

APPG ON DOWN SYNDROME

Meeting Tuesday 15th March 2022 1pm – 2pm Via Zoom

In attendance

Dr Lisa Cameron MP
David Duguid MP
Edward Timpson MP
Flick Drummond MP

Douglas Chapman MP
Baroness Hollins
Virendra Sharma MP

Flick Drummond MP
Gillian Keegan MP Minister
Robert Lentz PA

Annabel Tall (rep. Dr Fox MP)
Fionn Angus
Sam Eccles PA
Ken Ross

Prof Sue Buckley
Jonathon Angus
Amy Brodie

Dr Elizabeth Corcoran
Dr Monica Lakhanpaul
Lynn Murray

Apologies: Matt Western MP, Feryal Clark MP

1. Down Syndrome Bill

- Ken Ross of the National Down Syndrome Policy Group (NDSPG) updated the group on the Down Syndrome Bill, advising that the NDSPG is preparing to gather evidence to feed into the consultation
- Gillian Keegan said consultation will commence as soon as the Bill receives Royal Assent
- Flick Drummond MP asked why we don't start consultation now, Gillian Keegan said she felt that with the healthy progress of the Bill, it would be sufficient to begin consultation as soon as the Bill became law
- Edward Timpson asked if other political work such as the SEN review in Dept of Education, Access to Work scheme in the DWP and other issues in the health department that will compliment will support the Bill. Gillian Keegan informed that these and others will be helping the Bill.
- As a Scot, Douglas Chapman MP said he would meet with Scottish counterparts to ensure there is best practise nationwide. Gillian Keegan said she had written to devolved administrations.

2. Using data to plan services

- Professor Sue Buckley from Down Syndrome Education International gave a presentation about how data collection helps providers plan appropriate provision.
- She discussed how currently the hearing-impaired population, which is close in numbers of babies born to those with Down syndrome - has much better plans and legislation as well as data.
- Overall, the committee agreed on the importance of data collection and that it's not particularly difficult or costly to collect.

3. Advisory Group

- Fionn Crombie Angus, one of the founding officers of the NDSPG who has Down syndrome, spoke about what the members do and relayed a story about his colleague *Sally*, who is a member of the Advisory Group. He spoke about how she was deprived of communication and support during a recent serious illness and how her family weren't allowed to visit her. Sally would like all staff, including admin, to better understand the need of patients.

4. Health Matters

- Dr Elizabeth Corcoran gave an overview of a Covid Survey of 900 people undertaken by Down's Syndrome Research Foundation and Down Syndrome UK. Only a minority of the group are on no medication.
- She raised the issue of diagnostic overshadowing; we are often told 'this is normal for Down syndrome' without proper investigation taking place, relating to Fionn's input.
- Monica Lakhanpaul added that there is a challenge in the UK around specialised, targeted clinics which are not found all over the country. Lisa Cameron suggested a roundtable with a Minister to discuss the benefits of specialist clinics.

5. APPG Forward Plan

- Ken requested that it would be good to have more meetings in the diary, and to establish work groups in the work streams. An example was given that there's a belief that if a child can't speak, that they are limited by cognitive ability, not lack of input, a common misunderstanding.
- The point that the group needs to consider issues around budgets not being passed between departments was raised.
- Lisa Cameron suggested we create programmes for the coming year including roundtable discussions.