner Provision:** We now employ two Learning Disability and Neurodiversity Specialist Practitioners—double the provision at the time of Adrian's admission. These staff work closely with community providers to confirm diagnoses and understand individual needs.

- **‘My Care Passport’ Implementation:** My Care Passports’ are uploaded to patient records, providing immediate information on needs and adjustments. We are also developing a Learning Disability and Neurodiversity Champions programme across clinical areas and actively celebrate Autism and Learning Disability Week to raise awareness among staff and our hospital community.
- **Sharing Learning:** Patient stories are shared with clinical teams and the Trust Board to ensure lessons are widely disseminated. Our specialist practitioners and safeguarding lead also attend regional and national forums to inform best practice.

Please do not hesitate to contact me if you require further information or would like to discuss this matter in more detail.

Siobhan

Siobhan Harrington | Chief Executive

**Chief Executive’s Office – Cross site
University Hospitals Dorset**

0300 019 4242 | Siobhan.Harrington@nhs.net | www.uhd.nhs.uk

Executive Support | elena.woolston1@nhs.net