

**From:** Dan Watkins, Cabinet Member for Adult Social Care and Public Health  
Richard Smith, Corporate Director Adult Social Care and Health

**To:** Adult Social Care Cabinet Committee – 13 March 2024

**Subject:** **DOWN SYNDROME ACT 2022 UPDATE**

**Classification:** Unrestricted

**Electoral Division:** All

**Summary:** This report provides an update on the Down Syndrome Act 2022, including the progress on the guidance to be issued by the Secretary of State and the consultation on the draft guidance. This report also outlines the social care duties placed on Kent County Council and all local authorities for people with Down Syndrome and the system challenges for this area.

**Recommendations:** The Adult Social Care Cabinet Committee is asked to **NOTE** the contents of the report and that a paper on the Down Syndrome guidance to be issued by the Secretary of State will be provided to this Cabinet Committee.

## 1. Introduction

- 1.1 This report was requested at the Adult Social Care Cabinet Committee meeting on 1 December 2021 during the passage of the Down Syndrome Bill, which has since received Royal Assent but is awaiting statutory guidance to be issued.
- 1.2 The Down Syndrome Act received Royal Assent on 28 April 2022. The Act seeks to ensure that certain health, education, and local authorities take account of the specific needs of people with Down Syndrome when exercising their relevant functions. The Act is intended to raise awareness and making sure identifiable and unique needs of people with Down Syndrome are not overlooked when planning, designing and delivering services.
- 1.3 The Secretary of State must give guidance on steps it would be appropriate to take to meet the needs of people with Down Syndrome. The Secretary of State must consult on the draft guidance which is expected in 2024. It is important to note that the Act does not introduce new duties for the relevant authorities but a requirement to have due regard to the guidance when carrying out relevant functions. The Guidance will set out the steps and actions public authorities should take to support people with Down Syndrome.
- 1.4 This report details the provisions of the Down Syndrome Act 2022, the progress of the consultation and statutory guidance. This report also outlines the duties placed on Kent County Council (KCC) prior and subsequent to the legislation to

ensure members are informed ahead of the draft Down Syndrome Act guidance for consultation which is expected to be issued shortly.

## **2. Context**

- 2.1 Down Syndrome is a genetic condition caused by having an extra chromosome at birth. People with Down Syndrome will have some level of learning disability which varies between individuals and also have an increased risk of some medical conditions including congenital heart disease, seizures, dementia, leukaemia, and hearing and visual impairments.
- 2.2 There are an estimated 47,000 people in the UK with Down Syndrome ,according to the Down Syndrome Association and the House of Commons. In the Kent context, using information provided by the Kent Public Health Observatory, it is estimated that there could be 1000 people with Down Syndrome in Kent.
- 2.3 Local authorities have a duty towards people with Down Syndrome under the Care Act 2014 which sets out a range of duties to all adults including adults with Down Syndrome. This includes a duty to undertake an assessment of any adult with an appearance of need for care and support and a duty to meet an adult's assessed care and support needs.
- 2.4 Local authorities are required to ensure that a person carrying out an assessment has the skills, knowledge, and competence to carry out an assessment that relate to the specific condition or circumstances requiring expert insight. Assessors must be appropriately trained throughout their career.
- 2.5 The Health and Care Act 2022 introduced a new legal requirement for all health and social care service providers, registered with the Care Quality Commission to provide employees with 'Oliver McGowan Training' on autism and learning disabilities including Down Syndrome appropriate to the role of staff. Relevant KCC staff have had access to basic level eLearning training course for the past 12 months. Further information about an advanced face-to-face training has been requested from NHS Kent and Medway Integrated Care Board.
- 2.6 The Government ran a call for evidence from 19 July 2022 to 8 November 2022, to inform the development of the Down Syndrome Act statutory guidance. The Government has stated they will publish a report on the call for evidence findings shortly. They expect to issue the draft Down Syndrome Act guidance for consultation as soon as possible in 2024, and the guidance will be published at the earliest opportunity following the public consultation.
- 2.7 On 19 January 2024, the Secretary of State for Education announced that Down Syndrome is to be included in the school census for the first time from January 2025. The stated aim is to properly understand the number of students with Down Syndrome to guide future policy making and help to achieve greater inclusivity.

- 2.8 Kent and Medway support people with a learning disability within a delivery partnership which combines the expertise of people with a learning disability, including those with Down Syndrome, autistic people, social care professionals, community health professionals and mental health services. This partnership works to plan the delivery of services across the county taking into account the individual and collective needs of people with a learning disability and/or autism.

### **3. Duties on Relevant Authorities**

- 3.1 The Down Syndrome Act places a duty on relevant authorities in the exercise of their relevant functions. This applies to the NHS, Integrated Care Boards, councils, schools, academies, providers of early years education, youth offending teams and youth accommodation providers. The overall objective of the legislation is to ensure that people with Down Syndrome benefit from appropriate services and interventions to meet their specific needs.
- 3.2 For social care, the Act sets out county councils must have due regard to the guidance in the exercise of their relevant functions which includes:
- functions under section 117 of the Mental Health Act 1983 (after-care)
  - functions under section 50(2) of the Children Act 2004 (social services functions)
  - functions under Part 1 of the Care Act 2014 (care and support)
  - functions under Part 3 of the Children and Families Act 2014 (special educational needs or disabilities).
- 3.3 The duties apply to the NHS in all of its functions. The duties apply to housing authorities in their functions relating to the provision and allocation of housing, and homelessness assistance. The duties apply to education and youth offending authorities in their functions supporting children and young people with Special Educational Needs and Disabilities.

### **4. Overview of local service response**

- 4.1 The following three paragraphs provide practical illustration of how adults with Down Syndrome who have care and support needs are being assisted by adult social care working with key partners.
- 4.2 A case study in relation to the experience of the assessment process - Peter's story (changed name)

Peter lives in his own bungalow and was recently made redundant from a job that he had held and loved for 29 years. Peter's family approached his social worker to ask for a new assessment of his needs following changes to his behaviour and apparent memory loss.

The social worker supported Peter, his family and the carers working with Peter to think about any change in his needs. Peter had found that he had been leaving his flat at unusual times and had been shouting as passers-by but had no lasting memory of these events. It was also noted that he had been finding

some of the things he could do before, such as organising his food more difficult. The assessment also found many strengths in Peter's situation, including his many skills around maintaining his home and continuing to be part of his community.

The assessment also involved the community learning disability nurse who was able to complete an assessment of Peter's memory and any potential indicators of dementia. The assessment was able to take into account not just Peter's views but also those of others and the support network around Peter to give both Peter and the social worker a rounded view of his needs. Working with Peter in this way allowed his support plan to be amended to slightly increase his support while maintaining a high level of independence as per his wishes.

#### 4.3 A case study in relation to the experience of the care and support planning process – Mark's story (changed name)

Mark lives in his own home with other people under a supported living arrangement. He loves all things Harry Potter and Batman. He also has a passion for rock music. Mark has worked with his social worker, his family and other people who are important in his life to create his support plan.

Listening to Mark and his family and thinking about what is important to him, his experiences as a person with Down Syndrome means that his plan includes all the things that he loves to do and also tells people what to look out for and when he may need more support. This includes the areas of his life where his Down Syndrome may have more of an impact, such as his memory and his weight and subsequent impact on the health of his heart.

By planning in this way Mark has been able to keep safe and well but more importantly is thoroughly enjoying life and has been supported to stay in a Marvel themed hotel and indulge in his rock music and Harry Potter passions.

#### 4.4 A case study in relation to the experience of supporting people through joint working arrangements – Simon's story (changed name)

Simon lives with his mother in a small seaside town. He enjoys walks along the beach and has a very specific routine each day which includes visiting the town to buy his favourite drink and sausage roll. Simon has Down Syndrome and a range of health needs. Recently Simon had experienced changes in the impact of his health needs including his dementia.

Simon has a great insight into his health needs and the progressive impact of these on his independence and his ability to continue in his routine which is so very important to him. He has started to experience high levels of depression and anxiety in relation to these changing needs. Simon's mother who supports him most of the time is also concerned about Simon's increasing needs and his mental health. Her role as carer for Simon is also becoming more difficult due to her own health needs.

Simon and his mother have been working with the social worker, community learning disability nurse, his GP and the community learning disability occupational therapist to plan the support he may need both now and in the future. They have been able to talk about what is important to Simon, both in terms of his health and his relationships and activities. The Learning Disability Nurse has been able to review the impact of his dementia and work with the GP to manage his medication to reduce the impact of this and improve his mental health.

The social worker, occupational therapist and nurse have been able to work with Simon to review his activities and consider how these can continue to be supported to ensure the things that are important to him remain in his life while the impact on his mother is reduced. A contingency plan has also been created to plan for those times when Simon's mother is unable to support him or needs a break from her role as his carer. Working together across a wider health and social care system has allowed development of the best plan for Simon, supporting him to remain in his own home but with his needs and those of his mother to be met.

## **5. System challenges**

- 5.1 Due to funding and demand pressures, there can be barriers to service provision to people with learning disabilities, including Down Syndrome. This can lead to delays in accessing support, unmet need, and costs.
- 5.2 There can be a lack of understanding and attention given to people with Down Syndrome's increased risk of medical conditions which can lead to poor outcomes. This is particularly due to people with Down Syndrome being less likely, or able to, self-report health issues.
- 5.3 The life expectancy for people with Down Syndrome has increased in recent years to approximately 58 years. There is therefore a need to address services to support the long-term care needs of an ageing population of people with Down Syndrome. This is particularly important due to the reliance people with Down Syndrome have on their parents whom they may now outlive.
- 5.4 There is no official statistical collection measuring the number of people with Down Syndrome in the UK and by local authority. Although local authorities IT systems do not record specific health conditions these will be recorded within the person's assessment record. This is due to social care services being delivered based on a person's needs, not medical conditions, or diagnosis.
- 5.5 The work of adult social care is experiencing an increased level of demand and expectation in terms of access, quality of services and outcomes. The council will continue to monitor the draft statutory guidance expected to be published shortly to ensure compliance once finalised within established duties.

## 6. Conclusion

- 6.1 Following the Down Syndrome Act 2022, the Government ran a call for evidence to inform the development of the statutory guidance. The draft guidance is expected to be published as soon as possible in 2024 which will be subject to a public consultation. The purpose of the legislation was succinctly described by Baroness Hollins at the Second Reading of the Bill in the House of Lords when she stated: “The practical impact of this guidance should not be understated. It will raise awareness and understanding of the needs of people with Down Syndrome, and it will support authorities to recognise how to adapt services to meet those needs, ensuring that people with Down Syndrome, their families and carers can get the support they need.”
- 6.2 KCC will need to consider whether to provide a formal response to the consultation on the draft statutory guidance, with consideration of Local Government Association’s submission to the call for evidence.
- 6.3 KCC will need to review and adopt the new statutory guidance once finalised within established duties.

## 7. Recommendations

7.1 Recommendations: The Adult Social Care Cabinet Committee is asked to **NOTE** the contents of the report and that a paper on the Down Syndrome guidance to be issued by the Secretary of State will be provided to this Cabinet Committee.

## 8. Background Documents

None

## 9. Report Authors

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