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Dear Justin,

We are Disability Rights UK Our Voices, a group of organisations run by and for disabled people. We meet regularly to share the experiences of the people we work with. Our organisations are based in all regions of England and working together we offer a unique perspective on the lived experience of disabled people, enabling us to work together on shared priorities.

We are writing to highlight our serious concerns and disappointment with the government's engagement on the proposed National Strategy for Disabled People. Our concerns relate to:

- 1. The methods used to engage disabled people and their organisations and the disjointed and somewhat chaotic approach to engagement and 'insight gathering'.
- 2. The timescale of these engagements.

## 1. Methods used

- a) During 2020, we are aware that the government had committed to use a range of methods to engage stakeholders, primarily the use of thematic groups, and engagement via the Disabled People's Organisation (DPO) Ministerial Forum and Regional Stakeholder Networks.
- b) Some of our group are also members of the Ministerial Forum and Regional Networks. We are concerned about the recent cancellation of Ministerial Forum meetings and the lost opportunity to effectively engage with DPOs on the development of the National Strategy.
- c) The early contribution from the DPO Forum and Regional Stakeholder Networks has not been reflected in the recently published National Disability Survey, which is the first opportunity so far for individual disabled people to contribute to the strategy.
- d) The survey is unfocused, asking broad questions about the experiences of disabled people, with no apparent strategic link or any reference to the 'cross cutting themes' that have been used in other engagement.
- e) Whilst data on the experiences of disabled people is welcome, in this context there is no possibility it could be translated into meaningful insight on what should be in a National Strategy for Disabled People. There is no mention of the strategy at all in the survey, and we feel strongly that it in no way supports genuine co production.
- f) As a group of organisations, we are uncomfortable with sharing and promoting the survey, given that it is not clear how it will support the development of the strategy. Many of us have already encouraged our members to engage with us on the strategy, but we aren't able to demonstrate to them what has happened to the insight they shared with us and they are instead being asked for more information.

- g) We have also heard feedback that the survey is far too long and for many inaccessible in its length; it also isn't possible to tell how many questions are remaining, and some questions, particularly at the beginning, are intrusive. We feel that it is not made clear *why* this information is being asked for, and so people are left guessing as to how the information will be used. The UK General Data Protection Regulation requires there to be a clear reason to ask for data such as sexuality and ethnic background, and this is not made clear in the survey which therefore appears to be in contravention of the regulations.
- h) We are also concerned about the accessibility of the survey. There is only mention of alternative formats if you go onto the survey website, but many disabled people are digitally excluded, and so we would recommend a published telephone number that people can use to ask for different formats, and to understand more about the survey and the strategy.
- i) We stand ready to work with the government on the development of the strategy and would have been pleased to be consulted ahead of the survey being published, to give feedback on these kinds of issues.
- j) We are very disappointed that such consultation did not happen. We know that the government has worked extensively with the Disability Charities Consortium (DCC), however these organisations may speak on behalf of, but do not *represent* disabled people.
- k) Disabled People's Organisations (DPOs) offer a unique perspective. We are organisations that are run and controlled, by and for disabled people.
- I) Our organisations truly represent disabled people and our lived experience is sadly underutilised by government. We should be the first contact government make to understand the views and experiences of disabled people, with other organisations such as disability charities bringing their perspective, but not being the first port of call. It is vital that disabled people are part of the conversation at the earliest possible stage. We want to see government engagement reflect the idea that there should be "nothing about us without us".
- m) We would encourage more engagement with Our Voices, as we are able to act as a legitimate and authoritative collective voice for the sector and for disabled people, which is representative of all regions of England.
- n) We would be very happy to engage with the Disability Unit regularly and would like to suggest that we meet every 2 months to begin to work together.

## 2. <u>Timescale</u>

a) The deadline for responses to the survey is also a serious issue. As the deadline for responses to be considered in the development of the strategy is 13 February 2021,

this has given just 4 weeks to respond, which is far too short, and is made all the more challenging by the pandemic.

- b) We question why the strategy is being rushed through in this way? Although it is disappointing that more progress has not been made, we want to see a high quality, robust and meaningful National Strategy for Disabled People, with measurable and tangible outcomes. It is therefore imperative that more time is allowed for input.
- c) Many of our organisations would like to offer support to our users and members to complete a survey but are unable to do this under the current timescales offered.
- d) We continue to be supportive of the National Strategy for Disabled people, and feel that it is greatly needed, especially during the pandemic and beyond.
- e) Disabled people have been disproportionately affected by the pandemic. ONS reports that 59% of deaths from Covid 19 have been disabled people, and yet we are consistently forgotten, with the government slow to put in place guidance and support at every stage of its response to Covid 19.
- f) However, the strategy *must* reflect the lived experiences of disabled people. We are left with grave concerns about whether this will be achieved with the current approach being taken.
- g) With this in mind, especially given the impact of Covid 19, we would like to see the release of the strategy postponed until to the summer. This would allow all responses the survey collected until 23<sup>rd</sup> April 2021 to be considered in the strategy, but more importantly, to give time to undertake a genuine engagement exercise with disabled people and their organisations.

Kamran Mallick, Disability Rights UK and Victoria Armstrong, Chief Executive, Disability North Sandie Burns, Chief Executive, Disability Peterborough Dominic Ellison, Chief Executive, WECIL Isabelle Clement, Director, Wheels for Wellbeing Diana Crump, Chief Executive, Living Options Devon Laura Horton, Chief Executive, LCiL Emily Morton, Chief Executive, Disability Sheffield Michelle Scattergood, Chief Executive, Breakthrough UK Lynne Turnbull, Chief Executive, Disability Positive Yours Sincerely,

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