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Inpatient Care and the use of Restrictive Practices for Autistic Children and Young People, and those with a Learning Disability, in England, Scotland, Germany, Canada, and the US

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A 2022 Deep Dive report

Learning from Lives and Deaths - People with a learning disability and autistic people (LeDeR) report for 2022 (LeDeR 2022).

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Key Takeaways

England has the longest reported average length of inpatient admission stay of the 5 countries in the report.

England has the second lowest bed-to-patient ratio of the 5 countries in this report, and one of the lowest ratios in Europe.

Autistic children and young people with a learning disability who experience restraint may also experience physical harm as a result, with many experiencing negative emotional impacts. Families also often report the experience made their loved ones behaviour worse.

England reports the highest use of restraint amongst global comparable peers.

Contents

Abbreviations and Definitions

BASW: British Association of Social Workers

C(E)TR: Care (Education) and Treatment Review

CAMHS: Child and Adolescent Mental Health Service

CQC: Care Quality Commission

ICD-10/11: International Classification of Diseases (version 10/11)

Medicare/Medicaid: The Federally run, state sponsored health service in the United States of America.

NHS: National Health Service. The UK operates 3 separate health services, run by national governments and funded through taxation. These are NHS England and Wales, NHS Scotland, and the Health and Social Care system in Northern Ireland.

NICE: National Institute for Clinical Excellence

NIH: National Institute for Health

OBD: Occupied Bed Days

Purpose of this report

In England there are concerns that children and young people are admitted to inpatient mental health facilities too often, that the average duration of stay in these facilities is too long, and that they are subjected to more than minimally necessary levels of restrictive practices (e.g., restraint, both physical and chemical, and seclusion). The UK government recognise the need to reduce restraint and restrictive interventions in children and young people, particularly those with neurodevelopmental disabilities and/or mental illness and NHS England have set targets for reducing the number of admissions, length of stay, and the use of restrictive practices in hospital settings, and published a 'Long Term Plan' to address these. There is particular concern about the potentially high rate of admissions of autistic children and young people, and those with a learning disability, compared to the general population. Considering this, this report has been commissioned by NHS England to consider international metrics for comparison, and investigate possible room for further improvements, within England regarding the frequency of admission to hospital, the length of stay and the use of restrictive practices whilst in hospital.

Foreword and Background

This report explores inpatient mental healthcare for autistic children and young people, and those with a learning disability. It aims to examine the use of inpatient mental health beds and of restrictive practices in England and compare this with Scotland, Germany and select states and provinces in the USA and Canada. The goal of this work is to identify similarities and differences between policy and practice, with specific focus on admissions and restrictive practices, with the aim to inform service development in England.

We have selected high-income countries or states that have broadly comparable healthcare systems, data collection rigour, and population demographics to England. However, it is important to acknowledge the differences that exist between countries, and over time, which can make accurate comparison difficult, and the report should be read with this in mind. There is clinical variation in the diagnosis of neurodevelopmental conditions, and a lack of consensus on the definition of restrictive practices. Healthcare spending as a proportion of the economy is different across countries, and is notably higher in the US, and the organisation and provision of healthcare also varies considerably. Differences in legal, economic, political, and the prevailing cultural conditions between countries also limits direct comparisons. Furthermore, there is a lack of standardised, up-to-date, freely available clinical and epidemiological data in many countries, as noted by previous cross country comparison studies (Catalá-López et al., 2019). It is also important to emphasise that it is beyond the scope of this work to cover every law, guidance document and policy procedure in each country included in this report. Instead, we aim to provide a general overview of current policy and practice that have relevance to England.

In this report, the age range used to define ‘children and young people’ varies depending on the source of the data; the age ranges used by each source will be detailed beforehand. We have also, where possible, detailed what is meant by a “restrictive practice.” The reporting for this, for example, whether confining a patient to their room instead of a specific isolation room is considered a restrictive intervention or

not, has been shown to vary with some considerable degree between institutions, including those in England (Reid and Price, 2022).

Readers should also be aware of the lack of a definitive international terminology regarding people with a learning disability, autistic people, and people who have both a diagnosis of autism and a learning disability. In some sources the term “intellectual disability” is used to describe a condition which, in the UK, would more likely be termed “learning disability.” Likewise, there is some conflation regarding the use of autism, and whether this is distinct or inclusive in the definition of learning disability. For this report, we have tried to highlight this difference where it has been distinguished, however for some international sources this has not always been possible. For the purposes of this review, the definitions used by authors may not match the definition used by NHS England. In this deep dive, we will refer to autistic people, people with a learning disability, and people with a diagnosis of autism and a learning disability as distinct groups, where this is applicable and suitable.

Prevalence of autism in children and young people

Comparisons between admission rates and bed availability cannot be made without reference to prevalence rates of the condition. As noted by Anorson et al (2021), since the first study of the prevalence of autism in 1966, there have been repeated studies indicating that the recorded prevalence of autism is increasing around the world, in part due to greater awareness and the availability of diagnostic services. Three recent systematic reviews have synthesised the existing evidence to report global and regional prevalence rates. A review by Salari et al (2022), incorporating a combined sample size of 30,212,757 people, estimated the prevalence of autism to be 0.4% in Asia, 1% in North America, 0.5% in Europe, 1% in Africa and 1.7% in Australia. A review by Zeidan et al. (2022), estimated the global median prevalence to be approximately 1/100 children, with 33% of those also having intellectual disability. In addition, the systematic review published in the European Journal of Public Health by Anorson et al., (2021) included 75 studies from across the world to report the prevalence of autism in Europe, Oceania and North America. In Europe, the median prevalence was 59 per 10,000 people (approximately 0.6%). The authors found a higher prevalence in North America

of 86 per 10,000 (0.9%) and a marginally lower prevalence in Oceania of 47 per 10,000 (0.5%).

Autism prevalence rates by country show wide variation. Bachmann et al., (2018) suggested that in Germany the rate is about 1 in 264 children, or 0.38% of the population. This compares with about 1 in 44 children aged 8 years old who are estimated to have autism according in the United States. Meanwhile, the latest data available (2015) for Canada suggests that about 1 in 66 children between the ages of 5 and 17 years old have a diagnosis of autism. In England, current estimates suggest that about 1 in 100, or around 700,000 people are autistic, although some research indicates that this may be significantly higher, with an estimated rate of 1 in 57 children and young people, representing 1.76% of all children and young people between the ages of 2 and 21. In Scotland, current estimates are also about 1 in 57 to 1 in 100 children, which is the same as the English estimate.

For reference, below in table 1 are summarised estimates of the rates for autism in each of the countries used in this report.

Table 1: Prevalence summaries for autism in children in each country in the deep dive.

Country	Prevalence rate
England	Between 1 in 100 and 1 in 57 children (1% - 1.75%)
Scotland	Between 1 in 100 and 1 in 57 children (1% - 1.75%)
Germany	1 in 264 children (0.38%)
Canada	1 in 66 children (1.52%)
US	1 in 44 children (2.27%)

The estimated prevalence of autism, as demonstrated above, differs between countries. There are several factors underlying these differences, including differences in the diagnostic classification system used, the degree of understanding and recognition of autism, differing diagnostic practices and availability of diagnostic assessments, and differing cultural and healthcare systems that may enable, or discourage, a diagnosis. All of these should be considered when referring to the reported prevalence of autism in any one place.

In summary the prevalence of autism amongst children and young people in England is estimated to be higher than that found in some European countries such as Germany, and lower than that reported in the USA. In part, this may be due to differing diagnostic access and awareness.

Restrictive practice: A global issue

The 2019 UK Government report "Reducing the Need for Restraint and Restrictive Intervention" defines restrictive practices as "planned or reactive acts that restrict an individual's movement, liberty and/or freedom to act independently; and the sub-categories of restrictive intervention using force or restricting liberty of movement (or threatening to do so)". What these restrictive practices may entail can differ across the world, but in most cases, they involve either physical or chemical restraint, the use of seclusion and isolation, and the restriction of an individual's freedom in some way. The prevalence of potentially inappropriate admissions and restrictive practice in autistic children and young people is a global issue, and a hotly debated one. The use of restrictive practices can, when used correctly, be appropriate and necessary to reduce the risk of harm for both the person and those around them. However, its use also poses physical and psychological risks (Kamel, 2007). A recent study conducted in the US concluded that a diagnosis of intellectual disability and/or autism was significantly associated with the use of restrictive practice, defined as restraint and seclusion, with 78% of young people with a diagnosis of both autism and learning disability experiencing restrictive practice in acute inpatient psychiatric hospitals (O'Donoghue et al., 2020). A recent narrative systematic review of 13 studies of physical restraint in children, predominantly conducted in the US, concluded that young people with a diagnosis of a developmental disorder, psychotic disorder or externalising disorder (for example conduct/oppositional/disruptive disorders) were more likely to be restrained than those without these diagnoses (Nielsen et al., 2021). The authors also noted that young people with multiple comorbidities (those with both a diagnosis of a learning disability and another diagnosis) are more likely to be subject to physical restraint, with the most cited reason for restraint being risky behaviours, agitation, aggression, self-

harm, and threats towards staff (Nielson et al, 2021). In addition, Nielson et al, (2021) also noted that 5 of the 13 studies they reviewed cite that between 27% and 44% of children and young people in care experience some type of physical restraint during inpatient admission.

Perers et al (2021) noted that recent studies of inpatients wards for children and young showed considerable variation in the use of restrictive practices between nations, with reported rates of restraint or seclusion being between 6.5% (Norway) and 29% (Australia). Research in the US, Australia, and Finland found that there is a positive correlation between diagnosis of developmental disorders and incidents of restrictive practice (Azeem et al., 2011; Duke et al., 2014; Sourander et al., 2002). Returning to the UK, a 2021 report by NIHR Evidence likewise found that four out of five (81%) of the 315 wards for children and young people with mental health problems, a learning disability, or autistic young people had used physical restraint in their care in 2019.

Globally there have been calls for a reduction in the use of restrictive practices and, in some cases, an elimination of their use entirely (Perers et al., 2021). Indeed, studies are increasingly suggesting that their use is not only physically restrictive but may lead to emotional and long lasting harmful psychological impacts, for both patients and staff. A study by Vishnivetsky et al., (2013) from Israel reported that patients in adolescent inpatient psychiatric hospitals were left traumatised by the use of physical restraints and, if any restrictive practice was implemented, preferred the use of seclusion compared to physical restraints. Likewise, Kamel (2007) found that 38.75% of patients subjected to restraint felt humiliation and worthlessness, with 25% reporting feeling rage and resentment, sentiments further supported by Hottinen et al., (2012) who found that inpatient adolescents overall viewed restrictive practices as “distressing” and “inhumane”. In regard to the impact on staff, Lebel et al., (2004), in a US study, found that the implementation of restrictive practice reduction policy was both beneficial to the wellbeing of staff and patients, but also, as reported by Lebel and Goldstein (2005) offered financial savings whilst an Irish study, seeking the views of psychiatric nurses found that staff viewed the use of restrictive practices as “conflicting” with the role of nursing and as emotionally distressing and that they should only be used as a

last resort (Moran et al., 2009). Reducing the reliance on inpatient admission is in keeping with evidence that inpatient environments have been described by autistic people as “frightening” and “harmful” which may not promote recovery (Royal College of Psychiatrists, 2020). There are noted aspects of psychiatric admissions that could cause distress, including significant changes in daily routine, sensory overload in a busy ward environment, and unfamiliar social and communication demands (Maloret and Scott, 2018).

There is a growing body of literature suggesting alternatives to the current practice of hospital admission and restraint and restrictive practices, with publications such as Shepperd et al., (2009) finding that children who experienced home based multi-systemic therapy showed improved functioning in terms of their externalised symptoms (such as outwardly aggressive or disruptive behaviours) and were able to spend less days out of schooling than those in restrictive hospital placements. With that being said, the evidence is currently limited as to effective alternatives to inpatient admission in general, with a systematic review by Clisu et al., (2022) being unable to provide evidence for one intervention as a definitive alternative to inpatient admission. However, the authors did find there were benefits across a range of multimodal interventions, in particular multisystemic therapy, which suggested that even in cases of admission, having previous exposure to the therapy did decrease the length of stay.

England

The Mental Health Act (1983) is the main piece of legislation which governs the involuntary admission of people with mental disorders in England. An independent review of the Act was undertaken in 2017 and responded to by the government in the Reforming the Mental Health Act White Paper (2017) (again with an update in 2021). The proposed reforms include a number of modifications that relate specifically to people with a learning disability and/or autism. These include removal of learning disability and autism from the definition of mental disorder for purposes of an admission for treatment (Section 3). If these reforms become law, it will mean that autistic people (or people with a learning disability) will not be liable for detention under Section 3 of the Act in the absence of a co-occurring mental disorder of a nature and/or degree that warrants admission. In relation to children and young people, currently, the Mental Health Act (1983) does not have a lower age limit for its application, and there are no specific provisions for children under the age of 16. Other proposed changes that are intended to reduce the use of inpatient care or length of stay include the power of a tribunal to direct services in the community if there is a barrier to the person being discharged from hospital, and the power to transfer people to other, less restrictive settings to aid their recovery. Care (Education) and Treatment Reviews (C(E)TRs) are panels consisting of clinicians, social workers, support staff, and at least one person with lived experience, along with the patient themselves, who work together to provide recommendations towards a person's care, with the aim of reducing the need for hospitalisation. The 2017 White paper has proposed a number of adaptations to C(E)TR's which aim to reduce the number of compulsory inpatient admissions for these service users, and provide legally enforceable recommendations, but at the time of writing the final wording of the revised Act is still being debated.

In 2019 the UK Government produced advisory policy into the use of restrictive interventions for autistic children and young people, and those with a learning disability, with the aim of reducing their frequency, use, and their need. The policy suggests that

NHS trusts work with patients to develop care plans that avoid, or mitigate, the need for restrictive practices, and that, in accordance with already existing legislation, restrictive practices only be used when absolutely necessary, with the use of positive behaviour supports, de-escalation, and tackling the reasons for challenging behaviour “at the source”, being the preferred approaches. This is in addition to the 2018 Mental Health Units (Use of Force) Act, which further highlighted the disproportionate use of restrictive practices on autistic people and people with a learning disability, in addition to people from minority ethnic communities, and women and girls. The Act, which sits alongside the Mental Health Act (1983), provides guidance for the reduction of restraint within a mental health unit, guidance for the monitoring of the frequency of use, enhances the level of staff training provided around the use of restrictive practices, and develops the need to ensure accountability for the use of restrictive practices.

In sum, the proposed reforms of the Mental Health Act (1983) in England are attempts to reduce the frequency of admission for people with a learning disability and autistic people. There is focus on reducing the number of episodes of restrictive practice (including seclusion and restraint) that autistic young people and/or people with a learning disability experience. This is important because the evidence base indicates these service users are at a greater risk of these practices and are also subject to them for longer time periods when compared to the general population (Murphy et al., 2017; Sourander et al., 2002).

Scotland

NHS Scotland is distinct from the NHS in England and Wales as part of devolution. As such, Scotland operates its own policies and procedures regarding mental health and admissions, including the provision of the Mental Health Scotland Act 2015, which is distinct from the Mental Health Act (1983) in England and Wales. There are many similarities between the Mental Health Scotland Act (2015) and the Mental Health Act (1983) in England and Wales, but also some significant differences. For example, in Scotland a medical practitioner must apply for a patient's involuntary detention, whilst in England and Wales the nearest relative can, though it rarely

happens (Cronin et al., 2017). It is also worth noting that Scotland has limited CAMHS inpatient facilities in relation to its needs, and therefore some patients are transferred to in-patient units in England, if admission is necessary. This is particularly the case for autistic children (aged 0-17), where in 2017, 17 (Scottish) autistic patients were placed in CAMHS inpatient facilities in England; 9 of these were placed in specialist learning disability facilities (Child and Adolescent Mental Health Services: inpatient report, 2017).

A further notable difference in policy between England and Scotland is the use of Scottish "Children's Panels" or "Children's Hearings Scotland". These panels consist of supported volunteers and panel members who, on a local level, assist in making legal decisions with and for children and young people regarding a child's care and wellbeing. This can also include their placement in an inpatient psychiatric hospital, as well as the provision of support services in the local community. The panels are in addition to the Children's Hearings (Scotland) Act (2011, and updated in 2021), a Scottish Government initiative to reduce the rate of child and youth detention centres (either prison or residential homes) by working to enable alternative options and support, either in the community or through other social or legal interventions. Presently, such an open to members of the public (as in people can apply to be part of them), volunteer led panel system does not operate in England, although, as mentioned above, Care, Education and Treatment Reviews (C(E)TRs), do provide an analogous process of independent review and recommendations with the aim reducing reliance on in-patient care.

Germany

An important distinction between England and Germany is that in Germany there is no national law regulating mental health detentions or admissions and that each of the 16 states are responsible for their own legislation. However, as with the UK Mental Health Act (1983), a person may be admitted to hospital with a mental health condition if their health is at risk or there is a risk to the safety of themselves or others. In recent years, the rate of involuntary admission (Zielasek and Gabel, 2015) which is a similar trend to the UK, as shown by an increasing rate of compulsory detentions under the Mental Health Act (1983) (CQC, 2020). In Germany however, any patient who is

admitted to hospital involuntarily and subject to any restrictive practices must have their case heard independently by a judge, who determines if their hospitalisation is legal. Without such judicial approval, any restrictive practices or restraints are deemed illegal, and cannot be undertaken (Thome et al., 2020).

As stated by Murphy et al., (2012) there appears to be a global recognition that the conditions in in-patient settings are not representative of 'real life' in terms of day to day living and independent coping, and this is partly responsible for influencing the drive towards increasing outpatient and community support, often through assertive outreach interventions (Murphy et al., 2012; NICE, 2014; Winness et al., 2010). To address this, in 2018 the German government introduced new legal frameworks, known as the Social Code, Book Five, enabling psychiatric hospitals to offer "Inpatient Equivalent Home Treatment' promoting 'Flexible and Integrative Treatment' Models based on a 'Global Treatment Budget' financing approach. A small mixed-methods evaluation of this approach found that German service users had experienced improved need-adaptedness of treatment, greater understanding of safety and finally the opportunity to maintain everyday life during their psychiatric treatments (Schwarz et al., 2020). There is a lack of quantitative evidence on the effectiveness of these treatments given how recently they were introduced in Germany, but a published research protocol investigating the efficacy and costs of home treatment is likely to provide key evidence once the study is conducted (Baumgardt et al., 2021). The findings of this research may inform whether a focus on community care will shorten the duration of inpatient stays, reduce treatment duration, reduce emergency admission rates, and increase quality of life by enabling service users to remain in psychosocial environments.

US and Canada

The United States and Canada represent two large but quite different health care systems and encompass much of the population of North America. However, it is worth noting that, due to the Provincial system in Canada and the State system in the US, there is limited to no cross-country uniformity in provision of health care services and direct comparisons on a national level to other countries are not possible. Each state or

province may have different guidance and law around mental health. For example, in 2000 the Massachusetts Department of Mental Health passed guidance, backed by State law, to reduce, and ultimately eliminate, the use of all forms of restraint and seclusion in all child and adolescent inpatient and intensive residential treatment centres in the state. Between 2000 and 2004, episodes of restraint and seclusion (per 1000 patient days) decreased as a result by 84.4% in 2001, 80.4% in 2002 and 78.7% in 2003 in child (aged 5-12), adolescent (13-18) and mixed child/adolescent units, respectively (LeBel et al, 2004). In Florida, restrictive practices are permitted (termed "emergency treatment orders", provided by a clinician), but there is legislation requiring that they only be used in an emergency, for the protection of the person or others, and with the use of a prone position restraint being only permissible for immediate urgency and must be discontinued as soon as possible (Florida Administrative Code, 2006).

In the US, Federal awards and funding have also been established with the aim of reducing or eliminating the use of restraints (LeBel, 2008). For example, the Alternative to Restraint and Seclusion State Incentive Grant in 2004 showed, for hospitals that applied the grant to restraint reduction initiatives, an 89% reduction in the amount of restraint hours used, an 18% reduction in staff injuries and a decrease in workplace compensation costs by 24% (Dike et al., 2021). Guidelines such as those by the Substance Abuse and Mental Health Services Administration (SAMHSA) in the US Department of Health and Human Services, have previously laid out best practice guidelines with the aim to decrease or eliminate the use of restrictive practices nationwide (Curie, 2005). In 2000, the Children's Health Act sought to establish national standards for the reduction or elimination of restraints in all federally funded public hospitals in the US. However, in 2007, a new regulation named "Final Rule", was issued by the Centers for Medicare and Medicaid Services (CMS) which diluted some of the Children's Health Act guidelines aimed to reduce the use of restraint and moved towards a model of "safe restraint" instead (LeBel, 2008). In Canada, similar legislation has been passed. Like in the US, Canada's Provincial system largely leaves healthcare to each separate province. In 2001, Ontario passed the patient restraints minimization act, which outlined the legal requirement that restraint be used only as a "last resort" and only in cases where the patient, or others, lives or safety was at immediate risk.

Likewise, in British Columbia, the use of restrictive practice is legislated under the provinces Mental Health Act (1996) which stipulates that restraint can only be used without consent in cases of emergency, immediate risk to life, and with the minimal duration and amount of physical duress.

Current guidelines, such as those issued by the American Psychiatric Nurses Association (2022) state that seclusion and restraint should only be used as a last resort, and in cases of risk to the patient, staff or others, and that there is an aspiration to both reduce, and ultimately eliminate, the use of restrictive practices completely. However, due to the nature of the American healthcare system, much legislation and guidance refers only to State funded Medicare/Medicaid services, and not necessarily to private institutions, which provides a limitation to their effectiveness. Following the example of Massachusetts, several other States have followed with similar legislation, such as Virginia in 2001, New Jersey in 2005, and Florida in 2006, updated in 2022. Even earlier than Massachusetts, the Pennsylvania State hospital system implemented an effort to reduce the use of restrictive practices in state funded hospitals in the late 1990s, with the average rate of seclusion decreasing from 4.3 to 0.3 episodes per 1,000 patient days, the rate of physical restraint decreasing from 3.5 to 1.2 episodes per 1,000 patient days, and the average duration of the restraints (including seclusion) decreasing from 11.9 to 1.9 hours. Smith et al, (2005) noted that “many factors contributed to the success of this effort, including advocacy efforts, state policy change, improved patient-staff ratios, response teams, and second-generation antipsychotics.” Ferleger (2008), in a review of current US States policies regarding the reduction and limitation of restrictive practices, noted several features of successful restraint reduction programmes. These are:

- Leaders who set an organizational culture change agenda.
- Systematic collection of seclusion and restraint data.
- Use of data to inform staff and evaluate incidents.
- Improvement in environmental conditions.
- Individualized treatment and responsiveness to clients.
- De-escalation tools.
- Debriefing to both analyse seclusion and restraint events and to mitigate their adverse effects.
- Staff training.

An increased awareness of autism and the needs of people with a learning disability has resulted in governmental and academic research focus on both the care of and support of children and autistic young people and/or a learning disability in both the US and Canada. In the US, the 'Autism Collaboration, Accountability, Research, Education, and Support Act of 2019' (GovTrack.us, 2019) added a further $1.8billion USD of funding to the existing $3.1billion USD in federal US funding over five years towards research and development in the care, treatment, and support of autistic people. Several US government agencies, including the Centre for Disease Control (CDC), the National Institute of Health (NIH) and the Centres for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) are involved in research activities related to the care and treatment of autism and learning disabilities. In Canada, the federal government initiative 'the National Autism Strategy', led by the Canadian Academy of Health Sciences, has invested a further $1.67 million CAD to the existing $9.1 million CAD Autism Spectrum Disorder Strategic Fund and the Autism and Intellectual Disabilities Knowledge Exchange Network (AIDE Canada) to improve the provision of support, awareness and to research and improve the health and social wellbeing of autistic people.

Summary

Legislation and policy regarding the hospitalisation, and subsequent use of restrictive practices, for autistic children and young people and those with a learning disability varies globally. There is however a global discussion, backed by statutory change, for reducing the frequency of inpatient admission and increasing the availability of outpatient preventative and/or treatment options. Legislation designed to decrease the use of restrictive measures has not shown to eliminate the use of restrictive practices entirely. However, legislative efforts in certain US states have shown a decrease in the use and frequency of restrictive practices when presented with legislative regulations that seek to decrease, or even prohibit, their use. It is worth noting that, due to the COVID-19, much recent legislation has yet to show results regarding its impact.

Significant resources have also been utilised in many countries to enhance research and understanding into the effect of restrictive practices on both patients and staff, with the US and Canada devoting millions of dollars in funding to further research within autism and intellectual disabilities' care. Scotland has devised Children's Panels to provide more direct patient/clinical cooperation, and in an effort to reduce the use of hospitalisation through alternative suggested options, an initiative that is somewhat mirrored by the C(E)TRs in England. Meanwhile Germany has begun to implement policy to directly increase the likelihood of outpatient home care and coping strategies and has enacted individual legal oversight for each involuntary hospitalisation. This is in addition to already in place legislation stating that any individual who is hospitalised involuntarily must have a judge approve of their hospitalisation. This is also in place for the use of restrictive practices; without a judge ruling, any such use would be illegal.

The UK government has produced guidance for NHS England seeking to reduce and limit the use of restrictive practices for children and young people with learning disability and/or autistic spectrum conditions, however this was published in 2019 and, due to the pandemic, it remains to be seen how effective this has been. This is in addition to already existing legislation, and proposed reforms of the Mental Health Act (1983).

Rates of Admission and Bed Provision

England

In some cases, the mental health of a child or young person with an autism diagnosis can cause concern for their health and safety and that of those around them. In these situations, it may be determined that they could benefit from specialised assessment and treatment in an inpatient hospital setting. Hospital admissions for autistic people are typically designed to be used for assessment, crisis management and acute treatment and are not a long-term solution. When longer-term support is required, alternative community care options are considered more appropriate (care at home, or within a facility, such as a residential or group home). An autistic child or young person in England might be admitted to hospital if their presentation means that they are at considerable risk of serious self-harm or aggression, towards others or themselves, and that this cannot be managed safely within their home environment. Admission is also considered if the child or young person needs more intensive treatment that cannot be provided in a community setting, or if they need a 24-hour assessment by a team within a hospital. In the years 2019-2020, 1,172 children aged 17 and under were detained under the Mental Health Act (1983) in England (Article39, 2021). Of these, 115 (9.8%) were children with a learning disability and/or autism. For all children and young people admitted to hospital, girls were more likely than boys to be detained (69%), with 73% of all detentions being white children, 6% of mixed ethnicity, 8% Asian and 9% black. The comparable data on the demographics breakdown of the 115 who were children with a diagnosis of a learning disability and/or autism was not detailed for comparison.

According to NHS Digital data, in 2020/2021, 9,758 under 18s were admitted to hospital with a primary diagnosis of 'mental and behavioural disorders' where the average individual new monthly admissions of the previous 12 months were 220 people. The number of 17-year-olds and under subject to the Mental Health Act between 2020 and 2021 was 1,134 (9.4 people detained under the MHA per 100,000 of the population). Data from NHS Digital, Assuring Transformation shows that in September

2022 there were 1,965 people in hospital with a learning disability or autism diagnosis, of which 185 were under 18's. Of these 185 under 18's, 145 had a diagnosis of autism only, 15 a learning disability, and 25 both a diagnosis of a learning disability and autism. Combining these data therefore suggests that approximately 27% of all children and young people inpatient admissions to hospital for mental health and behavioural reasons were for those with a diagnosis of autism or a learning disability, although not necessarily because of these diagnoses (NHS Digital, Hospital Episode Statistics, 2023). A report from Autism.org.uk (2022), with data taken from NHS Digital reports, showing that in January 2022, 47% of the 2,030 people (all ages) hospitalised in England in learning disabilities inpatient care had a diagnosis of autism.

NHS England SDCS Data from April to June 2022 showed that there were 469 occupied beds for child and adolescent psychiatry, 554 for learning disability (all ages), 27 psychotherapy beds (all ages) and 3,416 paediatric beds (all paediatrics) as the average daily number of occupied beds across the three months. There were also a further 773 available beds in England for patients with a learning disability (all ages), although the "available" data does not break further bed categories down into age groups. When comparing data on bed availability and occupancy from NHS England Statistics for all ages however, there were 1,327 overnight beds specifically for people with a "learning disability" (773 available and 554 occupied) and 34,436 for "mental illness" (18,175 available, 16,261 occupied) in Q1 2022. This compares to 1,897 in Q1 2018 for the category of "learning disability" (1,078 available, 819 occupied) and 34,914 for "mental illness" (18,395 available, 16,519 occupied). Going back further, there were 3,061 beds for people with a "learning disability" (all ages) in Q1 2013 (1,706 available and 1,355 occupied) and 41,636 for "mental illness" (22,109 available, 19,527 occupied). Whilst it is the case that more recent year's data has been affected by the COVID-19 pandemic, and bed occupancy has affected by this, the decrease in "learning disability" and "mental illness" bed availability for the total population is still demonstratable for the years preceding the pandemic, too. Indeed, data of bed availability from 2010/11 to Q2 2022/23 shows a decrease in beds across the years in all NHS sectors detailed, (General and Acute, Learning Disability, Maternity, and Mental Illness), with a total of 144,455 available (122,551 occupied) across all sectors in Q1

2010/11, decreasing to 128,801 available (113,522 occupied) in Q2 2022/23. 2023 OECD data shows that, for all psychiatric (both adult and child and young person) the UK (as a whole) has 34 beds per 100,000 people. For reference, the OECD estimated that the UK in 2011 had 54 beds per 100,000 people.

A report by the Education Policy Institute (EPI), the "Children and Young People's Mental Health report" (2017), found that in 2015 there were 1,440 CAMHS beds available in England, which represented a 71% increase in raw bed numbers since 1999. However, this increase in bed totals is not evenly spread, and access to beds varies significantly by region, with the North East of England having the greatest provision of overall beds at 3.03 per 100,000 people, and the South West having the lowest, at 1.1 bed per 100,000 people. A concern of these overall low availability of beds for CAMHS is that, in some cases, children with mental health needs are being admitted to adult psychiatric wards, in contradiction to section 131A Mental Health Act of 1983, which states "the patient's environment in the hospital is suitable having regard to his age (subject to his needs)." The EPI report (2017) found that, in 2016, 83 under 18s were treated on adult wards instead of CAMHS units. Indeed, in 2021-22 there were 249 admissions of under-18s to adult psychiatric wards in England, according to data provided by NHS trusts to the Care Quality Commission (CQC), which was up 30% on the year before. 27% of these were due to situations where it was determined that there were no other age appropriate beds available, either inpatient or community based outpatient services (CQC, 2022).

When compared to European comparator countries, the UK (as a whole), has less availability of beds per population than many of its neighbours. Germany provides the largest number of beds per 100,000 young people for children and adolescents with ill mental health in Europe (64 per 100,000) (Boege & Fegert, 2021.; Signorini et al., 2017). Germany has 537 public CAMHS departments for child and adolescent psychiatry providing 8,400 bed spaces (which compares to the 939 CAMHS and 1,264 bed spaces in the UK. For context, the same report presented all (at the time of report writing) 28 EU states data, with the top 5 inpatient CAMHS bed numbers (for under 18s) and the rate of paediatric beds per 100,000 as displayed overleaf in table 2:

Table 2: The top 5 27 EU countries (plus UK) for CAMHS bed provision per 100,000 population and total bed numbers (France is added for population size contrast to the UK).

Rank	Country	CAMHS beds per 100,000 of population	Total number of CAMHS beds (for under 18s)
1	Germany	64	8,400
2	The Netherlands	56.6	1,981
3	Latvia	39	140
4	Czech Republic	34.6	628
5	Luxemburg	32.6	35
16	France	16.4	2,107
18	UK	9.4	1.264

In addition, France (more directly comparable in population total to the UK) had 2,107 beds, (16.4 per 100,000) with the UK having 1,264 beds (9.4 per 100,000). For context, the lowest number of CAMHS beds per 100.000 was in Sweden, with 1.2 per 100,000 (157 beds and 20 public in patient CAMHS units). For a chronological contrast, in England in 2003 there we 80 units providing around 900 beds, which represented about 7.1 beds per 100,000 for people under the age of 18, demonstrating an increase in bed provision in the past 10 years, both in total and per 100,000 (Green et al, 2007). Nonetheless, England is reported to have lower availability of CAMHS inpatient beds than most of its peer countries in Europe.

The 'least restrictive' principle of the Mental Health Act (1983) in England states that inpatient admissions should be a "last resort", in that they should only occur when treatment in the community or at home is not a viable option (Mental Health Act 1983: Code of Practice, 2015). Evidence suggests however that autistic children are overrepresented in in-patient services compared to non-autistic children (Thomas et al., 2015; Jones et al., 2021). One probable reason for this is a reduction in beds in learning disability and autism specific learning disability inpatient units alongside under-resourced community teams (BMA, 2023).

To reduce admissions, and to create inpatient environments that are more accessible when they are needed (for example through ease of access and increased family support in admission), several policies and recommendations in England have

been implemented including Transforming Care, Building the Right Support, The NHS Long Term Plan, and the national strategy for autistic children, young people and adults: 2021 to 2026. Inpatient environments that are more accessible when they are needed (for example through ease of access and increased family support in admission), several policies and recommendations in England have been implemented including Transforming Care, Building the Right Support, The NHS Long Term Plan, and the national strategy for autistic children, young people and adults: 2021 to 2026.

Scotland

Three hundred and ten 0–17-year-olds were admitted to psychiatric hospital in Scotland in 2020/21 and 350 in 2019/20 (Mental Health Inpatient Activity, Public Health Scotland). It is estimated that between 4,121 and 12,362 children and young people in Scotland have learning disability and mental ill-health and between 3,091 and 9,272 of whom have persistent mental ill-health. In a 2018 report, 37% of inpatients in Scottish CYP psychiatric units were autistic (Inpatient Census Part 1: Mental Health & Learning Disability Inpatient Bed Census, 2018).

In Scotland, most under 18s (60%) were admitted under the reason 'therapeutic/clinical crisis' (p.29, Inpatient Census Part 1: Mental Health & Learning Disability Inpatient Bed Census, 2018). In Scotland, the main reason for children and young people with a learning disability and/or autism to be admitted to psychiatric hospitals was respite care rather than treatment between 2015/16 and 2020/21. In just under six out of 10 admissions this was the case. Of the 2,266 admissions for under 15-year-olds, 2,238 were admitted under the reason 'respite/holiday care' (Learning Disability Inpatient Activity). This may suggest that, in many cases, respite care is needed when community services, carers, and families have become exhausted and need further support that is otherwise not available to them outside of a hospital setting. In Scotland, for inpatient young people who were autistic and or had a learning disability, 24% were also diagnosed with an affective disorder, 23% with anxiety and trauma related disorder, 21% with psychosis, 15% with ADHD and 13% with other

additional psychiatric diagnoses. (Child and Adolescent Mental Health Services: inpatient report, 2017)

Germany

Bolte et al., (2008) reported that, between 2000 and 2005, inpatient admission rates for autistic children aged up to 15 years old increased from 3.94 to 5.13 per 100,000, a 30.2% increase. The authors noted that, during the same years, the inpatient rates for all mental disorders in children up to the age of 15 rose from 296 to 358 per 100,000, a 20.9% increase. Boege et al (2021) reported that 58,831 children and young people were admitted to psychiatric inpatient beds in German psychiatric hospitals in 2021, significantly higher than the 7,160 that were admitted in England and Wales in 2021. For reference, there were 4,207 under 18's admitted in England and Wales between 2012 and 2013, demonstrating that, whilst admission numbers have increased in England, they are still significantly lower than in Germany. However, the sizeable difference in admission totals suggests that the threshold for admission to hospital in Germany is different, perhaps in both complexity and severity, than in England. Without access to detailed criteria for admission, which in this report is hampered through lack of data access and language barriers, this can only however be hypothesised.

US and Canada

According to Siegel and Gabriels (2014), 11% of autistic children are reported by their parents to have been admitted to a psychiatric hospital in the US by the age of 21, compared to 0.23% of non-autistic children. Likewise, of almost 4 million hospital emergency department visits, 13% of autistic children who visited the hospital were there for mental health problems, compared to 2% of children without autism who visited (Kalb et al, 2012). As noted by Nayfack et al (2014), the rates of admission for autistic children have been increasing from 1999-2009 by nearly three times in comparison to the general population. Whilst this is partially due to the increased

diagnosis of autism within that period, it also could suggest that previously people in hospital were not provided with the diagnosis, or support, that they may have required.

The number of beds available varies State-to-State and Province-to-Province, each with their own requirement for measurement and record keeping, and national data is therefore difficult to calculate. However, a study by Siegel et al (2012) found that, in hospitals that are classified as "specialist" units for autistic young people only (aged 4-21), there were only 137 beds nationally, with the average unit having 15.2 beds (range 9-22). Of note, the authors found that there were only 9 such specialist hospitals in the US and all were in northeast coast states, with the furthest south being Baltimore, and that all other institutions of care are mixed diagnosis settings. The authors noted that this showed a striking maldistribution across the country and demonstrated that most autistic children and young people were not provided with specialist autistic care in autistic specific facilities. Availability of psychiatric inpatient beds in general psychiatry varies, with an estimate by Allison et al., (2018) showing that the US had around 37,629 inpatient psychiatric beds (for all ages and requirements), around 6.2 beds per 100,000, whilst Canada had around 49 per 100,000. The OECD (2023) suggested that, in 2020, Canada had 37 psychiatric (all ages) beds per 100,000 and the US, in 2019, had around 31 beds per 100,000.

According to Mandell (2008), the top 5 reported characteristics associated with increased chance of psychiatric hospital admission rates for autistic children and young people (aged 2-21) in the US are:

1) Aggressive behaviour
2) Coming from a single-parent household (not a reason *for* but often associated *with* admission).
3) Depression.
4) Obsessive compulsive disorder.
5) Self-injurious behaviour.

As seen in other countries, the likelihood of admission also increased with age. Likewise, lower socio-economic status was associated with admission, true too of other

nations and for England (Emerson et al., 2007; Walker et al., 2021). Righi et al (2019) further found that adaptive functioning (a person's ability to cope with stressors in day-to-day life), the symptom severity of autism, the primary caregivers' marital status, the presence of any mood disorders in addition to an autism diagnosis, and the presence of any sleep disorders also increased the risk of hospitalisation. This may suggest that early intervention to treat sleep and mood disorders, as well as the symptom severity of autism, may help proactively prevent admission to hospital.

Summary

In England, the rates of bed availability in relation to population have decreased across many NHS sectors annually since 2010, with CAMHS now accounting for one of the lowest beds per 100,000 ratios in Europe, and one of the fewest in the comparable world (above the US (for data available) but below Germany, and most other comparable nations). This trend is not unique to England though, with the US and Canada also demonstrating a decrease in capacity (with Germany maintaining relatively high levels). The BMA, MIND, and the Royal College of Psychiatry, in their 2019 report by Wyatt et al; (2019) have commented on the challenging pressures faced by a decrease in beds. Contrasting the availability of beds between countries is complicated due to varying regional differences in provision (e.g., the use of private vs state healthcare providers, legislative focus on community or hospitalisation etc). With that in mind, England has been shown to have around 3 CAMHS beds per 100,000, with Scotland around 4, Germany at 64 per 100,000 (the highest in Europe), whilst the bed provision for both the US and Canada are more complicated to pin down (due to their State and Provincial set up), but are estimated to be between 6.2 and 25 per 100,000 for the US and 35 to 49 per 100,000 for Canada. Whilst these figures are not directly comparable, England provides many fewer in-patient CAMHS beds than other economically developed countries.

Across all 5 countries in this report, rates of admission for children and young people with a diagnosis of a learning disability and/or autism were found to be higher than in the general population, **with between 27% and 37% of all**

psychiatric inpatient admissions in Scotland and England being for autistic children/young people, or those with a learning disability. In the US, one study found that 11% of autistic children were had been hospitalised by the age of 21, compared with 0.23% of the general population, whilst studies from Germany, which does not explicitly detail how many children have a diagnosis of autism or a learning disability in their data, has suggested that the percentage of admissions with these diagnoses are increasing.

The data from Scotland regarding the number of admissions that are the result of people requiring respite care may be worth further investigation. Determining how services can best provide support in the community, at home, and outside of inpatient hospital care could provide insights into how to provide alternative supports in lieu of inpatient respite care.

Length of Stay

England

The April-June 2021/2022 (the most recent at the time of writing) data from the NHS Mental Health Dashboard indicates the number of bed days for CYP under 18 in CAMHS tier 4[1] wards was 77,188. Data from 2016/17 found that the mean average length of stay in CAMHS inpatient wards then was 72 days, with the median being 61 days (NHS Benchmarking Network 2018). Likewise, the NHS Benchmarking Network 2022 report, comparing England to 15 other countries, states that England had a mean general admission stay of 125 days, the longest duration out of all countries profiled that year. NHS Digital, as of September 2022, shows the median length of stay for children and young people with a learning disability and/ or autism is considerably longer than for the general CAMHS population - between 6 months and 1 year (182-365 days), compared to between 90 and 100 days on average for all children (which also includes data for those with autism and a learning disability, as the data is currently not broken down between categories of wards). The Children and Young People's Mental Health report (EPI, 2017) found that between October 2015 and February 2017, children (all children) spent in total nearly 9,000 delayed discharge days (waiting to leave mental health hospitals). Whilst autistic children and young people and/or young people with a learning disability were not specifically singled out, it is notable that the authors suggested that this was in part due to a lack of suitable subsequent outpatient supports and services for CAMHS in general in their local communities. This is likely to be greater for autistic people due to fewer specialist placements.

Overleaf in tables 3, 4, 5 and 6 is summarised data from table 4.8: "Patient bed type and total length of stay by learning disability or autism category" from NHS Digital LDA monthly statistics for September 2022.

[1] Tier 4 acute general adolescent units are the most common settings for children and young people to be admitted to when they need inpatient mental health care.

Table 3: The number of children (under 18) and duration[2] of stay of young people in mental health/learning disability beds in England in September 2022.

	Total	Learning Disability only	Autism only	Learning disability and autism
Children and young people in mental health/learning disability - beds (%)	185	15 (8%)	145 (78%)	25 (14%)
Up to 3 months	35	*	30	*
3 – 6 months	40	*	30	5
6 months to 1 year	50	*	45	*
1 year to 2 years	40	5	30	5
2 years to 5 years	14	*	15	*
5 years +	N/A	n/a	n/a	*

Table 4: The total number and duration of stay of children and young people (under 18) in secure mental health/learning disability units in England in September 2022.

	Total	Learning Disability only	Autism only	Learning disability and autism
Children and young people in mental health/learning disability – Secure unit (%)	45	*	30 (74%)	15 (16%)
Up to 3 months	*	*	30	*
3 – 6 months	5	*	30	5
6 months to 1 year	10	*	45	*
1 year to 2 years	10	5	30	5
2 years to 5 years	10	*	15	*
5 years to 10 years	*	*	*	*
10 years+	*	*	*	*

[2] Note: the wording from NHS Digital is: The total length of stay was calculated from: Date of the first admission to any hospital as part of this continuous period of inpatient care. This question was only answered if the patient had transferred from another provider. If the patient had not transferred from another provider, then the total length of stay was calculated from: Date that this hospital admission commenced with this provider."

Table 5: The total number and duration of stay of children and young people (under 18) in general child and adolescent mental health/learning disability units in England in September 2022.

	Total	Learning Disability only	Autism only	Learning disability and autism
Children and young people in mental health/learning disability – General child and adolescent mental health unit (%)	95	5 (5%)	75 (82%)	15 (13%)
Up to 3 months	20	*	15	*
3 – 6 months	30	*	25	5
6 months to 1 year	30	*	25	*
1 year to 2 years	10	*	10	5
2 years to 5 years	*	*	*	*
5 years to 10 years	*	*	*	*
10 years+	*	*	*	*

Table 6: The total number and duration of stay of children and young people (under 18) in mental health/learning disability units (e.g., other than specialist hospital beds or mental health units) in England in September 2022.

	Total	Learning Disability only	Autism only	Learning disability and autism
Children and young people in mental health/learning disability – Other (%)	50	5 (12%)	35 (75%)	5 (12%)
Up to 3 months	10	*	10	*
3 – 6 months	*	*	*	*
6 months to 1 year	10	*	10	*
1 year to 2 years	15	*	10	*
2 years to 5 years	*	*	*	*
5 years to 10 years	*	*	*	*
10 years+	*	*	*	*

Scotland

The average (mean) length of stay in a CAMHS unit in Scotland was 50 days in 2016/17 (NHS Benchmarking Network 2018). For autistic young people, 48% spent 90 days or more in hospital, whilst 28% spent more than 180 days in hospital. For those with a severe learning disability, 88% spent 90 days or more in hospital, with 50% admitted for longer than 180 days. The overall estimated length of stay for autistic children and young people and/or a young people with a learning disability in Scotland was between 180 and 365 days. (Child and Adolescent Mental Health Services: inpatient report, 2017), comparable therefore to that in England (reported as 182-365 days).

Germany

The average length of stay for all children and adolescent inpatients in Germany is 34.4 days as of the latest available data at the time of writing (August 2019). For children with an ICD-10 code of F80-F89 (disorders of psychological development) within which autism falls, the average length of stay in days is presented below in table 7. Between 2007 and 2014, inpatient child and adolescent (aged 6-18) admissions increased in Germany by 38% but the average duration of stay decreased by 14%, resulting in an overall increase of inpatient child and adolescent beds needed by 17%).

Table 7: German Federal Statistical Office (August 2021) data on length of hospital stay for children and young people with the ICD-10 codes of F80-F89.

Age group	1 to 5 years	5 to 10 years	10 to 15 years	15 to 18 years
Length of stay in days (for females)	5.4	9.9	23.0	31.6
Length of stay in days (for males)	5.9	12.6	28.1	29.8

US and Canada

According to Mandell (2008), autistic children and young people (aged 2-21) incurred, on average, 11.9 times more psychiatric hospital days compared to children without autism nationally in the US. In a review of specialised hospital psychiatry units that focused on children in the US, Wink et al (2017) also noted that around 11% of autistic people will have experienced hospitalisation by the age of 21 with their study finding the length of stay was between 3 and 163 days, with 25.6 days as the average.

Stewart et al (2013) found that, in a sample of 338 children aged between 6 and 18 years who were hospitalised in a mental health unit in Ontario, Canada, the average length of stay was 103.27 days for patients who received a form of chemical restraint, 103.90 days for those who received a physical restraint and 113.61 for those who received secure isolation with the average stay for the total population being 79.47 days. For children and young people who had a diagnosis of developmental disability their average length of stay, if chemically restrained, was 103.27 days compared to 85.64 for those with no developmental disability, if physically restrained was 103.90 days compared to 72.94 and if in secure isolation was 113.61 days compared to 81.48 days.

However, a study by Saeed et al., (2003) found that, through a total all ages population (including adults) in Ontario, Canada, the median length of stay at the two hospitals selected in the study was 9 days, with ranges 1-178 and 1-222 days. The authors found that the overall median length of stay in a psychiatric hospital for a person with a learning disability was 21 days compared to 16 days for a person without a learning disability. Whilst this will undoubtedly include a wide range of illness severity, it is worth noting.

The Massachusetts Acute Care Hospital Quarterly Update (2022), reporting solely on the state of Massachusetts, found that the average length of stay for autistic children and young people in acute care (ages 2-17) spectrum disorders, in the second quarter of 2022, was 9.9 days with 11.9 days being the average for children (ages 2-17) with a learning disability. Of note though, this is for children who have a diagnosis of autism and were admitted for any reason for acute care, not just psychiatric reasons.

That being said, the data does show that for the condition with the longest mental health stay in the data (schizophrenia), for children under 17, averaged 16.8 days in 2021.

Finally, Siegel et al (2011) found that, across the United States, in inpatient units for autistic children and young people and developmental disorders (aged 4-21 years old) the average length of stay was 42.3 days, with a range of 12-135 days. Furthermore, once the "outlier" of 135 days was removed, the average duration of stay dropped to 30.75 days - a significantly shorter length of stay compared to that in England. Allison et al., (2018) noted that there has been a trend to decrease inpatient bed numbers in the US and Canada, and that this may be contributing to a "revolving door" approach to mental health care, where people are admitted, stabilised and then as quickly as possible discharged. The shortage of beds may therefore be in part responsible for the shorter duration of admission, however, with Germany also recording shorter overall average length of stays and yet presenting with the most bed availability, it is likely a balance between bed provision, severity required for admission, and overall supports outside of hospitalisation could be met in order to ensure adequate resources are available to match the need. Furthermore, it is not clear whether the indications for admission, and severity of presentations, in these international comparators are comparable with those in England.

Length of Stay: Summary

Length of stay varies across all countries in this report, with England demonstrating the longest stay with a mean average of 72 days for Child and Adolescent Mental Health Services (CAMHS) in general, and between 182 – 365 days for autistic children or children with a learning disability. Scotland records 50 days as a mean average for CAMHS in general, with 180-365 days as the average for those with a learning disability or who are autistic. The average length of stay for all CAMHS admissions in Germany is around 34.4 days, whilst for autistic children this is slightly lower, between 5.4 to 31.6 days (increasing in average length with age). In the US, various studies have suggested that autistic children experienced a length of stay between 3 and 163 days, with 25.6 – 30.75 days being the average whilst in Ontario,

Canada, studies have suggested a range between 1 and 122 days, with the average being related to the type of in-patient restraint (if any) an individual experienced. Regardless, the average has been suggested at being approximately 21 days for a person with a learning disability, and 16 days for those without.

In sum, the length of stay in England is the longest of the five countries in this report, however, it also has one of the lowest CAMHS bed-to-population ratios (bar the US, although overall US data does not include their extensive private sector provision). It may therefore be the case that due to lower bed capacity, the complexity of illness required for hospitalisation may be greater in England than in other countries, thus resulting in fewer but longer admissions. **Further work is required to investigate outcomes and admission criteria for each region to better determine the reasons for differences in length of stay**.

England

In England, restraint and restrictive practices may be used in inpatient mental health hospitals for autistic people with or without a learning disability if it is necessary to ensure the health and wellbeing of the patient, and/or to manage risk to those around them. According to the UK Government report "Reducing the Need for Restraint and Restrictive Intervention (2019)", restrictive interventions and restraint include (depending on the circumstances):

- Physical restraint: a direct intervention which involves physical contact where the intention it to prevent, restrict, or subdue movement of the body (or part of the body) of another person.
- Restricting a child or young person's independent actions, including the removal or aids such as walking sticks, or including threats involving restraint to curtail a child or young person's freedom of action.
- Chemical restraint: the use of medication for the purpose of controlling or subduing violent/disturbed behaviour.
- Mechanical restraint: the enforced use of aids such as belts, cuffs, or other restraints to forcibly control the child or young person's movement.
- Withdrawal: removing a child or young person involuntarily from a situation. This may be one that causes them anxiety or distress (or causes this to others) and taking them to a safer location.
- Seclusion: the supervised confinement and isolation of a child or young person away from others in a place where they are prevented from leaving.
- Segregation: stopping the child or young person from mixing freely with others on a longer-term basis.

The number of children and young people who experienced a restrictive intervention and were in contact with NHS-funded secondary mental health, learning

disabilities and autism services in 2020-2021 was 569, of which there was a total of 23,258 restrictive interventions of all types.

General population

For the latest available data at the time of writing (July 2022 LDA monthly statistics MHSDS) there were 280 children and young people (of all diagnoses) subjected a diagnosis of a learning disability or autism subject to a restrictive intervention, with 23,258 instances of restrictive interventions. 'Physical restraint – seated,' the most commonly occurring type of restraint for under 18s with a diagnosis of autism and/or a learning disability, was used 1,600 times in July 2022. It is important to note that 2,368 of these instances were 'physical restraint – prone', even though section 26 of the 2016 Mental Health Act (1983): Code of Practice states that other options such as de-escalation "must" have been utilised with compelling justifications for the use of restraint in a prone position. For contrast, whilst the recording of restraint differs across the world, and therefore direct comparisons should be taken with caution, England was recorded to have the highest recorded use of restraint per 10,000 occupied bed days (OBD) population in CAMHS, with 1,308 used per 10,000 in 2022. This compares to 600 per 10,000 OBD in Wales, the second highest recorded out of the 16 countries profiled, and a mean of 569 used per 10,000 OBD. For the use of seclusion (again, with differing definitions), England recorded 92 uses per 10,000 OBD, second only to Australia at 95 uses per 10,000 OBD. The mean across all regions was 78 uses per 10,000 OBD (NHS Benchmarking Network, 2022).

Autistic Children and Young People and those with a Learning Disability

In England, NHS hospitals (and private institutions/charitable sector hospitals that provide NHS funded care) are required by law to record the use and frequency of restrictive practices via the Mental Health Units (Use of Force) Act of 2018. In July 2022, there were 70 under 18s with a diagnosis of autism and/or a learning disability subjected to restrictive interventions out of 205 people under 18 with a learning disability

or autism in hospital, with a total of 1,030 incidences of restraint used (July 2022 LDA monthly statistics MHSDS). This equates to 34% of the population of children and young people in hospital being subjected at that time to restrictive practices being children or young people with a diagnosis of autism and/or a learning disability. The most common methods of restraint in July 2022 were recorded as either 'physical restraint – standing' (275) or 'physical restraint – seated' (285). 'Physical restraint – supine' was recorded 140 times, with 'seclusion' being used 75 times. All other types of restraint accounted for less than 65 instances of use. When compared to the general CYP population, 34% of 'physical restraint – standing', 26% of 'physical restraint – supine', and 18% of cases of 'physical restraint – seated' involved young people with either autism or a learning disability diagnosis.

Scotland

General population

In England, mental health hospitals and services are required, by law, to record all incidents of force used on patients, whereas in Scotland this is not a legal requirement. As such there is a lack of available data on restrictive practice in Scotland despite calls from the Scottish Human Rights Commission for reliable data on restraints to be routinely published and analysed. Irrespective of the lack of statistical information available, reducing the incidence of restraint is viewed as an area of "national interest" in Scotland, led by the Patient Safety Programme (A Review of Mental Health Services in Scotland: Perspectives and Experiences of Service Users, Carers and Professionals, 2016).

Autistic Children and Young People and those with a Learning Disability

Despite a lack of data around restrictive practice in mental health services, a 2018 investigation into restraint and seclusion in Scottish schools (included here as an indication of the use of restraint and seclusion in Scotland in the absence of other data) concluded that restrictive practices were being used inappropriately and were disproportionately used on disabled children (No Safe Place: Restraint and Seclusion in

Scotland's Schools, 2018). Following this investigation, the Scottish Government agreed to produce national guidance aimed at not only reducing incidents of restraint and seclusion but also ensuring any incidents are accurately recorded. A draft version of this report was published in June 2022 which sought consultations on the document, including enhancing the recording, reporting, and monitoring of the use of restraints in schools. This consultation is ongoing at the time of writing.

Germany

General population

In Germany, much of the literature uses the term 'coercive measures' rather than restrictive practice. Coercive measures are defined as any measure which restricts the young person's freedom of movement against their will over extended periods of time with medication, mechanical or other methods which they are unable to overcome without assistance. Geissler et al (2021) note that there are no large-scale studies in Germany looking into the frequency of coercive practices in inpatient psychiatric units. Following the amendment to the §1631b BGB law in 2017, a German law governing adolescent and child mental health care, institutions are however now legally required to obtain permission and supervision from family courts for the use of coercive measures in care (Geissler et al., 2021).

Autistic Children and Young People and those with a Learning Disability

Following concerns in the German media of excessive use of coercive measures, law §1631b BGB came into force at the end of 2017 which made parental consent mandatory before residential units for children and adolescents with intellectual or developmental disorders in Germany were able to subject young people to coercive measures (Geissler et al., 2021). Prior to this law, residential institutions had full decision-making power on this. The authors found that this law had not statistically significantly reduced the prevalence of coercive measures in such institutions in the German Federal State of Bavaria compared between 2017 and 2019. However, the authors noted that a small percentage of children (out of a population of 1,661 in 2017

and 1,673 in 2019) were affected by any type of coercive measures. The most frequently being the use of Kayser beds (which resemble cots with moveable sides to restrict movement/getting out of them, and thus a restriction of movement) with 10% in 2017, 7.7% in 2019. No other coercive measure was used for more than 5% of children in care. In this study, medication was not seen as a strictly coercive measure as it is also medically necessary, however the use of this also decreased from 18.9% in 2017 to 14.4% in 2019. This is a smaller percentage of instance of restrictive practices than is recorded in England, all be it within a much larger general population (there are around 84 million people in Germany compared to 56 million in England).

US and Canada

General population

Green-Hennessy & Hennessy, (2015) investigated the use of seclusion and restraint in all US residential treatment centres for children and adolescent mental health services. 88.8% of these institutions responded and the study found that 82% used seclusion and/or restraint. However, there was no data provided on the number of patients affected by these practices and there was no record of the number of incidents

A study by Donovan et al (2003) found that, from a population of 442 children and young people (aged 5 – 11 years old) who were inpatients at a psychiatric hospital in Connecticut, 61% experienced seclusion at least once and 49% experienced physical restraints at least once. They found that children under 11 years old were more likely to undergo seclusion and that children who were admitted on an emergency basis or who belonged to an ethnic minority group were more likely to undergo seclusion or restraint.

In 2000, in response to mounting pressure to respond to increasing number of deaths of patients in psychiatric hospitals, the US federal government passed legislation to reduce the amount of, types of and use of restrictive practices in all federally funded hospitals (NAMI, 2000).

Stewart et al (2013) evaluated data collected from information on the use of restrictive measures in a child and youth (ages 6-18) treatment centre in Ontario,

Canada found that 48.8% of patients were subjected to chemical restraint, 42.3% subjected to physical restraint and 39.3% experienced seclusion. This study found that developmental disabilities increased the risk of being subjected to restrictive practice in this sample (Mah et al, 2015). Stewart et al., (2013) also noted that the use of restrictive practices (restraint and seclusion specifically) was more likely to occur in the first few days of admission, with Fishel et al., (1994) finding that 80% of patients to a child/youth (under 18) mental hospital received psychotropic chemical restraint during their first 4 days. In addition, Dosreis et al (2010) found that the time taken for a restrictive practice to occur was significantly and positively related to the time the child/young person spent in the psychiatric hospital ward.

Autistic Children and Young People and those with a Learning Disability

Evidence from New York, USA, suggests that 50% of autistic children, 68% of children with a learning disability, and 78% of children with a diagnosis of both a learning disability and autism experience either restraint or seclusion whilst hospitalised, compared to 35% of children with neither a diagnosis of autism nor a learning disability. Likewise, evidence from Ontario, Canada suggests that children with developmental disabilities are 4.8 times more likely to experience chemical restraint whilst in hospital compared to the general population, with 50% of males and 53% of females with both mental health and developmental disabilities receiving at least one restraint, compared to 35% and 18% of the general population, respectively. O'Donoghue et al., (2020) noted that, in one psychiatric hospital in New York in the US, 52% of pre-adolescents ages 5-12 experienced at least one restraint or seclusion whilst hospitalised. When broken down into groups, 35% of children with neither a diagnosis of autism or a learning disability experienced a restraint or seclusion, 68% of children diagnosed as having a learning disability experienced at least one restraint or seclusion, and 78% of children with both a learning disability and autism experienced at least one restraint or seclusion. 50% of children who had only a diagnosis of autism experienced at least one restraint or seclusion. Likewise, Stewart et al., (2013) reported, in their analysis of child and youth (aged 6-18 years) mental health inpatient hospitals in Ontario, Canada, that

the odds of receiving chemical restraint were 4.8 times higher for children with developmental disabilities compared to those without. 50% of males with both mental health and developmental disabilities received at least one physical restraint compared to 35% of males with no developmental disability. Furthermore, approximately 52% of females with both mental health and developmental disabilities received at least one incident of seclusion compared to 18% of females with no recorded developmental disability.

Salvatore et al (2021) notes that the use of restrictive practices in US hospital, school and residential settings is “common”. However, several initiatives in the US are currently underway to attempt to reduce the frequency of these practices, as outlined previously, which seek to increase protection of children with health care needs, including those with a diagnosis of autism, and to increase research funding into autistic needs. As noted previously, in the US and Canada there are limited federal laws regarding the implementation and use of restrictive practices, and limited data collection on a federal level about their use in hospital settings. As such, national data available to the authors of this report is limited. However, a report by the U.S. Department of Education Office for Civil Rights (2016) noted that, between 2013-14, students in American schools with a learning disability made up about 12% of the population but comprised 67% of the students who experienced restraint or seclusion.

Use of Restrictive Practices: Summary

Restrictive practice definitions vary across the world. Likewise, the accuracy and completion of recording on their use varies, even within regions that have enacted legislation to attempt to ensure their accuracy. With that in mind, we can summarise the following:

The use of all restrictive interventions is shown to be more common in populations of children and young people with a learning disability and/or autism, in contrast to the general population. For example, in England, about 58% of children or young people in CAMHS hospitals are autistic or with a learning disability, and 34% of

all recorded ‘physical restraints – standing’ involved an autistic child or young person or a child with a learning disability. Although intended to reduce risk, there may be harms associated with restrictive practices: the Reducing Restrictive Intervention of Children and Young People report (2019) by the British Association of Social Workers (BASW) in the UK found that 58% of families whose disabled child experienced restraint said that it led to a physical injury, 91% said it had resulted in an emotional impact on their child, including incontinence, meltdowns, and shutdowns, and 78% of families stated that the use of restrictive interventions had made their child’s behaviour worse. The report also noted how 84% of parents want to see greater accountability for harm caused by restrictive practices.

In England and Scotland, restrictive practices are currently used in hospital settings, with around a quarter of all instances of restrictive practices used on children and young people with a learning disability or autism. This is higher than many comparable countries, with the NHS Benchmarking Network (2022) noting that England recoded significantly higher uses of restraint in CAMHS than other comparable countries in its data set with 1,308 uses per 10,000 Occupied Bed Days (OBDs) for England, compared to Wales, the second highest frequency, at 600 uses per 10,000 OBDS, followed by Australia third with around 300 uses per 10,000 OBDS. When restrictive practices of restraint were separated from seclusion, Australia recorded 95 uses of restraint per 10,000 OBDS (as the highest frequency of use recording country) with England at second, with around 93 per 10,000 OBDS). A Caveat of this is that England combined forensic beds with other forms of hospitalisation beds to compile their data, which may not be the case for the other reporting nations.

Recommendations and Implications for Policy and Practice

The CQC, in the 'Restraint, Segregation and Seclusion Progress Review: March 2022' (2022) noted that none of their recommendations from their 2020 report had yet been fully implemented, and that in the 2 years since, state; ""Restrictive interventions continue and are often used inappropriately when people communicate their distress and unmet needs. There are more people in long-term segregation now than there were in 2019." A systematic review of interventions aimed at reducing the frequency of restrictive practices in various countries around the world noted that a variety of interventions for groups settings reduced, or even eliminated, restraint and other restrictive practices within 6-24 months of application (Sturmey, 2018). The author noted that 1) packages of organisation reform, target setting, training for staff and feedback from patients 2) interventions held in community settings prior to hospitalisation, 3) mindfulness and positive behaviour support, and 4) interventions in schools which included goal setting, organisational reform and feedback, all contributed to reduced need for and use of restrictive practices in the studies that were looked at. Sturmey (2018) noted that the use of restrictive practices with autistic individuals and those with a learning disability is problematic in that it has been demonstrated to be dangerous (for both patient and staff), is dehumanizing and, in rare unfortunate cases, is lethal. This is a demonstrable concern of Parliament, and the House of Commons Health and Social Care Committee published the Treatment of Autistic People and People with Learning Disabilities (2021) calling for greater investment in local community services with the aim of reducing the need for, and even eliminating entirely, long term admission and inpatient psychiatric hospitals for people with a learning disability and autistic people, to be replaced with community care and supports.

As awareness around autism increases, so do the levels of diagnoses and the rate of people seeking diagnosis for either themselves or others. Across all countries, admission to hospital for autistic children and young people is shown to be greater than for children from the general population, and the use of restrictive practice is more likely amongst this group. Simultaneously, across all the regions investigated in this deep

dive, efforts to reduce admission rates and reduce the frequency of restrictive practices can be found, with apparent varying success, in so far as they have been measured. Legislation to ban the use of restrictive practices have been utilised to dramatically decrease the frequency of restrictive practices in Massachusetts, whilst Germany has begun to enact policies to increase the focus on community care in order to attempt to decrease the length of stay in hospital and the rate of admissions in general. Within the UK regions, data shows a greater similarity in length of stay, admission rates and the use of restrictive practices, all be it with differing legislation in place. As data are not always directly comparable between different countries or regions, it is difficult to draw definitive conclusions, however, with the data that is available we can draw several tentative conclusions:

1. With some exceptions in North America, there are fewer inpatient beds per head of population in England than in other comparable regions, particularly in Europe.

2. Admission duration appears to be longer in England than in other countries. The lengthy admission duration may be due to a higher threshold for admission resulting in inpatients being more unwell and requiring longer periods of care than in other areas. Without sufficient data to determine severity of symptoms and other clinical features, this can however only be inferred in this report.

3. Based on the evidence outlined in the report above, and the general discussion in research publications, it seems likely that a reduction in admissions in England would require improving care options outside of hospital for those children and young people at higher risk of admission and the most severe need for hospitalisation. It may also result in an increase in bed stays if community options are not implemented alongside reductions in bed availability, and as the US experience suggests, a risk of increased “revolving door” admissions.

4. For those autistic children and adolescents who require admission, specialist inpatient units (a model used in some states in the US) could be considered, but such services are likely to be rare. However, it is presently unclear whether without significant adaptations, mainstream CAMHS wards currently may be ill-equipped and unsuited to autistic children. The best model of in-patient care for autistic children and adolescents in terms of patient experience and clinical outcome needs to be determined.

5. There are indications that certain factors increase the likelihood of admission to hospital suggesting that proactive supports when the need is high, and better treatment of co-occurring conditions in the community, could result in lower admission rates.

6. The use of restrictive practices around the world varies significantly, but there is emerging evidence that reducing the frequency of their use supports better outcomes for patients and a safer environment for both patients and staff. This seems to be from a combination of both reducing the use of restrictive practices and by also reducing the need for restrictive practices. By examining places where legislation and practice has resulted in successful reduction of use and outcomes, ideas for improvements can be made for the care system in England.

Conclusion

Further improvements can be made regarding hospital admissions and the use of restrictive practices in England (see recommendations), including the implementation of the recommendations and findings as outlined in reports such as the CQC “Out of Sight, who cares?” and the National Autism Strategy for Autistic Children, Young People and Adults: 2021 to 2026. Further efforts to both improve access to supports closer to, or within, the person’s home, as well as to increase training and awareness to limit restrictive practices, is therefore an area worth investigating. The National Strategy for Autistic Children, Young People and Adults: 2021 to 2026, outlines a number of proposals for increasing outpatient support and community supports for autistic children and young people, with a target to reduce the number of autistic people and people with a learning disability in inpatient psychiatric units by 50% by 2023-2024 compared to pre 2021 figures. Whilst work is ongoing, further efforts for community interventions could be implemented, including the expansion of outreach supports to better enable autistic young people and those with a learning disability to get the support and care they need at home. The policies implemented by Scotland (the Children’s Panels) in increasing engagement with people directly regarding their care, and by those states that have implemented legislation to restrict and reduce the use of restrictive practices, are also areas where NHS England could consider further research. The provision of beds in relation to the population size is also an area of further research, alongside strengthening of community supports.

Regarding the higher recorded use of restraint in England compared to other countries, this must be viewed in tandem with the lower bed capacity and the longer length of stay. Presumably, this would suggest that in England the threshold for hospitalisation is greater than in comparable countries, resulting in more severe and complex cases being admitted. This in turn would presumably result in longer hospital admission duration itself, along with a more increased risk of the use of restraint. However, in this report, outcome measures, as well as hospitalisation thresholds, were not directly obtainable within the report scope. Further work to compare the requirements for admission, on an international level, including severity and expected

outcomes, could be prudent. In addition, further work to determine international comparability regarding community and home supports, with the intention to reduce the requirement for hospitalisation, would be useful. Finally, a contrast of resource allocation, in relation to preventative vs responsive treatment, could be illuminating.

One notable area where NHS England is performing exceptionally strongly is in the availability of public access data and statistics. NHS England has developed transparent and accessible data collection regarding the use of restrictive practices and hospitalisation in children and young people than in comparison to many other countries, which has allowed for a greater ease of examination of data and identification of areas of success and improvement. The openness of the data and the access provided to the public and researchers is valuable, and it was notable how often it was referenced in many papers around the world, and is something to be commended now, and expanded upon, in future years.

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