

Parliamentary briefing: Effect of the covid-19 outbreak on people with learning disabilities

Westminster Hall debate, 15 December 2020

NHS Providers is the membership organisation for the NHS hospital, mental health, community and ambulance services that treat patients and service users in the NHS. We help those NHS trusts and foundation trusts to deliver high-quality, patient-focused care by enabling them to learn from each other, acting as their public voice and helping shape the system in which they operate.

NHS Providers has all trusts in voluntary membership, collectively accounting for £87bn of annual expenditure and employing more than one million staff.

Key points

- Trusts providing mental health and learning disability services have played a key role throughout the pandemic by transforming care, both to maintain services and respond to the significant challenges presented by COVID-19 pressures.
- The majority of learning disability and autism services provide people with good care and there are a number of NHS services that have been rated as 'outstanding' by the Care Quality Commission, which provide helpful learning for all those involved in commissioning and providing care and support for these groups of individuals.
- However, COVID-19 pandemic has brought into sharp focus the longstanding, structural inequities facing people with a learning disability and autistic people. There is clear evidence of a historical inequity in the development, commissioning and provision of care and support for these groups of individuals, leaving service users disadvantaged in terms of their health and wellbeing, life chances and expectancy, and in extreme cases open to abuse.
- Further challenges impacting trusts' ability to provide the right level and nature of support for people consistently include: increasing demand; workforce shortages – particularly of specialist staff; and constrained funding for high-quality services in the community and social care. These issues are placing unsustainable pressures on the health and care system and mean too many

people are not able to access the care and support that they need in a timely way, from the point of diagnosis and throughout their lives.

- Rapid progress needs to be taken in the following areas to ensure high-quality care and support is available for everyone, no matter where they live in the country or the complexity of their needs:
 - tackling stigma and raising awareness of the need to improve the accessibility and quality of care and support.
 - improving and increasing the transparency of funding mechanisms to guarantee funding reaches the frontline services that need it most.
 - securing sustainable levels of funding across health, social care and wider public services to provide people and their families with the upstream support they need, including high quality housing provision in places where people want to live.
 - promoting careers in the sector and enabling the training, recruitment and development of the full range of professionals with the specialist skills required to deliver high quality care.
 - progressing plans to provide care closer to home and invest in community support: this work must be properly resourced and effectively commissioned with service users and experts by experience playing a leading role, and learning from what works shared nationally and locally.

Overview

The COVID-19 pandemic has brought into sharp focus the **longstanding structural inequities** people with a learning disability and autistic people, and the services they rely on, have faced over many years. This has meant too many people are not receiving the care they need and should expect from the health and care system. Most recent analysis of available data related to the deaths of people with a learning disability from COVID-19 found the death rate for these groups of individuals was at least four times higher than the general population (**LeDeR, November 2020**), whilst the Office for National Statistics has highlighted the uneven impact of coronavirus and the wider social consequences on disabled people more broadly (**ONS, June 2020**).

A challenging context

The pandemic has presented a host of new challenges for trusts providing services for people with a learning disability and autistic people, as it has for services across the NHS. However, these services were facing a distinct set of challenges long before the outbreak of COVID-19 began. Chief amongst these is historic underfunding of learning disability and autism services: in many instances they have lacked the investment in modernisation and development available to other parts of the health and care sector. Learning disability and autism services also face particular challenges in recruiting and retaining key groups of staff. While there are a number of challenges impacting on the system's ability

to provide the right level and nature of support for people consistently in all areas of the country, most learning disability and autism services are providing people with good care and there are a number of NHS services that have been rated as 'outstanding' by the CQC (CQC, April 2020).

Responding to the challenges of COVID-19

Trusts providing mental health, learning disability and autism services have been working hard to maintain services and best meet people's needs during the pandemic. Those delivering high-quality care for people with a learning disability and autistic people have focused on maintaining levels of meaningful activity for individuals by delivering inpatient rehabilitation, therapy and social activities on wards as well as virtually. They have also been communicating regularly with staff and service users, via emails and their websites as well as through co-produced resources and information packs, to ensure people have accessible, accurate and up to date information about COVID-19 and what the trust is doing in response.

Specific examples of trusts responding to COVID-19 challenges include:

- South West Yorkshire Partnership NHS Foundation Trust has continued its work during the pandemic to ensure all communication is accessible and all information is easy to read: public posters, leaflets and information have all been co-designed with service users in an easy read format. The trust has also promoted its translation service and provided translated information to staff, service users, carers and families.
 - Tees, Esk and Wear Valleys NHS Foundation Trust has been supporting relatives on a 1:1 basis to be able to use the digital solutions the trust has implemented for the pandemic period, whilst Berkshire Healthcare NHS Foundation Trust has developed a tool to help individuals caring for people with a learning disability who are displaying symptoms commonly associated with coronavirus.
 - Gloucestershire Health and Care NHS Foundation Trust and Gloucestershire County Council have worked together to make positive behaviour support consultation clinics available to staff teams or families to support them to offer the opportunity for individuals they support to reflect upon current circumstances, and develop ideas and proactive strategies to best meet the individual's needs in order to improve quality of life and reduce the need for restrictive interventions. In response to COVID-19, these clinics are currently conducted using video calls and the remit has been broadened to reach the needs of not only those described as displaying these behaviours but anyone with a learning disability who could benefit from some early intervention and advice.
- However, COVID-19 has presented some specific challenges for trust leaders and frontline staff. For instance, while a significant number of medically fit patients having been supported to move safely

out of hospital and back to their own home or an appropriate care or community setting, social distancing has made it challenging for trusts to progress home leave or visiting other services in preparation for discharge in some cases, and discharging older people and individuals with a learning disability or autism with the right community support package has been particularly difficult.

Effective infection prevention and control has been another key challenge for all trusts, but particularly for those providing learning disability and autism services, given the significant underinvestment historically in mental health estate: reconfiguring physical space, while ensuring people are kept safe, has been a challenge for these services because of the lack of appropriate places, such as wards with ensuite bathrooms, in which to 'cohort' patients.

Implementing visiting guidance to enable compassionate care while also protecting service users and staff has been a further challenge. Many trusts have prioritised visits for their most vulnerable service users, such as those with a learning disability and autistic people, with visitors supported to wear PPE, and computer tablets and smartphones supplied for patients to use to keep in contact with their friends and loved ones. Frontline staff have also placed an even greater focus on being there for the people and giving them extra support while limitations on visiting have been in place.

NHS Providers view

The pandemic has presented a host of new challenges for trusts providing services for people with a learning disability and autistic people, as it has for services across the NHS. Trusts have worked incredibly hard to ensure people are kept safe during the pandemic alongside maintaining services and developing innovative ways of delivering care and support for those who need it. However, these services were facing a distinct set of challenges long before the outbreak of COVID-19 began. Indeed, the pandemic has brought into sharper focus the longstanding, structural inequities people with a learning disability and autistic people have faced, which has meant too many individuals are not receiving the care and support they need and should expect from the health and care system. Immediate action needs to be taken – to tackle stigma as well as address the sector's significant workforce, funding and commissioning challenges – to ensure high-quality care and support is available for everyone, no matter where they live in the country or the complexity of their needs. Trust leaders are clear that if we get how we commission, modernise and provide person centred care right for people with learning disabilities and autistic people, we will get this right for everyone.