

# GETTING IT RIGHT FOR EVERYONE

## Meeting the needs of people with a learning disability and autistic people in NHS services

### Key points

- The COVID-19 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 people 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 ensure high-quality care and support is available for everyone, no matter where they live in the country or the complexity of their needs.
- The majority of learning disability and autism services are providing people with good care according to Care Quality Commission (CQC), and there are a number of services that have been rated as 'outstanding'. Our interviews with trust leaders providing high-quality care and services endorse this, demonstrate their commitment to coproducing high-quality, person-centred support, and provide helpful learning for all those involved in commissioning and providing care and support for these groups of individuals.
- However, there is clear evidence of a historical inequity in the development, commissioning and provision of care and support for people with a learning disability and autistic people, which has left these groups of service users disadvantaged in terms of their health and wellbeing, life chances and expectancy, and in extreme cases open to abuse. A significant number of recent cases of poor care relate to NHS-funded care in the independent sector. Given this, there are questions to be asked and answered around the quality of service commissioning and the impact of a mixed market of independent and NHS provision on these vulnerable groups of service users.
- 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.
- Trust leaders strongly support the long-held ambition to move people inappropriately placed in hospital into community-based care, however, they have significant concerns about how this policy has been implemented and the process of change to date. Trust leaders described the latest programme for delivering on this agenda, *Transforming care*, as "a paradigm shift" in how care and support is delivered that is as much about high-quality, supported-living provision as it is about health services. From the outset, more

focus, resources and time needed to be dedicated to ensuring high-quality, resilient community-based alternatives and wider support packages are available to enable people to live in their local communities more independently.

- To address these historical inequities and improve their access to high-quality care and support as close to home as possible, national bodies, providers and their partners must work together to ensure rapid progress is made on the following priorities and challenges:
  - **Immediately tackling the stigma associated with learning disabilities and autism and raising awareness** of the need to improve the accessibility and quality of care and support for these groups of individuals nationally and locally. Discussions and decision making regarding the best approach to delivering high-quality, person-centred care in highly-specialist and forensic settings also need to be more balanced and evidence-based.
  - **Improving and increasing the transparency of funding mechanisms** to guarantee funding for the sector reaches the frontline services that need it most and is invested in the establishment of high-quality services people need where these do not currently exist. The ambition to give people a personal health budget, with the appropriate governance and safeguards, is particularly important to prioritise so that funding truly follows service users and they get tailored packages of care that fully meet their needs.
  - **Securing sustainable levels of revenue and capital funding across health, social care and wider public services** – including education, housing and employment support – to invest in high-quality services in the community that provide people and their families with the upstream support they need, and secure, high-quality housing provision in places where people want to live.
  - **Maintaining the focus on the strategic development of the learning disability and autism workforce** in the framework of the final people plan. National policy makers also need to align their thinking on a coherent approach for health and social care more broadly, and the upcoming spending review must include financial allocations for multi-year funding for training and professional development for existing staff. The costs of delivering adequate supervision, support and systems for reflective practice and learning also need to be factored in, given their key role in enabling good practice development and improving staff retention.
  - **Progressing the plans set out in the NHS long term plan to support local providers to develop new models of care** to provide care closer to home and invest in intensive, crisis and forensic community support: this work must be properly resourced and effectively commissioned, with service users and experts by experience playing a leading role in partnership with lead providers and commissioners. Nationally and locally we need to share and learn from what works in provider collaboratives as they develop.

## Introduction

The COVID-19 pandemic has brought into sharper 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. While more evidence needs to be gathered and further work done to better understand the risk factors in terms of COVID-19, we are seeing growing evidence of the uneven impact the pandemic is having on these groups of individuals: CQC figures have shown a **significant increase** (CQC, June 2020) in the number of deaths of people with a learning disability and autistic people, while **recent findings from the ONS** (Office for National Statistics, June 2020) suggest disabled people more broadly are more worried about the effect of the pandemic on their wellbeing, more likely to report worsening health problems, and feeling more lonely as lockdown continues, than non-disabled people.

The pandemic has also 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. Unusually, given the healthcare setting, these services are reliant on a mixed market of provision: the independent sector delivers a significant proportion of NHS funded inpatient services, while the majority of community services are **provided by the NHS** (CQC, October 2019). In addition, learning disability and autism services 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. On 1 April 2020, all NHS community mental health services for people with a learning disability or autism **were rated** good (92%) or outstanding (8%) by CQC, as were the majority (62% as good and 21% as outstanding) of wards for people with **learning disabilities or autism in NHS hospitals** (CQC, April 2020). CQC also rated the sole independent community mental health service for people with a learning disability or autism as outstanding. However, a smaller majority of wards in independent hospitals were rated as good or outstanding (51% and 7% respectively), and there has been a significant increase in the proportion of wards in independent hospitals that have been rated inadequate over the last nine months – 22% were rated inadequate on 1 April 2020 **compared to 5% on 31 July 2019** (CQC, July 2019). The recent examples of poor quality care and abuse, including the shocking treatment of people at Whorlton Hall and prior to that at Winterbourne View, show that progress in improving the availability of consistently high-quality care for these groups of service users across all settings has been unacceptably slow.

Based on interviews with the leaders of seven trusts in the NHS providing good and outstanding learning disabilities and autism services prior to the outbreak of COVID-19, and broader ongoing engagement with trust leaders since, this briefing seeks to:

- share examples of high-quality care across the NHS
- explore the challenges that are most impacting the sector's ability to provide the right level and nature of support for people consistently
- set out where we might go next to address key, structural issues in the co-development, commissioning and resourcing of learning disability and autism services to ensure that the tailored care needs of every patient and service user are met.

We would like to thank all of the trust leaders who have contributed their insights. We hope that this briefing provides a helpful contribution to the debate about how we work collectively to improve learning disability and autism services for all over the next decade.



***My brother Brian has a learning disability and he often reminds me that his challenges have never been his disability but only the mindset of others. He has always wanted to live independently and has done so successfully for over 10 years. He and we have found great joy in his independence and what I have learned most on my journey with him is that we are only constrained by our lack of understanding and ambition. He and his friends wanted me to let you know that it's not they but we that have to change.***

BRENDAN HAYES, CHIEF EXECUTIVE, LINCOLNSHIRE PARTNERSHIP NHS FOUNDATION TRUST

## A challenging context

Over the last five decades, national policy has been rightly focused on moving people with a learning disability and autistic people that are inappropriately placed in hospital settings into **community-based care** (House of Commons, 1971). The **Transforming care programme** has been the key national policy vehicle for delivering this ambition since 2015. However, the programme has faced considerable criticism – progress has been much slower than hoped and timelines for delivery have shifted significantly. Last year the sector missed the key aim of closing 35-50% of inpatient beds by March 2019. Yet, the **NHS Long Term Plan** is clear that improving the care and support for people with a learning disability and autistic people is a key priority (NHS England, January 2019). The plan sets a new target to reduce inpatient provision by 50% by 2023/24 alongside committing to a range of further steps over the next decade, including increasing access to support for children and young people with an autism diagnosis, improving community based support, and investing in workforce and training.

Demand for personalised care for people with a learning disability and autistic people has risen alongside that of other services across the health and care sector over recent years. Prior to the COVID-19 pandemic, **referrals** into NHS funded secondary mental health, learning disabilities and autism services were increasing overall, and the number of people in contact with learning disabilities and autism services has also steadily been rising since records began (NHS Digital, May 2020). However, there is particular evidence of a need to address longstanding structural inequities for users of learning disability and autism services, many of whom are particularly vulnerable individuals. We know for example that people with a learning disability are **more likely to suffer** (Mencap, 2019) from physical health issues which are often not addressed promptly, more likely to **experience poor mental health** (Mencap, 2019), and **more likely to die earlier** (University of Bristol, July 2020) than those without. People with learning disabilities also make up a disproportionately large percentage of **the prison population** (Prison Reform Trust, June 2012).

Historical under investment in the NHS's core capacity to deliver services for people with a learning disabilities and autistic people, exacerbated by a sustained period of cuts to local authority support, has impacted on the 'market' of provision for these services. Given that a significant number of recent cases of poor care relate to NHS-funded care in the independent sector, there are broader questions to be answered – as NHS England and Improvement's chief executive Sir Simon Stevens has made **clear** (Health Service Journal, October 2019) – around the quality of service commissioning and the impact of a mixed market of independent and NHS provision on these vulnerable groups of service users.

Further significant challenges impacting trusts' ability to provide the right level and nature of support for people consistently include: disjointed and fragmented approaches to commissioning; 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, from diagnosis and throughout their lives, in a timely way.

## What makes high-quality care?

An individual's experience of what constitutes high-quality care will be highly personal, particularly when they may be receiving lifelong support as can be the case for people with a learning disability and autistic people. However, there were a number of common themes that emerged from our conversations with trust leaders about their view of the features of high-quality care, which are outlined below:

- Trusts work in collaboration with service users and people with lived experience to plan services and, in some cases, help deliver them.
- Care is person-centred, family-friendly and trauma-informed: the issues service users are experiencing are seen in the context of past events and their care helps them feel safe and build on their strengths and the support around them.
- Care is holistic, taking into account meeting people's general physical health needs as well as their wider personal, social and employment needs. One trust chief executive we spoke to emphasised clear sustained evidence of life planning with services users and carers is paramount to getting the best outcomes.
- Services are delivered by skilled staff from a range of disciplines with the right values and behaviours. Staff having respect, compassion, courage, understanding, and good communication skills are particularly important, as are staff being an advocate for the people in their care and trained in positive behaviour support (PBS).
- Secure, high-quality housing provision is available in places where people want to live alongside specialist community services with the capacity and resources to support people to remain living their life in their own homes.
- If inpatient care is required, it is specialist, short-term and focused on people's return to recovery, supported by high-quality, robust and regular care and treatment reviews.
- Trusts take a collaborative approach within their organisation (e.g. physical health and learning disability and autism teams working well together) as well as with local system partners more broadly such as commissioners and social care and housing providers.
- In mainstream inpatient settings, when they are appropriate, reasonable adjustments are put in place for people with a learning disability and autistic people and staff supported to provide these through appropriate training, such as PBS, and awareness raising initiatives.
- All of the systems supporting these services, including governance and leadership, are "wrapped around the service user" to use a phrase used by one of the trust chief executives we spoke to.

## What steps are trusts taking to deliver high-quality care?

The majority of wards and community services for people with a learning disability or autism are providing good care, according to CQC's [latest State of care report](#) (October 2019) and ratings as of [1 April 2020](#), and there are a number of trusts with learning disability and autism services that have been rated as 'outstanding' that other providers can take learnings from.

This section sets out some examples of how such trusts are delivering high-quality care, based on interviews we conducted with leaders of seven trusts providing good or outstanding learning disabilities and autism services. The final part of this section shines a spotlight on some notable steps we are aware of trusts taking most recently to meet the specific challenges the COVID-19 pandemic has posed for the delivery of high-quality learning disability and autism services.

### Co-producing person-centred and holistic care

Many of the trusts we interviewed have been undertaking work in collaboration with service users, families and carers to deliver high-quality, person-centred and holistic care that best meets people's needs. Service users at Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust have access to their own clinical data dashboard so they can be part of conversations about managing their own care as part of the trust's Talk First initiative. A number of trusts are also running employment and work experience schemes for service users. Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust deliver the [Project choice](#) (August 2018) programme with the [support of Health Education England](#), which has given young people using the trust's services the opportunity to learn new skills in a real work environment and the confidence to help them gain employment or further training in the future. South West Yorkshire Partnership NHS Foundation Trust also runs a work experience scheme and a significant number of the latest cohort gained employment with the trust following their participation in the scheme.



***As an organisation that exists to help people fulfil their potential and live well in their communities, I believe that "if we get it right for people with a learning disability and autism, we get it right for everyone". The trust has a values-led, person-centred approach, built on co-created solutions which ensures the person remains in the centre. The involvement of people who use our services is critical to ensure we maintain individual autonomy, reduce health inequalities and support people to reach their potential.***

ROB WEBSTER, CHIEF EXECUTIVE, SOUTH WEST YORKSHIRE PARTNERSHIP NHS FOUNDATION TRUST

Gloucestershire Health and Care NHS Foundation Trust is working collaboratively with Inclusion Gloucestershire, a user led organisation, alongside Family Partnership Solutions, a family carer led community interest company, and Gloucestershire County Council, to develop the national **Oliver McGowan mandatory training** on autism and learning disabilities for all health and social care staff. This training will be based on the findings of *Right to be heard* (Department of Health and Social Care, November 2019) and **core capabilities frameworks** (Skills for Health, October 2019). The experts by experience employed by Inclusion Gloucestershire will be integral to the development and delivery of this training, sitting on the planning board and acting as co-facilitators on every training event.



***We at Inclusion Gloucestershire are very good at providing user led, and user designed and delivered training, as everything we do has our service users and people with lived experience at the heart of it. I am very much looking forward to being involved in this project because we are raising awareness and helping people to understand our conditions which is something that I am very passionate about.***

SAMMY, EXPERT BY EXPERIENCE, INCLUSION GLOUCESTERSHIRE

## Putting service users at the heart of service design and innovation

With regards to innovative service design, Mersey Care NHS Foundation Trust involved service users, families and carers and experts by experience in the design and delivery of its **Life Rooms sites and services**, which focus on providing a safe and welcoming space to meet others, access opportunities and learn about community resources.

The trust also **plans** to open a high-quality, regional, medium secure unit, as part of its wider ambition to establish a new centre of excellence in forensic care, with the users of the building firmly at the heart of each stage of the design process. It will be a place of innovation, using the latest technology and therapeutic techniques to improve recovery times for people, staffed by a range of specialists in mental ill health and learning disability care from a wide range of disciplines.

Similarly, Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust has worked in partnership with staff, service users and families to design its **Mitford Unit**, which has been a leading centre for providing timely mental health support for adults with autism since 2016. There is a strong focus at the unit on working with families and carers to get people back home as soon as possible and the innovative design of the building has received particular praise for the way it incorporates a range of elements to make it as welcoming

as possible and to reduce anxiety for adults living with autism (January 2018). The trust's **Monkwearmouth clinic** has also been recognised as a national centre of excellence, and has been visited by several other trusts across England who are looking to develop similar processes.

More broadly, Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust is playing a **leading role** in the efforts to stopping the over-medication of people with learning disabilities and autism (STOMP), and has changed models of services delivery to make better use of clinical pharmacists in particular. NHS England has **published** a number of blogs and case studies online that highlight how the STOMP programme is making a difference to people's lives.

Alongside designing innovative, high-quality bed-based services for people who require a specialist inpatient setting to meet their needs, trusts are also working hard to reduce the number of hospital beds they have and investing in community-based provision and infrastructure. Most of Kent and Medway NHS and Social Care Partnership Trust's assessment and treatment unit has been decommissioned by the clinical commissioning group (CCG) to develop a community service, while there are almost 250 people who are being successfully supported in a community setting by Mersey Care NHS Foundation Trust's specialist forensic learning disability teams, who would otherwise have had to receive care and support in a forensic inpatient setting.

South West Yorkshire Partnership NHS Foundation Trust was able to reduce its local bed base from 11 to 6 in 2016 and reinvested the savings made to establish intensive community support teams in each of the four localities the trust provides services in. A community assessment and treatment service, and a regional forensic outreach liaison service was also established by the trust and system partners. These new teams and services were set up in line with national recommendations and have helped ensure – alongside other key elements such as the use of dynamic support registers; rigorous, frequent care and treatment reviews; and the wider efforts of the system to work effectively together more broadly – that more people's needs are met in the community and inappropriate hospital admissions and lengths of stay are reduced. This model of care has also meant the trust has not needed to send people 'out of area' when care in an inpatient setting is required, despite now having a significantly lower local bed base.

Tees, Esk and Wear Valleys NHS Foundation Trust has also achieved significant bed reductions – in one hospital beds were reduced from 16 to 6. In Durham and Darlington, the trust reviewed its community provision and held a **kaizen** event to re-model how the behaviour team, assertive outreach and intensive home support teams could work as one specialist health team with multi-functional workers able to deliver PBS, mental health, crisis, and provider liaison support. Additional funding has been used to deliver seven day community support, which provides a crisis response to help keep people out of hospital and facilitate discharge in the area: the trust is currently reviewing this model with a view to making further improvements and replicating it across other areas the trust serves.

## Working collaboratively with local and system partners

Trust leaders highlighted how they are working with a range of local and system partners – from local authorities and housing associations to GP practices and general hospitals – to ensure high-quality care and support is available for people when and where they need it.

Kent and Medway NHS and Social Care Partnership Trust is part of an alliance led by Kent County Council that brings physical health, social care and community services together to meet people's needs in a more joined up and strategic way. The alliance has involved pooling budgets and has been particularly effective in supporting people with complex needs and those at risk of their current placement in the community breaking down. The trust has been able to minimise the number of people it has had to place in services out of area significantly and credits the alliance as a key reason for this.

South West Yorkshire Partnership NHS Foundation Trust has been able to bring down the number of children waiting for an autism assessment in Wakefield (some of which had been waiting for as long as three years) significantly due to system partners working effectively in collaboration: the trust, local council, general hospital and CCG worked together to agree the delivery of a different model of assessment that was in line with NICE guidelines and possible to deliver within the same funding envelope.

In order to address the lack of high-quality, supported living options available in the local area for people who were ready to leave hospital, Tees, Esk and Wear Valleys NHS Foundation Trust created a subsidiary specialist social care provider, Positive Individual Proactive Support (PIPS). PIPS's support staff and specialist nurses have been able to provide the skills, support and training to an increasingly growing number of housing associations so they have the confidence to let homes to people with a learning disability or autistic people. PIPS is currently supporting 39 individuals and families have praised the model of support and the work of staff.



***The service we have created has significantly reduced the scale and intensity of packages from, in some cases, more than 5 staff to a patient to more like a 1:1 service now, at the same time as vastly improving quality of life and the environments people are living in. It is a properly sustainable option for people who have historically been subject to huge amounts of institutional care over the years and can now live in their own tenancies, with very personalised support packages and good, strong therapeutic and care relationships.***

BRENT KILMURRAY, CHIEF EXECUTIVE, TEES, ESK AND WEAR VALLEYS NHS FOUNDATION TRUST

Gloucestershire Health and Care NHS Foundation Trust have emphasised that agencies within Gloucestershire have a long history of partnership working, reflected by One Gloucestershire's status as an integrated care system, which brings together expertise, experience and commitment from health and social care services with lived experience from service users and their families and carers.

## Values-based recruitment, growing supply and developing existing staff

Several trusts are increasingly using a values-based approach to recruitment, to help ensure they have a workforce that is not only the right size with the right skills, but also with the right values to support effective team working and the delivery of high-quality, safe and compassionate care to service users. Tees, Esk and Wear Valleys NHS Foundation Trust has an **established set of values** and a behaviour framework which inform the questions used by recruitment managers when recruiting new staff. The trust always involves experts by experience from its service user reference group, supported by independent advocates, in the recruitment process of new staff. Similarly at Gloucestershire Health and Care NHS Foundation Trust, applicants participate in a values based interview where they are asked to demonstrate skills and behaviours in relation to the **trust's values**.

To address the sector's significant workforce gaps, a number of trusts are working with local universities to sponsor courses to grow the supply of key workforce groups as well as develop staff who already work in their organisations. North Staffordshire Combined Healthcare NHS Trust is working closely with its local university to promote learning disability nursing courses, while Tees, Esk and Wear Valleys NHS Foundation Trust sponsored university courses for its staff during the period that central funding was not available, and has also made use of the apprenticeship levy to recruit and train staff.

Many of the trusts are also focusing on ensuring their staff are trained in PBS, which is an evidence-based approach recognised as best practice in supporting people with a learning disability and behaviours that challenge. Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust and Tees, Esk and Wear Valleys NHS Foundation Trust are two trusts with a particular level of expertise in PBS and are part of a regional programme delivering PBS training to staff in community teams and specialist inpatient services so they are able to offer PBS to their service users in addition to a range of other specialist interventions.

## Raising awareness, upskilling staff and embedding reasonable adjustments

Trusts highlighted that they are taking organisation-wide approaches to raising awareness, upskilling mainstream staff and embedding reasonable adjustments. A number have implemented the **Green Light Toolkit**, which provides a framework to help mental health services adequately respond to the needs of people with a learning disabilities and autistic

people, including by making reasonable adjustments. Implementation of the framework involves an annual audit that provides ongoing monitoring of quality improvements. Cumbria, Northumberland Tyne and Wear NHS Foundation Trust is now including the work of the Green Light Toolkit in their embedding of NHS Improvement's **Learning Disability Improvement Standards** (2018).

Kent and Medway NHS and Social Care Partnership Trust has embedded awareness raising and training initiatives across its organisation, and has a learning disability multi-disciplinary team that works to support staff in general mental health services to plan care and provide the right support to people with a learning disability or autistic people so their individual needs can be met within mainstream services when this is the most appropriate setting.

Gloucestershire Health and Care NHS Foundation Trust has organised a large-scale, interactive event called *The big health check day* during learning disability awareness week for the last 11 years, which has involved people with a learning disability in a range of sporting and other activities. This year's event had to be cancelled due to the COVID-19 pandemic, but the trust created this **newsletter** and put on a **range of other activities** as a virtual alternative.

## Responding to the challenges presented by 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, despite the significant challenges presented by COVID-19.

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.

South West Yorkshire Partnership NHS Foundation Trust has highlighted that communication during the pandemic has been essential and it has continued its work 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 – the people most impacted by the virus. Further examples we have come across include **daily video updates** produced by experts by experience and health and social care partners from across the North West, and **14 videos** created by Surrey and Borders Partnership NHS Foundation Trust that look at aspects of the virus and social distancing; help people to understand and deal with anxiety; and support people to plan their day and give ideas for activities to do while at home.

Trusts have also looked to facilitate visits for their most vulnerable service users where possible, with visitors supported to wear personal protective equipment (PPE), and supplied computer tablets and smartphones for service users to use to keep in contact with their friends and family more broadly. Tees, Esk and Wear Valleys NHS Foundation Trust has also been supporting relatives on a 1:1 basis to be able to use the digital solutions the trust has implemented for the pandemic period, while 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.

Tees, Esk and Wear Valleys NHS Foundation Trust and Mersey Care NHS Foundation Trust are among a number of trusts we are aware of that has taken a flexible and compassionate approach to the application of restrictions set out in national guidance to keep service users and staff safe, and set up an ethics committee to support decision making when there are particularly difficult choices to make. A service user and executive and non-executive directors sit on the ethical 'cell' Mersey Care NHS Foundation Trust set up for the pandemic period to look at and maintain the rights of service users and provide appropriate challenge to any clinical decisions being made as a result of national guidance. The cell commissioned a piece of work to look at the impact of isolation on service users and what could be done to minimise it, which has informed the development of guidance and a separate standard operating procedure around isolation, which uses a general citizens approach and helps balance people's human rights with maintaining everyone's safety during this time.

Mersey Care NHS Foundation Trust has also built in an additional, independent process using mental health act (MHA) manager reviews when there are service users that are finding it difficult to self-isolate, and is also working to supply independent advocates with uniforms and PPE to be able to get them back onto their wards given the crucial role they play in supporting service users. The trust is also looking to implement new interventions, such as employing physician associates in primary care networks, to fill gaps it found in annual health checks during the pandemic period, which it will be evaluating, taking learning back to the system and widening the scopes of if effective.

In order to meet the rising needs of individuals who may present with behaviours that challenge, 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.

## Challenges to be overcome

While most trusts in the NHS are delivering good care to people with a learning disability or autistic people, and several are delivering services CQC has rated as 'outstanding' from whom others can learn, there remain too many people who are not receiving the right level and nature of support in all areas of the country. There are significant, and often systemic, challenges facing trusts that are impacting on their ability, and the system's more widely, to provide the care and support people need and should expect from the health and care system, as we explore below.

### Historical inequity

As is the case for the **mental health sector** (NHS Providers, 2020), many of the challenges the learning disability and autism sector face are rooted in the fact these services have suffered a historical, structural disadvantage compared to physical health provision, with the stigma associated with learning disabilities and autism one of the key reasons for this disadvantage. However, in many respects the challenges for learning disability and autism services run even more deeply: efforts to challenge stigma and raise awareness of the need to improve the nature and quality of care people with a learning disability or autistic people lag considerably behind the strides we've seen made to increase access to and improve the quality of mental health care, and have gained significantly less traction to date. This has in turn impacted to an even greater extent on the scale of investment and innovation in learning disability and autism provision, how these services are commissioned, contracted and paid for, and the transparency and governance of funding flows.

The level of stigma and lack of awareness has not only had a fundamental impact on how learning disability and autism services are viewed, supported and delivered, but has also impacted on the national policy debate concerning these services and their development. This is a particular issue with regards to discussions concerning the most appropriate service models for highly specialist and forensic learning disability and autism services, which seems to contrast considerably from the – often more balanced, nuanced and evidence-based – discussions national policy makers, trusts and their partners have about the best approach to delivering **specialised physical health services** given the nature of the activity and the geographic spread of their patient populations (NHS Providers, 2020).



***It is widely accepted that complicated heart surgery should not be performed in every district general hospital, nor is it common to see widespread support for the dismantlement of physical health services rated 'outstanding' by CQC, yet the same cannot be said when it's a highly specialist learning disability and autism service in question.***

TRUST LEADER

Stigma is also having an impact on attracting healthcare professionals to work in services for people with a learning disability and autistic people. Several trust leaders spoke of their frustration and deep sadness that some staff feel ashamed to say they work in a learning disability and/or autism service. They stressed the negative perceptions of the sector need to be tackled, and a positive narrative developed around this area of work, if the significant workforce issues the sector faces are to be effectively addressed. Trust leaders have expressed particular concerns about the prevailing misconception that staff providing care for people with a learning disability or autistic people are in some way 'low skilled', highlighting staff are working in a highly regulated environment, caring for service users with some of the most complex needs of all.



***I have worked in learning disability services clinically/operationally and in nurse education for 39 years and feel that we make the same mistakes every decade and never quite manage to embed the learning effectively. We need to focus on discrimination as an issue for people with learning disabilities and highlight the skills that the learning disability workforce have that can help to tackle this across the system. Learning disability nursing is a great career and wonderfully fulfilling so we need to get the message out there.***

TRUST HEAD OF LEARNING DISABILITY SERVICE

## Commissioning

There has been a deep, historical under investment in the NHS's core capacity to deliver services for people with a learning disability and autistic people, which has been exacerbated over recent years by a sustained period of cuts to local authority support. This has meant that these services are, unusually for services in a healthcare setting, reliant on a mixed market of provision with the independent sector delivering a significant proportion of NHS funded inpatient services, while the vast majority of community mental health services are provided by the NHS. This has led to an unacceptable number of people not being able to access high-quality care and support and the range of services required to meet this group of individuals' sets of needs are not prioritised across the system.

The trusts we interviewed identified that the split in the commissioning of health and social services between NHS England, CCGs, and local authorities can lead to particularly disjointed and fragmented care for people. CCGs and local authorities, in particular, approach commissioning very differently and have distinct standards and models of commissioning and contract monitoring that create difficulties in the system. Furthermore, often there is not a single commissioner commissioning packages of care and services strategically across an area, which trust leaders identify as a significant barrier to joined up, holistic care being

available that fully meets people's individual needs. Trusts may be commissioned to carry out autism assessments – the waits for which can span years – but not commissioned to deliver services that would provide the care and support for people diagnosed by such assessments. In such cases, individuals may have to travel beyond their local area to access the care and support they need: while this may be warranted if highly specialist, short-term, inpatient care is required, it should not be acceptable for longer-term care and support not to be available for individuals within their local area.

Trust leaders have told us commissioning challenges are particularly significant for services funded by CCGs and local authorities if there is a lack of commissioning expertise within these local bodies, particularly for those with more complex needs. The sheer number of different agencies often involved in commissioning and delivering various aspects of care and support people may need to meet their individual set of needs means that, even when people do finally receive a diagnosis, this does not 'unlock doors' despite early diagnosis and a coordinated response being so crucial.

## Funding

Revenue and capital investment are important factors that trust leaders have identified as impacting on the delivery of high-quality care and support for people with a learning disability and autistic people. A key requirement for delivering on the *Transforming care* agenda is the availability of robust multidisciplinary community services, including 24/7 access to crisis care services. However, trust leaders have stressed that there have not been adequate levels of funding available to local areas to date to deliver the community services needed to support the discharge of people inappropriately placed in hospital, or help avert the need for an inpatient admission in the first place.

There are three key elements to the funding challenges trusts face:

- It was intended that money released through the decommissioning of inpatient beds to local health bodies would be transferred to invest in community services. However, beds in learning disability and autism services have closed at the same time as investment in community care has reduced: according to analysis of data collected by the NHS Benchmarking Network from specialist learning disability services across the UK, **total expenditure on community learning disability and autism services decreased** by 35% between 2013/14 and 2017/18 (NHS Benchmarking Network, 2018).
- More broadly, trust leaders have stressed that the *Transforming care* programme is not cost neutral. While there has been national transformation funding allocated, this has not been enough given the complexity and level of challenge in meeting the programme's ambitions. The ad hoc, non-recurrent nature of funding allocations over the years has also limited trusts' plans for investment due to the level of the uncertainty over the availability of funding in future years.
- Trust leaders have highlighted that historically low levels of capital investment and the length of time and difficulties it takes to get capital investment bids approved, even for small schemes, have been a further significant issue. Much needed capital investment

would improve facilities and timely access to high-quality support for people. It would also improve the morale of staff working within services, and their safety: staff are more likely to suffer from assault and injury if they are working in facilities that are ill-equipped to look after people with more complex needs.

Beyond this, severe funding constraints and uncertainty for social care and wider public services is a further important challenge. These services provide vital upstream support to people and their families and minimise the risk of people reaching crisis point in the first place, or averting the need for an inpatient admission if they do. Trusts leaders are deeply concerned about the continued, long-term neglect by successive governments and a failure to fully fund the social care sector in particular. This has left many areas without a sufficient number of social care providers that are able to provide the right care and support to people with a learning disability and autistic people, nor able to deliver high-quality supported living and domiciliary care packages, in particular for people with the most complex needs. Indeed, the stability of the adult social care market was a key concern highlighted by CQC in its *State of care report* in October of last year, and the *incredible pressures* (Association of Directors of Adult Social Care Services, June 2020) social care providers have been managing in very difficult circumstances during the current COVID-19 crisis has only brought the longstanding issues facing the social care sector into even sharper focus and underscored how urgent the need is for real investment and reform.

## Workforce challenges

Staff are central to delivering high-quality, personalised care, and workforce shortages are a key factor impacting on trusts' ability to provide the right level and nature of support for people with a learning disability and autistic people. The supply of clinical and non-clinical staff with the right skills and expertise to deliver care and support that meets people's individual needs is heavily constrained. Trust leaders expressed particular concerns about the extent to which learning disability nurse training has diminished over recent years and the disproportionate impact ending the student bursary had on learning disability nursing applicants – both have exacerbated the *gaps* (National Audit Office, March 2020) in learning disability expertise that already exist in the NHS workforce, which trust leaders fear will only deepen in the most immediate term due to the fact many nurses currently working in the sector are nearing retirement age.

Recent announcements by the government that *financial support* for student nurses will be reinstated is welcome, but trust leaders have stressed there are also significant gaps in the number of occupational therapists, psychiatrists, psychologists and other allied health professionals with specialisms in learning disability and autism who play a crucial role in delivering the right care and support for people. It is important to note that, currently in the NHS overall, vacancy levels have come down as final year student nurses and doctors and returners have been able to work on the frontline to support the NHS during the pandemic. However, it is not clear whether this will be sustainable going forwards nor whether this has boosted the learning disability and autism workforce specifically.

During our interviews with trust leaders, the importance of training came to the fore, particularly training to ensure staff working in learning disability and autism services are equipped with the right skills and feel confident to manage challenging behaviours, such as positive behaviour support, personal safety and trauma informed care. Trust leaders also stressed that ensuring staff had time for supervision and reflection is crucial to maintain the ongoing learning, development and confidence of staff to manage the complexities of this area of practice.

The right training and time for supervision and reflective practice was stressed as particularly important to reducing the use of restraint and other restrictive practices. There has been a national programme of work, the **Reducing restrictive practice (RRP) collaborative programme**, underway since 2018 with the aim of supporting wards from 26 trusts across England to reduce the use of restrictive practice. Some trusts stand out for the significant, positive progress they have made in this area: Mersey Care NHS Foundation Trust has significantly reduced the use of restraint in its units and has even been able to sustain a reduction in levels of restraint during the pandemic period despite the significant pressures COVID-19 has presented for staff and service users. However, as CQC has **made clear** (2019), while the day-to-day responsibility for quality of care sits with managers and staff, shared learning and effort is needed from across the health and care system – and broader systemic issues addressed – in order to tackle the inappropriate use of these practices in all settings in every part of the country, and fundamentally improve the current quality and system of care for people with a learning disability or autism.

Training for staff working in other NHS services and settings so they can make reasonable adjustments and greater awareness is raised of learning disabilities and autism has also been highlighted by trust leaders as essential to tackle and overcome the issues of stigma and discrimination.

## Delivering change and the policy environment

As highlighted in the introduction, the *Transforming care* programme has been the key vehicle for delivering on the ambition to move everyone with a learning disability and/or autism that is inappropriately placed in hospital into community-based care since 2015.

Trust leaders stressed that they support the programme's aspirations of 'homes not hospitals' and welcome the intentions behind the policy, however, they have significant concerns with how the programme has been implemented and the process of change to date. Trusts stressed the complexity and level of challenge in delivering the programme's ambitions, which has hampered progress. What has emerged in our interviews is that the complexity of cases and level of resources and time required to implement the policy effectively were not fully understood prior to the programme being put in train. This echoes **conclusions** reached by the National Audit Office in 2015, when it looked into the policy following the government missing its initial goal set in 2012 to transfer all people inappropriately placed in hospital into the community by June 2014.

In particular, trust leaders described the *Transforming care* agenda as “a paradigm shift” in how care and support is delivered, which is as much about high-quality supported living provision as health services. Yet, meeting targets to reduce the number of inpatient beds in the NHS and independent sectors has been the overriding focus to date, as opposed to, and in advance of, ensuring high-quality, resilient, community-based alternatives and wider support packages to enable people to live in their local communities more independently are available. Trusts highlighted that, for some people and in certain areas, inpatient services are providing a more therapeutic environment than any provision currently available in the community, and they are increasingly concerned about the risks of providing sub-optimal care to people with a learning disability and autistic people – particularly adults – if they continue to try to deliver the *Transforming care* agenda within this current context.



***Transforming Care was not realistic in terms of the timescales and in the focus on reducing beds which should have come after strengthening the resilience of community provision. We have seen this approach work at our former Calderstones services – bed reduction has been possible and successful because we stepped up a community forensic offer.***

JOE RAFFERTY, CHIEF EXECUTIVE, MERSEY CARE NHS FOUNDATION TRUST

Trust leaders also expressed concern that some areas are so short of beds in the right setting that people, as an absolute last resort, are being placed in inappropriate mainstream mental health beds or placed out of area. This is a particular issue for forensic services, where there has been a significant reduction in beds and there is a severe lack of appropriate, community-based models of care, which is also leaving vulnerable people in prison inappropriately.

The knock on impact on the NHS when services are rated inadequate by CQC, and closed in the most serious cases, is an additional concern raised by trust leaders: it has an immediate impact on NHS services, which are required to step into the breach and provide additional services and support despite already being under significant pressures themselves.

## Where next?

Significant action is needed to address the historical inequity surrounding learning disability and autism services, which still impacts individuals' lives and continues to challenge how we commission, modernise and provide person-centred care for service users.

However, despite the challenges, trusts feel there are number of opportunities to affect change: after all the NHS long term plan recognises that improving the care and support for people with a learning disability and autistic people needs to be prioritised over the next decade, and there is renewed momentum behind the ambition to fundamentally tackle health inequalities following the UK's experience of responding to COVID-19 so far.

We have distilled what trusts leaders have told us into a number of key priorities and challenges that national bodies, providers and their partners must all work together to ensure significant progress is made on as soon as possible, in order to meet the shared ambition of making high-quality care available for everyone, as close to home as possible, no matter where they live or the complexity of their needs. These include:

### Tackling stigma and raising awareness of historical inequities

Immediate action needs to be taken nationally and locally to tackle the stigma associated with learning disabilities and autism, and raise awareness of the need to improve the accessibility and quality of care and support for these groups of individuals. This is vital to ensuring appropriate support and priority is given to the full range of services people rely on, at levels which reflect the significant structural inequities these groups of individuals and services have suffered historically.

Discussions and decision making regarding the best approach to delivering high-quality, person-centred care in highly specialist and forensic settings also needs to be more balanced and evidence-based, taking into better account the nature of the care and support provided by these services and the geographic spread of their service user populations as per the approach taken for specialist physical health services.

### Improving funding mechanisms and securing wider investment

Systems need to keep a sharp focus on the need to invest and strengthen community services and disinvest in inappropriate and poor-quality care. However, funding mechanisms also need to be improved and made more transparent to guarantee funding for the sector reaches the frontline services that people with a learning disability and autistic people rely on and need most, and is invested in the establishment of the full range of high-quality services these groups of individuals need to live as independently as possible in their local communities where these do not currently exist. Prioritising the NHS long term plan's ambition to give people a personal health budget where possible, with the appropriate governance and safeguards, is also important so that funding truly follows service users and they can get the tailored and bespoke packages of care required to fully meet their individual needs.

Securing sustainable levels of revenue and capital funding across health, social care and wider public services – including education, housing and employment support – is crucial to invest in services for people with more complex needs that require bespoke care and support. Wider investment in local government and social care is particularly needed to create a more coherent and sustainable supported living and housing market so that all people, no matter the complexity of their needs, have access to secure, high-quality housing provision in places where they want to live.

### Expanding and developing the workforce

The focus on the strategic development of the learning disability and autism workforce must be maintained in the framework of the final People Plan. Plans for the workforce need to build on the welcome recent reinstatement of grants for student nurses, prioritise the promotion of careers in the sector and incentivise the training and values-based recruitment of the full range of professionals with the specialist skills required to deliver high-quality care. However, we note that the national People Plan only focuses on the NHS workforce, as expected, and there remains a need for national policy makers to align their thinking on a coherent approach for health and social care together, reflecting the work now underway by local systems.

Ensuring a multi-year funding package is allocated in the upcoming spending review to invest in training and professional development for existing staff is also crucial to ensuring services are delivered by staff equipped with the right skills, values and behaviours to deliver high-quality, person-centred care. The cost of delivering adequate supervision, support and systems for reflective practice and learning also need to be factored in, given their key role in enabling good practice development and improving staff retention. More broadly, we need to secure an adequate workforce supply so that staff are able to undertake training, reflective practice and supervision, separately to the time they spend delivering care and support to service users directly.

### Integrated planning, joint working and genuine coproduction

There are welcome plans set out in the NHS long term plan to support local providers to develop new models of care to provide care closer to home and invest in intensive, crisis and forensic community support. This work must be properly resourced and effectively commissioned, particularly taking into account the ongoing pressures the NHS expects to face due to COVID-19. Service users and experts by experience have a key part to play in leading the *Transforming care* programmes in their areas in partnership with lead providers and commissioners.

Nationally and locally we need to share and learn from what works so that commissioners, trusts and other local partners within all systems can make the progress needed on designing the right services and pathways for their local populations proactively together, and ensure they have the flexibility, capacity and resource to deliver them.

Your feedback on this briefing and the development of our wider offer is very welcome – to share your learning so far or offer feedback on our approach, please contact [ella.fuller@nhsproviders.org](mailto:ella.fuller@nhsproviders.org)

For more information:

[www.nhsproviders.org/getting-it-right-for-everyone](http://www.nhsproviders.org/getting-it-right-for-everyone)

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