Briefing: community support for people with a learning disability and autistic people

- *Approximately **1.5 million** people in the UK have a learning disability, and approximately **700,000** people in the UK have been diagnosed as autistic.*
- *Learning disabilities and autism are **not mental health conditions** and **cannot be treated or cured**. Learning disabilities are not the same as learning difficulties such as dyslexia or ADHD.*
- *Many people with a learning disability and autistic people need community-based support to lead full and happy lives, but access to these community services is a **postcode lottery**.*
- *When community services are not available, needs can escalate and too many people with a learning disability/autistic people can end up sectioned under the Mental Health Act and detained in mental health inpatient units. Once detained, many get stuck for a long time as the lack of services also prevents them from being discharged back into the community. The average length of stay for current inpatients is **nearly five years**.*
- *Getting community support right **improves quality of life** and is **more cost-effective** than mental health inpatient services, which are **high-cost environments** that are rarely appropriate for someone who is autistic or has a learning disability.*
- *There is a **significant evidence base** on how to develop **high-quality, cost-effective community support** for people with a learning disability and autistic people; this requires a **cross-government and cross-system, coordinated approach**.*

Policy context

The national 'Transforming Care' programme, established after a serious abuse scandal in 2011, committed to move people with a learning disability and autistic people out of mental health hospital inpatient units by June 2014. The National Audit Office[1] found that this deadline was missed because:

- **Data was not available** on what community support currently existed and what would be needed
- There were **financial disincentives to developing community support** and **ring-fenced funding was not made available** to discharge people from hospital

Because these issues have not been addressed, subsequent targets have all been missed. As of July 2024, there are **2025**[2] people with a learning disability and autistic people in inpatient units. The current target is to reduce the number of people with a learning disability/who are autistic in inpatient units by 50% - but **at the current rate of change this will not be achieved until 2030** at the earliest[3]. The number of autistic people without a learning disability in inpatient units has **more than doubled since 2015**, and nearly half of people with a learning disability in inpatient units have been detained for **over 5 years**.

Barriers to developing the right community support

When someone with a learning disability/who is autistic is supported in the community, the local authority is responsible for commissioning and paying for this support, but if they are

[1] NAO
[2] NHS Digital
[3] Mencap

detained under the Mental Health Act in an inpatient unit, this is funded by the NHS. This creates **perverse incentives** for local authorities to avoid commissioning community support that meets the needs of their local population, despite this being the law under the Care Act, and a disincentive to develop support that will enable them to be discharged. Without appropriate community support, for those who reach crisis point detention in inpatient units becomes the 'default' option - or the only option left[4].

High-quality community support for people with a learning disability **improves quality of life** and is more **cost-effective**[5], but because of these perverse incentives and because funding is distributed in the wrong places[6], there is neither the investment nor the political will at national, regional and local levels to develop this. There is also insufficient financial oversight of what taxpayer money is being spent on - a DHSC-commissioned report on funding flows[7] found that this lack of oversight and analysis meant that the DHSC, NHS England, and other partners **could not be assured that resources were being spent effectively**.

What evidence-based steps can be taken to improve community support?
See attached document for further information and case studies

- **Invest in early intervention for children and young people with a learning disability/who are autistic**
  Early intervention improves quality of life, develops new skills[8], and reduces the likelihood of challenging behaviours[9]. This helps to avoid inpatient admissions and residential care, supports independent living, and supports improved educational outcomes and future employment - leading to significant cost savings[10].
- **Address the lack of suitable housing for people with a learning disability and autistic people**
  Over half of delayed discharges from inpatient units[11] are because the right housing is not available - increasing the availability of capital funding to develop suitable housing would enable discharges to occur and would prevent admissions to inpatient units.
- **Improve pay to address the low recruitment and retention of support workers**
  Many support workers are leaving the sector and people are being put off from entering due to low wages for difficult work[12], which leads to poorer outcomes for people with a learning disability and autistic people. Matching pay for support workers to NHS Band 3, increasing the ability of skilled supported workers to remain in the sector and thereby addressing both high staff turnover and reliance on expensive agency staff who may not have the appropriate skills[13], has widespread public support[14].
- **Improve access to respite and short breaks**
  These enable family carers to support their own wellbeing and continue caring for their relative sustainably – helping to avoid 'crisis' situations and inappropriate hospital

[4] Health and Social Care Committee
[5] BASW; CBF et al.; Iemmi et al.; McGill and Poynter
[6] VODG; ITV News/Mencap; Autism Alliance
[7] DHSC
[8] CBF and CDC
[9] CBF
[10] Pro Bono Economics; CBF and CDC; CBF et al.
[11] NHS Digital
[12] Mencap
[13] Community Integrated Care
[14] Learning Disability England

admissions. Emergency accommodation (for example, if the person's house is unsafe or if they have had to leave a tenancy before a new provider is found) also prevents admission. Access to these is a postcode lottery; every area should have enough respite and emergency accommodation to meet their local needs.

- **Make it easier for public services to pool budgets and work collaboratively**
  Improving coordination between a) health and social care, b) children's and adult services, and c) other different parts of the system will help to address the perverse financial incentives that are barriers to developing the right community support. For example, investing in early intervention for children and young people with learning disabilities/who are autistic can create significant savings in adulthood, but children's services and education (who would be investing) would not be the ones (adult services) seeing these savings and so they are not incentivised to invest - pooling budgets and sharing risk between these bodies improves outcomes and creates savings.
- **Empower commissioners to engage in market-shaping**
  Commissioners should not be restricted by what is currently available to purchase if this does not meet the needs of their local population. Guidance for commissioners[15] sets out what is needed and what is possible - this needs to be promoted and commissioners need to be supported to take mitigated risks. Developing a sustainable market of provision is also a legal duty under the Care Act.
- **Ensure people who are discharged from inpatient units continue to receive support**
  People that we support and their families have shared experiences of funding for support and therapies being cut as the situation was stable, which then resulted in further issues and in some cases, re-admission to inpatient units. Learning disabilities and autism are lifelong and many people require ongoing and sustained support; removing support that is needed without proper assessment can lead to crisis.

Contact details

If you have any further questions or would like to arrange a meeting to discuss community support/the issues facing people with a learning disability and autistic people further, please refer to this list of key contacts for our organisations:

- **ARC England:** Clive Parry (England Director) - clive.parry@arcuk.org.uk
- **Autism Alliance:** Adam Micklethwaite (Director) - adam@autismalliance.org.uk
- **British Association of Social Workers (BASW):** Maris Stratulis (National Director) - england@basw.co.uk
- **Challenging Behaviour Foundation (CBF):** Vivien Cooper (Chief Executive Officer) - vivien.cooper@thecbf.org.uk
- **Learning Disability England (LDE):** Samantha Clark (Chief Executive) - samantha.clark@ldengland.org.uk
- **Mencap:** Jameela Khan (Parliamentary Affairs Officer) – jameela.khan@mencap.org.uk
- **National Autistic Society (NAS):** Sam Forrester (Policy and Parliamentary Officer) – sam.forrester@nas.org.uk
- **Rightful Lives:** Julie Newcombe (Co-Founder) - julienewcombe@rightfullives.net
- **VoiceAbility:** Stephen Hinchley (Senior Policy and Public Affairs Officer) – stephen.hinchley@voiceability.org
- **Voluntary Organisations Disability Group (VODG):** Sarah Woodhouse (Head of Policy and Influencing) - sarah.woodhouse@vodg.org.uk

[15] E.g., Service model for commissioners; NDTi and CBF; NICE NG11; NICE NG93; Services for adults with learning disabilities who display challenging behaviour; Services for children and young people who display challenging behaviour