From: Angelman UK
Cri du Chat Support Group
Genetic Alliance UK
MAX Appeal
Prader-Willi Syndrome Association UK
Ring 20 Research and Support UK
The Smith-Magenis Syndrome (SMS) Foundation UK
SWAN UK (syndromes without a name)
Unique

The Rt Hon. Liam Fox MP
House of Commons
London, SW1A OAA
(by email)

21 December 2021

Dear Dr Fox,

Subject: Down Syndrome Bill

We write to request a meeting to ask for the objectives of the Down Syndrome Bill to be extended to improve the lives of all those affected by all genetic conditions and learning disabilities, not just Down syndrome.

We congratulate you on your success in introducing a Private Member's Bill, and on using this opportunity to benefit people living with Down syndrome. Your speech on the occasion of the second reading of the Bill was powerful and introduced many topics which are familiar to the people we support. The medical problems, educational needs and long-term care challenges you described overlap with those of the people we support. The interventions

from your fellow MPs were just as familiar. Fragmented services; the need for integrated children's services; education, health and care plans that do not reflect the child's needs; and the need for awareness raising, are all issues that our groups face too. In the same way that we have a desire for people affected to have the most fulfilled lives possible and know many aging parents are concerned about the welfare of the children they love.

The needs of the people we represent overlap so much with people living with Down syndrome as to cause us concern at the possible unintended consequences of the Down Syndrome Bill. This is especially concerning in the environment we live in now where resources of the NHS, education providers and local government are stretched by the challenges of the pandemic. We support the current needs-based allocation of support and care and are concerned that this would be disrupted or undermined by singling out people living with Down syndrome. In a resource constrained environment we worry that such changes might disadvantage or discriminate against those with learning disabilities caused by other diagnoses. All need better support, not at the expense of any other group. We are also concerned that the creation of an environment where two children with very similar needs are treated differently because of the name of their condition could be divisive, and we are sorry to see some of that become apparent in reactions to this Bill.

We know that most people are even less familiar with chromosome and genetic conditions other than Down syndrome. We write to request a meeting so that we can discuss the concerns of our groups in more detail and propose that you broaden the scope of your Bill to include all that face the same challenges as those living with Down syndrome. We have included all of those MPs who spoke at the second reading of the Bill in the cc list to this letter and would be grateful for the opportunity to meet with them all. We have also added Liz Twist MP to the cc list as the chair of the APPG for Rare, Genetic and Undiagnosed Conditions.

Our groups are engaged in the implementation of the UK Rare Diseases Framework and believe it offers significant opportunities to our community in the policy areas of health and research. We urge you to seize the momentum and support you have generated with the Down Syndrome Bill and develop a Learning Disability Strategy to achieve the same result for healthcare, education and support for people affected by Down syndrome and all other diagnoses.

We are a group of nine non-profit organisations supporting people living with genetic learning disabilities. **Angelman UK** is the longest standing UK charity providing support, education and research for families and individuals impacted by Angelman syndrome, a rare neurogenetic disorder. **Cri du Chat Support Group** is a national charitable organisation that supports those with, and families of those with, the rare condition Cri du Chat Syndrome. **Genetic Alliance UK** is an alliance of more than 200 organisations supporting people with rare or genetic conditions. **Max Appeal** supports children, adults and their families affected by 22q11.2 Syndromes throughout the UK. **Prader-Willi Syndrome Association UK** supports about 2,000 families affected by Prader-Willi syndrome. **Ring 20 Research and Support UK** promotes research, education and continuous support to end undiagnosed and misdiagnosed Ring20 epilepsy. **The Smith-Magenis Syndrome (SMS) Foundation UK** serves families affected by this condition with the vision that every person with Smith-Magenis Syndrome shall have a fulfilling life within a supportive and understanding community. **SWAN UK (syndromes without a name)** is a support network for families with

children with undiagnosed genetic conditions. **Unique** supports all those affected by a rare chromosome or gene disorder. All of our organisations support people with learning disabilities with needs that overlap with people living with Down syndrome.

Yours sincerely,

Emma Goodson, Trustee, Angelman UK
Martin Roberts, Chair, Cri du Chat Support Group
Nick Meade, Joint Interim Chief Executive, Genetic Alliance UK
Claire Hennessey, Development Officer, MAX Appeal
Susan Passmore, Chief Executive Officer, Prader-Willi Syndrome Association UK
Allison Watson, Chief Executive Officer, Ring 20 Research and Support UK
Nigel Over, Chief Executive Officer, The Smith-Magenis Syndrome (SMS) Foundation UK
Lauren Roberts, Coordinator, SWAN UK (syndromes without a name)
Sarah Wynn, Chief Executive Officer, Unique

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Cc:
Robert Buckland MP
Douglas Chapman MP
Elliot Colburn MP
Flick Drummond MP
Nick Fletcher MP
Sally-Ann Hart MP
Dame Meg Hillier MP
Ruth Jones MP
Gillian Keegan MP)
John Lamont MP
Kerry McCarthy MP
Lia Nici MP
Alex Norris MP
Ian Paisley MP
Mark Pawsey MP
Tom Randall MP
Greg Smith MP
Liz Twist MP
Sir Charles Walker MP
Suzanne Webb MP