Skipton House
80 London Road
London SE1 6LH

21 May 2021

Dear Jeremy,

Re: Health and Social Care Committee: Inquiry into the Treatment of People with a Learning Disability and Autistic People Session on 27 April 2021

We were greatly moved by the accounts of parents who spoke to the Committee and we agree that these experiences are unacceptable and illustrate why this agenda matters so much. We are absolutely determined to make the changes in the model of care available to support people with a learning disability and autistic people have healthy and fulfilling lives.

We were pleased to be asked to give evidence to the Committee at the last session. There are some important points that we did not have the opportunity to discuss on the day and we have set them out below with additional detail in the Annexe. Our view is that these points are crucial for informing next steps and building on what works:

- Sharing good practice and culture: it is important not to characterise all the work of the NHS in the field of learning disability and autism in the shadow of poor practice. Many people have a beneficial experience of inpatient care with outstanding support by health staff.
- Building on the progress we have made and strengthening what we know works: more than 80% of community Care Education and Treatment Reviews (C(E)TRs) lead to a decision **not** to admit a person to hospital. Of the original 2,895 patients in hospital in March 2015, 72% are no longer in inpatient care. Since March 2015 an additional 6,845 patients have been admitted to hospital and of these 82% are no longer in hospital. Since March 2015, overall inpatient numbers have reduced by 30%.
- A strong focus on support for autistic people: autistic people make up a large share of the Transforming Care inpatient population (85% of our children in hospital have autism and no learning disability). In 2021/22 we will be investing a further £25m in the development of community services with a key focus on autistic young people aged 14-25; a further £15m in keyworkers for children, including those at risk of admission to mental health inpatient care; and will be further developing NHS-led provider collaboratives to support improved pathways of care and quality of inpatient care.
- Community services: the development of community services is crucial for ensuring that people do not need to be admitted to hospital to get the care and treatment they need. It requires a whole-system cross agency solution with a transformative level of investment, not least because there are not cheap or easy community solutions for people with the most complex health and care needs.

- Admission avoidance: finally, an unstinting focus on admission avoidance is crucial, including a strong focus on and strengthening of dynamic support systems; community C(E)TRs and services to prevent crises. This will require strong local partnerships; access to excellent and proactive community mental health support; and capital to deliver community accommodation.

You also asked us to address four specific questions which we have set out below:

1 The Trieste model of care. At this stage, the effectiveness of the Trieste model for people with a learning disability and autistic people who present severe challenges is not clear to us. Our current policy for C(E)TRs already provides the opportunity for community services to intensively consider how individuals can be supported to prevent admission. We will continue to engage with colleagues in Trieste and elsewhere to learn from their experiences.

2 The Mental Health Act reform supporting improvements in the quality of inpatient care. We support the proposals set out in the White Paper to narrow the grounds upon which people with a learning disability and autistic people can be detained in mental health inpatient care. We would welcome a strong emphasis on some additional areas in the Act, which we have referenced in the Annexe.

3 Should LeDeR reviews be a legal / mandated requirement for every person with a learning disability? Every death that is notified to the LeDeR programme is reviewed. It is a matter for Government as to whether it should be mandatory to notify the death of every person with a learning disability. We would anticipate some difficulties in implementing such a mandate in terms of who would be required to do the notification of a death and in ensuring that people's (and their family's) choices made in advance about a LeDeR review are respected.

4 The merit of having an independent doctor regularly reviewing the cases of people in long term segregation. The issues surrounding lengthy inpatient stays and delayed discharge are, in the majority of cases, not purely "medical" and so interventions need to be multidisciplinary and multi-agency. C(E)TRs already provide independent clinical expertise to review cases.

We are very happy to provide any further information that the Committee would find useful.

Kind regards,

Claire Murdoch C.B.E. and Dr Roger Banks

Annexe 1

Further detail on the NHS learning disability and autism programme

1 Reducing reliance on inpatient care

1.1 Assuring Transformation data shows reducing reliance on inpatient care for children, young people and adults with a learning disability, autism or both:

- At the end of March 2021, there were 2,035 people in a mental health inpatient setting (1,820 adults and 215 under 18s). 30% were subject to Ministry of Justice restrictions. This represents **a 30% reduction since March 2015.**
- **At the end of February 2021, 2,090 (72%) of the original group of 2,895 people with a learning disability, autism or both who were in inpatient care on 31 March 2015, were no longer in inpatient care.**

1.2 The inpatient population is not static. Of the original 2,895 patients in hospital in March 2015, 72% are no longer in inpatient care. Since March 2015 an additional 6,845 patients have been admitted to hospital and of these 82% are no longer in hospital.

2 Investment in community alternatives to inpatient care

2.1 The learning disability and autism programme is underpinned by Long Term Plan (LTP) investment that increases year on year during the life of the LTP: £17m in 2019/20; £23m in 2020/21; £76m in 21/22; £80m in 22/23; and £131m in 2023/24.

2.2 In 2021/22, we are investing £25m in the development of community services to reduce admissions to inpatient care (with a particular focus on support for autistic young people aged 14-25); £15m in the further development of keyworkers for children and young people and £31m of Mental Health Recovery funding for a range of projects including admission avoidance.

3 Programmes of work to develop community support

3.1 *Housing:* Since 2016, NHSEI has invested capital to develop community accommodation (both short term and permanent) to support people with a learning disability and autistic people to be discharged from an inpatient care setting or to prevent admission. In 2019/20, just over £15m was given in grants to support the development of 92 units of accommodation; in 2020/21 this figure was more than £16m, supporting the development of 63 units.

3.2 *Support for commissioners:* We are working with partners to develop and support a range of improvement programmes to develop commissioning capability and the development of small supports.

3.3 *Dynamic support registers:* We are developing guidance to strengthen the use of dynamic support registers to identify children and young people who may need additional support. £3.5m of mental health recovery funding in 2021/22 will support

identification and clinical triage of autistic young people on diagnosis waiting lists at risk of admission.

3.4 *Admission avoidance for children and young people:* In Autumn 2020, we strengthened the C(E)TR policy: shortening the timescale in which post-admission C(E)TRs should take place (from 10 to 5 days) and making available extra money for individuals to prevent admission or to expedite discharge, including £3m in additional funding for community respite / short break provision for children and young people as a response to pandemic pressures, and a further £3m from the Mental Health Recovery funding for 2021/22.

3.5 Keyworkers for children and young people with the most complex needs

3.5.1 In September 2020, we piloted a keyworker programme for autistic children and children with a learning disability with the most complex needs. This started with those in mental health inpatient care, or those identified at risk of admission.

3.5.2 A further 14 early adopter sites will join the programme in 2021/22 and we are aiming for full roll out in 2022/23.

4 Quality of care and use of restrictive practices in inpatient settings

4.1 *HOPES Project:*

*4.*1.1 The Hopes Project offers training to support improvement in the quality of care, focused on alternatives to restrictive practices that avoid escalating behaviours and long-term segregation.

4.1.2 We have commissioned Merseycare (the provider of the HOPES model) to recruit HOPES teams to begin to roll out this model of care. HOPES has proved extremely successful in reducing restrictive practices and the use of long-term segregation (particularly for autistic people) by addressing staff culture and practice.

4.2 *Clinical contract:* We are at the scoping stage of a nationally led pilot to develop a contract that details the clinical intervention and assessment a person can expect to receive as a minimum on admission and during their stay in a specialist mental health / learning disability hospital.

4.3 Long length of stay, children and young people: We will be implementing a new escalation process for children and young people with longer lengths of stay.

4.4. *Review of advocacy:* We are working collaboratively with the Department of Health and Social Care to review the provision of and test new approaches for advocacy for people with a learning disability and autistic people in a mental health inpatient setting. This is to support the proposal regarding advocacy in the Mental Health Act White Paper.

4.5 *Focus groups in inpatient care:* We have completed a programme of focus groups in 4 mental health inpatient units (3 independent sector and 1 NHS Trust) during which we talked to groups of people about their experiences of care, including any issues and concerns. Outcomes have included changes to the provision of care.

4.6 *Senior Children's Intervenor:* In April 2020, the role of Senior Children's Intervenor (SCI) was introduced, on a pilot basis, for young people with extensive lengths of hospital stay, complexities in discharge planning and requirements for restrictive practice in inpatient mental health settings. It has seen positive outcomes and will be extended in 2021/22.

4.7 *Life Planning Work:* Aligned to the Baroness Hollins Review, funding has been agreed to support additional life planning for individuals in long-term segregation and the piloting of a national Senior Intervenor role: similar to the SCI role.

4.*8* *Host commissioner and commissioner oversight arrangements:* We have published guidance including COVID-19 adjustments to give additional local scrutiny and oversight of the quality of inpatient care https://www.england.nhs.uk/publication/monitoring-the-quality-of-care-and-safety-for-people-with-a-learning-disability-and-or-people-who-are-autistic-in-inpatient-care/.

5 Reducing Restrictive Practices

5.1 Restrictive interventions and restraint should only ever be used as a last resort, when all attempts to de-escalate a situation have been employed. We would wish to move to a position where manual interventions as part of a planned approach to care are at an absolute minimum and exceptional and as such are subject to specific reporting requirements.

5.2 There are key challenges around culture change, promoting human rights and person-centred care; embedding alternatives to restrictive practices including across agencies and settings. Reviews undertaken for people subject to the most restrictive experiences (especially those in long-term segregation) show that many of those people have a history of inadequate support leading to failed education and community placements, often from an early age.

5.3 We have developed training standards with Health Education England, the Care Quality Commission, Directors of Adult Social Services, Skills for Care, and the Local Government Association. As part of the NHS contract, providers are required to train in line with these standards and we have introduced a requirement for all NHS commissioned services to use a certified training provider to train their staff.

5.4 We have introduced Human Rights training and an assessment framework across Children and Young People inpatient services. The Mental Health Service Improvement Programme is supporting improvement work around reducing restrictive practices via the academic health science networks and has developed resources for providers. Additional level 3 safeguarding training has been provided for case managers of children and young people who are in hospital.

5.5 We are developing policy and guidance on seclusion and long-term segregation and the use of mechanical restraint in NHS commissioned services (for services for children and young people initially). Work to reduce blanket restrictions in inpatient settings will include a suite of resources for staff.

6 Children and Young People Quality Taskforce

6.1 Current work by the Taskforce includes: development of human rights training; delivery of specialist autism training to all CAMHS providers from April 2021 and a targeted 'safe wards' programme to reduce restrictive practices and improve culture across 20 wards (50% in Trusts and 50% in the independent sector)

6.3 A new family ambassador post is being rolled out. People with lived experience will offer support to families of children and young people admitted to an inpatient unit.

7 Data on restrictive practices

7.1 Data on the use of restrictive practices in learning disability and autism inpatient settings is reported by providers on a monthly basis through the Mental Health Services Data Set (MHSDS).

7.2 Over time, MHSDS definitions regarding restrictive practices have changed to be more inclusive to support transparency and oversight.

7.3 We are focused on improvements to data quality and reporting compliance.

8 NHS-led provider collaboratives

8.1 It is a Long Term Plan commitment that, by 2023/24, all appropriate specialised mental health services, and learning disability and autism services, will be managed through an NHS-led provider collaborative.

8.2 NHS-led provider collaboratives have developed from the NHS New Care Models programme where the most successful sites showed real evidence of providing good quality care at better value than other ways of working eg people returning from out of area placements to local hospitals; savings for investment in new community teams.

8.3 NHS-led provider collaboratives are **always led by an NHS provider** who remains accountable to NHSEI for the commissioning of services. They are based on local clinical leadership and co-production with experts by experience to drive services for local people. The NHS lead provider has responsibility for the commissioning budget for specialised services for the local area; for quality oversight of the services commissioned and for care pathways.

8.4. *Services provided by NHS-led provider collaboratives*

8.4.1 NHS-led provider collaboratives cover the commissioning and provision of specialised services only. They are responsible for the following services:

- Children and Young People's inpatient mental health, learning disability and autism services (often referred to as Tier 4 services)
- Adult Low and Medium secure services (often referred to as forensic services)
- Adult Eating Disorder inpatient services

There are currently 21 (out of 47) Phase One NHS-led provider collaboratives which are 'live'.

8.5.4 We have specifically required that each NHS-lead provider appoints a learning disability and autism Clinical Lead.

8.6 Funding Pathway Panels

8.6.1 Each NHS-led provider collaborative is required to establish a Funding Pathway Panel to make decisions on how any savings made from reducing reliance on inpatient care are reinvested into the community.

8.6.2 Pathway Panels are required to make a publicly available online feedback report at the end of each financial year, reflecting on the previous 12 months. The report will confirm what the panel's priorities were for the year, based on its Pathway Strategy and what action has been taken to deliver them.

9. Support for Mental Health Act White Paper proposals

9.1 We support the proposals set out in the White Paper to narrow the grounds upon which people with a learning disability and autistic people can be detained in mental health inpatient care. We would welcome a strong emphasis on additional areas in the Act:.

- applying the principles of autonomy, choice and least restriction to the whole of the Mental Health Act;
- making sure that any inpatient admission is 'purposeful' with clearly evidenced care and treatment plans / goals;
- supporting a more robust and informed mental health tribunal to make it a requirement that tribunal hearings include advocacy and the recommendations from C(E)TRs;
- rolling out the HOPEs model across inpatient care;
- investment and incentives for collaboration across health, social care and education to ensure there are sufficient alternatives to inpatient care
- putting dynamic support registers and CETRs on a statutory footing.