

DOWN SYNDROME BILL

Memorandum from the Department of Health and Social Care to the Delegated Powers and Regulatory Reform Committee

Introduction

1. This memorandum has been prepared for the Delegated Powers and Regulatory Reform Committee to assist with its scrutiny of the Down Syndrome Bill ("the Bill"). The Bill was introduced in the House of Commons on 16th June 2020 by Dr Liam Fox MP as a private member's bill, which the government is now pleased to support. This memorandum identifies the provisions of the Bill that confer powers to make delegated legislation. It explains in each case why the power has been taken and explains the nature of, and the reason for, the procedure selected.

Purpose and effect of the Bill

2. The intention behind the Bill is, via the publication of guidance, to offer assistance to certain public authorities in the provision of services under existing legislation to those with Down syndrome, in order that these bodies may better take account of the specific needs of such persons.
3. Concern has arisen that the interests of those with Down syndrome may not be appropriately taken into account in the general exercise of functions in respect of health, social care, housing and education sectors, and guidance to the relevant public authorities may be appropriate to achieve these ends.
4. Provisions are described below in the order in which they appear in the Bill.

Delegated Powers

Clause 1: guidance on meeting the needs of persons with Down syndrome

Power conferred on: the Secretary of State

Power exercised by: guidance

Parliamentary procedure: laid before Parliament only

Context and Purpose

5. Subsection (1) of clause 1 provides that the Secretary of State must give guidance to an authority (listed in the Schedule) on steps it would be appropriate for that authority to take in the exercise of a function (also listed in the Schedule) so as to meet the needs of persons with Down syndrome.
6. The authorities listed are those responsible for the provision of health, education, housing and social care, the provision of services in respect of which require particular consideration of the specific issues encountered by those with Down syndrome.

Justification for the power

7. It is considered that delegating a power to issue guidance rather than providing for guidance to be on the face of primary legislation is appropriate due to:
 - 7.1. the breadth of functions listed in the Schedule to which the guidance relates, these being in relation to four complex areas of a person's life and for each of which the

guidance will need to take account of significant practical and operational detail within a multitude of scenarios;

- 7.2. the requirement to amend frequently and swiftly, in order to maintain relevance:
- (a) notwithstanding changes in the needs of persons with Down syndrome,
 - (b) taking into account changes in medical science and advances in care and treatment, and
 - (c) considering the flexibility with which a relevant authority may, in accordance with applicable primary and secondary legislation, exercise a relevant function.

8. Guidance will need to:

- 8.1. Maintain pace with new and emerging research and evidence that could consider matters such as:
- (a) tailoring education to meet the unique learning profile of persons with Down syndrome;
 - (b) gaining a better understanding of the level of health and care needs of an aging population of such persons;
 - (c) the most appropriate housing arrangements for such persons;
- 8.2. respond to:
- (a) ongoing government programmes and strategies such as the Special Educational Needs and Disabilities Review and the National Disability Strategy;
 - (b) changing commissioning structures, by virtue of the Health and Care Bill currently before Parliament.

Justification for the procedure

9. Mindful of the Delegated Powers and Regulatory Reform Committee's 12th Report of Session 2021-22, and in particular paragraphs 91 to 100 in Chapter 4 of that Report, it is not considered that a Parliamentary procedure is necessary for guidance issued under clause 1 of the Bill.
10. The intention behind clause 1 is not to secrete a regulatory wolf beneath the ovine mantle of statutory guidance, making legislative or quasi-legislative provision that would properly be suited to a regulation-making power (such as to the manner in which or time within which a function should be discharged) but to assist within an already suitably prescriptive legislative landscape.
11. Guidance under clause 1 will be issued by reference to functions already conferred by a number of regimes set out in primary legislation, and the intention is that these should continue to operate as constituted. It is considered that functions within these regimes are already sufficiently regulated as to general provision, in accordance with Parliament's intention upon the passing of each relevant enabling enactment.
12. The power in subsection (1) of clause 1 is to provide guidance on steps it would be appropriate for a relevant authority to take in the exercise of a relevant function specific to persons with Down syndrome, and it is not intended that these steps should alter the function or the manner in which it is exercised; the step should be one which would be appropriate for an authority to take within its current remit and scope of

implementation (and which some authorities may already have adopted as best practice).

13. For example, a function may include provision for the performance of a service in respect of persons with a learning disability, but steps might be included in guidance as to how to cater for those also possessed of congenital heart problems, as often present in persons with Down Syndrome.
14. Although the Bill makes provision at subsection (2) of clause 1 for an authority to have due regard to guidance issued, this is not absolute and it is conceivable that there are strong and justifiable reasons why relevant authorities will be unable to adhere to the guidance in their exercise of their functions. It is not considered that such a provision materially elevates the obligation placed on relevant authorities by guidance issued by the Secretary of State beyond what is already expected through other statutory powers and frameworks and the functions are in the main tightly cast and suitably prescriptive, with in a number of cases provision already made as to how a function is to be discharged; for example:
 - 14.1. in respect of social care under section 117 of the Mental Health Act 1983 (after care), functions are to be provided for a period of time determined in accordance with statute, and the Secretary of State already has the power to make regulations as to the manner in which they are to be exercised (by virtue of subsection (2B) and section 32);
 - 14.2. in respect of housing under Part 6 of the Housing Act 1996 (allocation of housing accommodation), schemes under section 166A and 167 are subject to principles as may be prescribed by the Secretary of State by regulations (subsection (10) and (5) respectively);
 - 14.3. in respect of housing under Part 7 of the Housing Act 1996 (homelessness assistance), functions are subject to statutory restriction over the manner in which they may be discharged (sections 205 to 209).
15. Given the prescriptive nature of the primary legislation and provision where necessary already made for delegated regulation, guidance under clause 1 should not trespass on the exercise of the relevant functions in this respect. It is not considered, therefore, that the guidance would be of a legislative character such as would warrant attracting a Parliamentary procedure.
16. In doing so the Bill accords with comparable approaches elsewhere in healthcare legislation, whereby guidance is employed to illustrate steps which may be taken under functions already suitably provisioned as to secondary legislation; for example, guidance under section 23 of the Health and Social Care Act 2008 addressing compliance with the requirements of regulations under other provisions of that Act.
17. Further, section 24 of that Act requires consultation on the regulations, as does subsection (3) of clause 1 of this Bill. This will include wide engagement with stakeholders, preparing draft guidance and subjecting the draft to a public consultation before publication. The Government considers that a similar approach is appropriate for the guidance-making power within the Bill and will preserve a measure of consistency.
18. However, although no procedure for an automatic Parliamentary scrutiny has been provided by the Bill, it is considered that the guidance will undoubtedly be of interest to Parliament given those to whom it relates; accordingly, subsection (5) of clause 1 provides that the guidance must be laid before Parliament once published.

Clause 2: extent, commencement and short title

Power conferred on: the Secretary of State

Power exercised by: regulations made by statutory instrument

Parliamentary procedure: none

Context and Purpose

19. Subsection (2) of this clause provides a power for the Secretary of State to bring the legislation into force.

Justification for taking the power

20. The precise timing for commencement of provisions is delegated to the Secretary of State in order that preparatory steps precedent to implementation may be taken in advance of commencement, so as to avail the Secretary of State of a timely fulfilment of the obligations set out in clause 1 (the first being to consult on proposed guidance).

Justification for the procedure

21. As is common with commencement regulations bringing into force an enactment and making no substantive provision, it is considered that in respect of these regulations no Parliamentary procedure is indicated.

Department of Health and Social Care

4th February 2022