

**All-Party Parliamentary Group on Down Syndrome (APPGDS)
General Meeting: Tuesday 7th March 2023
Room R, Portcullis House**

Present:

Liam Fox (chair)
Flick Drummond (vice-chair)
Kate Kniveton (Cons)
Ian Paisley Jr (DUP)
Greg Smith (Cons)
Iain Stewart (Cons)
Lord (James) Touhig (Lab)
David Goss (Assistant to Liam Fox)

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

Florence Garrett
Ken Ross
Rachael Ross

Notes of Meeting

Action

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<p>1.0 Preliminaries Liam Fox (LF) welcomed all present</p> <p>1.1 Apologies: Lord (David) Alton of Liverpool, Dr Lisa Cameron MP, Lord (Alf) Dubs, Marion Fellows, Baroness (Llora) Finlay of Llandaff, Lord (Kevin) Shinkwin, Lord (Dafydd) Wigley</p>	
<p>2.0 Minutes</p> <p>2.1 Minutes of the previous APPGDS meeting were approved as a fair record of the meeting. (Actions are to be carried out in advance of the next meeting).</p>	ALL
<p>3.0 Progress of Down Syndrome Act Consultation and Guidance</p> <p>A briefing on the progress of the Down Syndrome Act and Guidance, prepared by civil servant Dave Nutall (DHSC), was presented by Rachael Ross (RR) and Ken Ross (KR) from the National Down Syndrome Policy Group (NDSPG). See attached document <i>'Update on the Down Syndrome Act call for Evidence and Development of Guidance'</i>.</p> <p>Concerns we raised about the lack of reference to 'Down syndrome specific' guidance, training and interventions. LF reiterated the importance that any Guidance should be Down syndrome specific, as it is an Act for people with Down syndrome and must reflect this. He stated that Ministers made specific</p>	

<p>representations during the passage of the Bill, stating that this would be the case, and requested that the APPGDS Secretariat revisited Hansard to locate these statements. LF will raise the importance of Guidance being Down syndrome specific with Ministers and the DHSC.</p> <p>The briefing stated <i>‘civil servants have been asked by ministers to proceed at pace...therefore it has been decided that a formal Govt response to the Call for Evidence will not be published as previously stated. An update on the Call for Evidence webpage will thank people for participating and let them know there will be no formal response’</i>. LF and Lord Touhig (LJT) felt that there should be a formal response to the Call for Evidence, and they should seek a commitment for this from the DHSC, which should reduce the need for select committees. The group agreed, and LF will raise this with Ministers and DHSC.</p> <p>Flick Drummond (FD) reminded the group that Down syndrome specific questions can be raised in Parliament/Prime-Minister’s Questions as previously discussed, highlighting Down syndrome specific questions and issues. She advised this should be done regularly to keep the topic relevant. FD offered to do this in the House of Commons and LJT offered to do this in the House of Lords. Questions need to be provided, and the NDSPG were asked to help with this. LF also said questions could be raised in the Down Syndrome Debate taking place in the House of Commons on 23.03.23.</p>	<p>LF RR</p> <p>LF</p> <p>All NDSPG</p>
<p>4.0 Update on Including Down Syndrome as a separate category in the School Census for 2024</p> <p>RR referred the group to the document <i>‘Formal Request to Add Down Syndrome to the School Census as a Separate Category to the Annual School Census’</i> prepared by the NDSPG, outlining the benefits of the addition (see attached). A number of clear benefits were highlighted, including the more <i>‘effective dissemination of Down syndrome specific education guidelines, strategies and resources, including those resulting from the Down Syndrome Act 2023.’</i></p> <p>RR and KR from the NDSPG updated that a formal request for ‘Down syndrome’ to be added as a separate category to the school census had been submitted to the DfE, but there has been no engagement to date. Several meetings in a row to discuss this matter with the Minister of Education have been cancelled. RR reported frustrations that the process is taking so long, and the window for 2023 has been missed despite the request being first submitted in April 2022 and wide-spread backing in favour of the addition. It is believed the next date it could be implemented is Autumn term 2024. Resistance seems to be coming from the DfE who support a pan disability approach and do not see the addition as beneficial – reasons given included concerns it would create increased workload for headteachers, the need to carry out a survey to check schools to approve the addition, another category would have to be removed to make space for the addition of Down syndrome, and it was implied that the workload to make this happen would be greater than the benefit. All agreed this is very disappointing.</p>	

<p>4.1 Next steps</p> <p>All APPGDS members present reaffirmed their support for Down syndrome to be added to next school census 2024 and acknowledged that this is time critical.</p> <p>LF has requested a further meeting to discuss the matter with the Minister and representatives from the NDSPG, and it is hoped that this meeting on 26.04.23 will go ahead.</p> <p>Questions will also be raised at the Down Syndrome Debate on 23.03.23 during Down Syndrome Awareness Week, asking Ministers to consider and commit to the request.</p> <p>5.0 Education Guidance</p> <p>KR and RR from the NDSPG, referred the group to the former APPGDS Education Guidelines created in 2012. Download available here: https://www.down-syndrome.org/en-gb/reports/2012/appg-down-syndrome-education-guidelines/ . These guidelines were compiled by some of the leading educationalists and experts in Down syndrome, alongside members of the previous APPGDS, but sadly this excellent Down Syndrome specific education guidance had not been widely disseminated. The NDSPG and the NDSPG Expert Education Panel requested that in light of the Down Syndrome Act, that a new working group is formed to revisit this guidance and rewrite/update, to be a more detailed accompaniment to the forthcoming Down Syndrome Act Guidance to help ensure successful inclusion. The NDSPG asked for APPGDS backing once again.</p> <p>LF explained that the APPGDS are not permitted to commission new guidance, but they would be happy to host the previous APPGDS Education Guidelines on the current APPGDS website with a note to say they are currently being updated. NDSPG to form a working party of expert professionals in due course to review these guidelines.</p>	<p>FD LF NDSPG</p> <p>NDSPG</p>
<p>6.0 Invitation to the Liam Fox and NDSPG World Down Syndrome Day Celebrations and photo opportunity.</p> <p>NDSPG Ambassador, Florence Garrett, talked briefly about her life and experiences of employment, before extending an invitation to all APPGDS members to attend the World Down Syndrome Day Celebratory Reception on 21.03.23 in Westminster Pavilion, hosted by LF and the NDSPG.</p> <p>APPGDS members were also invited to take advantage of the photo opportunity on 08.03.23 with officers and ambassadors from the NDSPG and invited to support the Down Syndrome Act progress on social media on World Down Syndrome Day.</p>	<p>LF NDSPG</p> <p>ALL</p>

<p>LF reported the exciting news that he had just had confirmation that he would be speaking at the United Nations in New York about the UK Down Syndrome Act on World Down Syndrome Day 21.03.23. Members of the group offered their congratulations. FD very kindly offered to host the World Down Syndrome Day Pavilion Celebrations in the absence of LF.</p>	
<p>7.0 Any Other Business</p> <p>None stated. LF thanked everyone for their support.</p>	

Next APPGDS Meeting: Annual General Meeting of the APPGDS

Date: 12.09.23, 2pm - 4pm

Venue: Jubilee Room, Westminster Hall

Attachments are below.

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

Update on the Down Syndrome Act Call for Evidence and Development of Guidance

- **In July 2022 a national call for evidence was launched to inform the development of the Down Syndrome Act guidance.** The government wanted to hear views on the specific needs of people with Down Syndrome, as well as on examples of best practice across health, social care, education and housing. The call for evidence was open for 16 weeks and closed in November last year.
 - **There were over 1500 responses in total** to the consultation, which has provided a significant body of evidence to inform the guidance
- **The government has also engaged with a broad range of individuals and organisations** through in-person and online engagement events, including people with Down Syndrome and/or other genetic conditions, their parents and carers, as well as experts and practitioners from multiple sectors who work with people with Down Syndrome and/or other genetic conditions.
- In-depth analysis of the responses has now been completed, and the following are a summary of the main themes:
 - **Person-centred support** – each person with Down syndrome is an individual and should be treated as such. Support should be tailored to the needs and wishes of each individual and people with Down syndrome must be treated with dignity and respect
 - **Skilled workforce** - it is essential that professionals have an understanding of Down syndrome. Diagnostic overshadowing is often an issue where symptoms are assumed to be due to the person having Down syndrome or a learning disability rather than a medical or mental health need.
 - **Reasonable adjustments** – professionals need to be aware of their legal duty to make reasonable adjustments and would like practical examples of how best to do this in practice.
 - **Integrated care** – services need to work in partnership to provide multi-disciplinary support. There needs to be greater forward-planning in services that will be needed by people with Down syndrome throughout their lives.
 - **Availability and access to services** – there's often a shortage of services available such as adequate housing, respite care and access to therapies like speech and language therapy. Where services are available, parents and carers don't always have the information they need to access support in their local area.
- **Civil servants have been asked ministers to proceed at pace with developing the guidance, therefore it has been decided that a formal government response to the CfE will not be**

published, as we previously stated. An update on the CfE webpage will thank people for participating and to let them know that there will not be a formal response. Next steps will also be briefly explained.

- **The Department of Health and Social Care are now in the process of drafting the guidance based on the evidence collated, and stakeholders will be consulted throughout this process.**
- A high-level summary of findings from the call for evidence will be shared with stakeholders who are supporting us to develop the guidance and **a governance group of key stakeholders will also be set up to provide expertise as the guidance is developed.**
- **The Department of Health and Social Care are currently aiming to carry out a public consultation on the draft guidance over the summer.**

Formal Request to add Down syndrome as a separate category to the annual school census (January 2023)

Why Down Syndrome?

The Down Syndrome Act 2022 aims to address the specific needs of people with Down syndrome (DS) in education, health care, social care, and employment, and provide guidance for local authorities and related bodies to improve awareness, practice and outcomes. This will be difficult to implement, as there is currently no DS specific school data available including numbers, location and education setting as individuals with Down syndrome are only included in the general Special Educational Needs and Disability (SEND) school numbers.

Down syndrome is recorded at birth as a diagnosis, so this is a clearly definable and manageable group with a unique profile of need. Based on the current birth-rate, it is estimated that there are in excess of 10,000 pupils (aged 4 to 18) with Down syndrome. Numbers who progress into further education are unknown. All will have a specific range of common needs which as a whole 'learning profile' is not generally present in the SEND school population:

- Significant speech and language (all will need speech and language intervention)
- Significant fine and gross motor delay (all)
- Cognitive delay (all)
- Hearing loss (most)
- Vision issues (all)
- Social emotional needs/behaviour (all)
- Specific and unique learning profile associated with Down syndrome (all)

Every student with Down syndrome will need an individual EHCP with targeted support and provision in their individual setting, and this support will also vary depending on the type of education setting. It is almost impossible to provide this targeted support effectively and economically without the specific data needed for effective planning, evaluating and delivery of provisions, and as a result, many children with DS continue to be inadequately supported.

There is a national shortage of speech therapists, and this lack of speech and language provision for children with DS is a key concern. Most teachers do not automatically receive the training they need to successfully include children with DS in the mainstream setting where research has proven has the best educational outcomes for children with Down syndrome with added benefits to the community, and is the least expensive setting.

Research based strategies for successful school inclusion have existed for decades but are frustratingly not filtering down into educational settings where they are needed. There are significantly better outcomes for children with Down syndrome in areas where these strategies are implemented.

Adding 'Down syndrome' as a category in a school census can be done at minimal cost if any, and benefits locally and nationally would be significant ensuring:

- effective dissemination of Down syndrome specific education guidelines, strategies and resources including those resulting from the Down Syndrome Act 2022
- effective planning and evaluation for targeted provision (school/LA budgets)
- identification of specific school support, staffing and training needs, as well as regional and national needs (training of speech and language therapists)
- improve efficiency and effectiveness of services
- an increase in children successfully included in mainstream at all levels (less costly than special schools)
- seamless monitoring of school placements (estimated 85% start their education in mainstream - falls to 25%-37% by secondary) and any rise or decline in numbers
- increased accountability
- levelling up (remove postcode lottery)
- reduction in costly tribunals and appeals
- effective and comprehensive research including everyone (currently those in most need do not volunteer)
- improved support for children and families, and improved outcomes to benefit pupil and community ensuring every child has the possibility to reach their potential
- increased independence and opportunities
- a reduction in support costs and family breakdowns
- improved quality of life for individuals and families

Is there a precedent already?

The precedent has already been set with Autism which is included alongside SEND on the school census already and has been for many years as a direct result of the Autism Act 2009. There are also plans to add 'child carers' to the census this year.

Please contact Rachael Ross rachaelross@ndspg.org if you have any questions.