Down Syndrome Act 2022 draft statutory guidance – RCGP Comments

Organisation: Royal College of General Practitioners

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To what extent do you agree or disagree with the following statements?

1. *The guidance meets its aim to raise awareness of the needs of people with Down syndrome by bringing together in one place everything that relevant authorities must and should already be doing to support them and meet their needs.*

Agree

2. *The guidance will have a positive impact on people with Down syndrome and their families and/or carers.*

Agree

3. *If you have any further comments on the content of the guidance, please outline them here. Please include comments about the following sections of the guidance if you have any specific comments:*

- *Accessible and person-centred services*
- *High-quality and holistic healthcare*
- *Independence through social care*
- *Effective education and preparation for adulthood*
- *Meaningful employment*
- *Appropriate housing*
- *Where to find help and support*
- *Inclusion of guidance about people with other chromosomal conditions, genetic conditions and/or a learning disability*
- *The resources and examples of good practice annex*

We welcome the intent of the statutory guidance and the effort to bring together a comprehensive framework to support people with Down syndrome. However, we are concerned that, without significant additional resource, the guidance risks having limited impact in practice. Bringing information together in one place does not, in itself, improve care delivery, and the ability of general practice and wider services to provide high-quality, person-centred care is fundamentally constrained by workforce and capacity pressures.

We would emphasise that improving care is more likely to be achieved through investment in frontline services rather than additional layers of system leadership or governance. This includes appropriate resourcing for primary care, social care, safeguarding services, interpreting services, and community provision. Without this, many of the aspirations set out in the guidance may not be deliverable. We also note that several areas referenced in the guidance, such as training provision, safeguarding thresholds, access to NHS dentistry, and support for carers, are currently variable or under strain. For example, access to BSL interpreters remains inconsistent, safeguarding teams are often operating with high thresholds due to capacity constraints, and access to NHS dental care is limited. Similarly, unpaid carers continue to face financial and practical challenges that are not addressed within the guidance but are central to the delivery of care.

We would also highlight current system pressures within integrated care boards (ICBs), which may limit their ability to take on additional organisational responsibilities at this time.

We welcome the inclusion of the Reasonable Adjustment Framework. It would be helpful to include clear information on how both service users and NHS staff can access and apply the framework in practice, and a simple case study could further support understanding.

In relation to advocacy, we note that there are multiple forms, including local authority-based advocacy and Mental Health Act advocacy, each with different eligibility criteria. It would be helpful to include an overview of the different types of advocacy available, alongside cross-referencing to independent mental health advocates (IMHAs), which are referenced later in the document. The inclusion of case studies would also be beneficial.

We welcome the reference to autism training and the Oliver McGowan training. However, it is important that training programmes are high quality and deliver meaningful improvements in confidence and capability, and this should be carefully considered in future development.

The list of relevant legislation should include the Autism Act 2009. We also welcome the explicit reference to diagnostic overshadowing, which is an important and often under-recognised issue.

With regard to system planning, leadership and use of data, we recommend that local authorities and ICBs have robust mechanisms to use general practice registers to produce accurate prevalence data for people with Down syndrome, understand co-morbidities and health inequalities using primary care records, and track patient pathways across NHS datasets such as CSDS, MHSDS, ECDS and HES. There should also be linkage with local authority datasets, such as EHCPs and care packages, using NHS numbers to support more effective population health planning.

In relation to neonatal and postnatal care, where an antenatal diagnosis is made, it is essential that parents are provided with balanced and comprehensive information about available support if they choose to continue the pregnancy. Decisions must be fully informed and voluntary.

We welcome the inclusion of a dedicated section on general practice. Where annual health checks are offered, it is important that information is recorded using recognised templates, such as Ardens, and coded consistently using SNOMED to support continuity and data quality.

We welcome inclusion of the Dynamic Support Register and note that it may be helpful to reference the anticipated transition to Complex Support Registers.

The recommendation that GPs complete baseline assessments of adaptive behaviour is not aligned with current general practice roles or training and would be more appropriately undertaken by professionals such as occupational therapists or social workers.

Education, Health and Care Plans have historically focused on educational needs, and greater emphasis on the health and care components would be beneficial.

The term “integrated” is used in multiple contexts and would benefit from clearer definition, whether at the level of individual patient care, local service delivery, or strategic system working.

Consideration should also be given to cross-referencing local authority registers of disabled children with primary care registers using SNOMED coding, to improve data completeness and coordination.

We also note several practical challenges that may limit implementation without further clarification or resource. Responsibility for baseline investigations, such as hearing tests, should not default to general practice where systems fail, and proactive follow-up processes are needed. Recommendations such as regular vision testing require clarity on funding and access. Transitions from paediatric to adult services remain a significant area of risk, with patients often experiencing gaps in care.

Overall, while the guidance is comprehensive, its successful implementation will depend on realistic alignment with workforce capacity, clear delineation of responsibilities, and adequate resourcing across the system.