

Feature

Long-term segregation and seclusion for people with an intellectual disability and/or autism in hospitals: critique of the current state of affairs

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In November 2023, the Department of Health and Social Care published guidance, entitled ‘Baroness Hollins’ Final Report: My Heart Breaks – Solitary Confinement in Hospital Has no Therapeutic Benefit for People with a Learning Disability and Autistic People’. The report’s commendable analysis of the problems and identification of the areas where practice should be improved is unfortunately not matched by many of its recommendations, which appear to be contrary to evidence-based approaches. The concerns are wide-ranging, from the use of the term ‘solitary confinement’ for current long-term segregation (LTS) and seclusion, to presumption that all LTS and seclusion is bad, to holding clinicians (mainly psychiatrists) responsible for events beyond their locus of control. Importantly, there is a no guidance on how to practically deliver the recommendations in an evidence-based manner. This Feature critically

appraises the report, to provide a comprehensive summary outlining potential positive impacts, identifying specific concerns and reflecting on best practice going forward.

Keywords

In-patient treatment; human rights; intellectual disability; neurodevelopmental disorders; autism.

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In November 2023 the Department of Health and Social Care released a report on solitary confinement and people with intellectual disability (also known as learning disability in UK health services) and/or autism.¹ As stated in the report, ‘the Independent Care (Education) and Treatment Review (IC(E)TR) programme reviewed the care and treatment of 191 people who were detained in long-term segregation between November 2019 and March 2023’.¹ The report was developed following concerns about several informed findings from these reviews, including a lack of therapeutic benefit, iatrogenic harm, diagnostic overshadowing, trauma secondary to the hospital environment, and a lack of access to and involvement in care decisions from patients’ families/friends. The report’s commendable analysis of the problems and identification of the areas where practice should be improved is unfortunately not matched by many of its recommendations, which appear to be contrary to evidence-based approaches. Table 1 provides a summary of the report’s recommendations, with our analysis of their strengths and weaknesses.

Premise of the report

The report’s title labels long-term segregation (LTS) and seclusion as ‘solitary confinement’, a term generally used in prisons. The terminology is itself confusing as it is not defined in English law, but has made its appearance in various parliamentary committee meetings and government publications.

However, it is universally recognised that solitary confinement is inherently punitive. It indicates that the prisoner is being denied any active interaction/engagement with others, often because of a violent act. Although LTS and seclusion in healthcare settings is often initiated because of the threat of violence toward others, it does not preclude active engagement with staff. Patients under LTS may spend significant periods of the day with others, including healthcare professionals and family members, as well as accessing community opportunities (including hospitals and schools) through escorted leave (Appendix 1). The blanket assertion

in the report summary, that all LTS and seclusion is solitary confinement that has no therapeutic benefit, is not evidence-based.

A systematic review on the use of seclusion and restraint in adult psychiatry⁵ found a mixed picture among eligible studies. Fourteen studies reported negative effects of seclusion and restraint, four reported beneficial effects and 17 reported negative and beneficial effects. Unfortunately, there has been no similar research involving people with intellectual disability and/or autism, which is imperative for evidence-based policy.

Many people with intellectual disability and/or autism can find the presence of others in their living environment challenging. In such situations, it is the absence of appropriate community health and social services that results in their admission to hospitals.⁴ Once that happens, what in the community could be labelled as single-person accommodation becomes LTS in a hospital setting. It is also worth recognising that people with intellectual disabilities are often expected to live in group settings, which may not be conducive to their behavioural/mental health. This is in contrast to the general population, where the choice to live alone is increasing.² To equate the need for solitude within a busy ward environment, while living alongside peers that one has not chosen, to solitary confinement, is not representative or equal.⁴ These nuances have not been captured in the report.

Definitions for LTS/seclusion and solitary confinement are provided in Table 2. The report summary, as well as Recommendation 9 in the main report, recommends that all instances of enforced social isolation, including LTS/seclusion, should be renamed ‘solitary confinement’. In practice, the widely accepted definition of what solitary confinement constitutes is derived from the United Nations Standard Minimum Rules for the Treatment of Prisoners (the Nelson Mandela Rules) (Table 2).⁶ This is markedly different from the experience of people with intellectual disability and/or autism in LTS/seclusion, where contact with healthcare professionals is regular, and any segregation usually relates more to isolation from fellow patients rather than human contact more generally. These are governed by clear policies and legal frameworks from supporting hospitals, and monitored internally and externally.

Table 1 Summary analysis of the recommendations in Baroness Hollins’ final report			
Number	Recommendation	Strengths	Weaknesses
1	All staff working with people with an intellectual disability and/or autism should be delivering therapeutic and human rights-based care.	This is consistent with the fundamental role of intellectual disability psychiatry professionals.	Not applicable.
2	Practice leadership should be improved by commissioners of services for people with intellectual disability and/or autism undertaking the following training: tier 2 of the Oliver McGowan Mandatory Training or equivalent training on tier 2 capabilities from the Core Capabilities Frameworks, and the HOPE(S) model.	We agree that such training of commissioners is important, but further research is required to determine what training package best meets this need.	Not applicable.
3	Professional bodies should issue good practice guidelines on the assessment and treatment of people with an intellectual disability and/or autism in solitary confinement.	We are in broad support of the development of good practice guidelines, and that such guidelines could be further supported by having a corresponding outcomes framework that measures guideline adherence.	Unclear regarding how clinicians would be held accountable and the corresponding consequences. An example the report gives is ‘failing to develop a clinical environment that does not rely on enforced isolation in solitary confinement’. However, this is not the sole responsibility of the clinician. Within the recommendation, it is implied that withholding Section 17 leave is occurring with punitive (rather than therapeutic) intent.
4	Everyone in solitary confinement must have access to independent specialist trained advocacy, specialist free legal advice and a redress scheme must be available to them.	We agree that people with an intellectual disability and/or autism should have access to independent specialist advocacy, particularly where there are no friends or family members able to advocate for them.	The term ‘redress’ implies that patients have been wronged by virtue of being placed in seclusion and/or LTS, despite such practices being codified in the Mental Health Act Code of Practice. ²
5	Solitary confinement for people with an intellectual disability and/or autism should become ‘never events’ in the following instances: for children and young people under 18 years of age; where it does not meet minimum standards for adults; where it lasts for longer than 15 days.	We would agree that seclusion and LTS events require oversight and review, with subsequent learning to examine the decisions made and reduce the likelihood of future occurrence where achievable.	Seclusion and LTS are not always entirely preventable, and thus do not meet the NHS England ³ definition for never events.
6	Solitary confinement should become a notifiable event to the CQC as well as to the ICB executive lead for intellectual disability and autism and the provider board. The notification should be made within 72 h of a person entering solitary confinement.	Not applicable.	LTS is currently notifiable to commissioners and should be undertaken at the earliest opportunity – it is unclear how this recommendation differs from current practice.
7	Before admission, clinical contracts must be agreed between commissioners and hospital managers regarding the services for people with an intellectual disability and/or autism being commissioned. These clinical contracts should be outcomes based and include the responsibility of local services, including community clinicians and hospital clinicians, to collaborate to achieve timely discharge.	The collaboration of hospital and community professionals in achieving timely discharge is vital, and should already be happening. However, the availability of appropriate specialist community placements is also instrumental in ensuring that patients are discharged from hospital in a timely manner.	Contracts may not be able to be drawn up in a timely fashion, particularly if patients are admitted in an emergency. Furthermore, a patient’s progress when in hospital cannot be predicted at the point of admission, and if such clinical contracts were breached what would be the resulting consequences?

(Continued)

Table 1 (Continued)

Number	Recommendation	Strengths	Weaknesses
8	<p>To protect those in solitary confinement, safeguarding processes must be strengthened by:</p> <ul style="list-style-type: none"> – ensuring that patient, relative and staff voices are acted on immediately when a complaint or concern is raised – the CQC's 'closed cultures' guidance should be reviewed to see if the guidance remains fit for purpose – family members and advocates should be able to visit those in solitary confinement at any time of day or night if they consider it necessary, in the environment in which they are living – family members need to be provided with information about how to raise a safeguarding or other concern, including having contact details of the responsible commissioner for the hospital placement – current protections for whistle-blowers should be reviewed to ensure protections are adequate and fit for purpose – a safeguarding register should be maintained and shared on an agreed frequency, with the CQC documenting indicators of poor care and treatment – the CQC should make greater use of covert surveillance in a way that does not add to the power imbalance between the staff and patients that already exists. Blanket use of technological surveillance must be regularly reviewed to ensure it continues to meet the principle of least restrictive and remains rights-respecting. 	We support the review of protections for whistle-blowers.	The authors do not agree with the assertion that 'family members and advocates should be able to visit those in solitary confinement at any time of day or night if they consider it necessary'. Such visits may not always be in the best interests of the patient, risk being disruptive to other patients and places an unrealistic demand on services.
9	Both LTS and seclusion of people with an intellectual disability and/or autism are renamed 'solitary confinement'.	We feel that this proposed change in terminology comes from a place of concern for people with intellectual disability and/or autism who are placed in seclusion or LTS, which does require ongoing oversight and scrutiny.	We disagree with the proposed change in terminology, as neither seclusion nor LTS satisfy the definition of solitary confinement according to the United Nations. ⁴
10	The government must publish an annual report on the progress toward ending the use of solitary confinement for people with an intellectual disability and/or autism.	We would welcome this recommendation.	It would be helpful for the authors to expand on the proposed contents of these reports. Furthermore, the report should have balanced views of the patients, loved ones and professionals involved.
11	To prevent admission or readmission into hospital at times of acute distress where the community support services do not meet a person's immediate needs, we recommend: alternative accommodation to hospital should be available within each ICS area in times of acute distress, or emotional and behavioural crisis, and to facilitate earlier discharge; commissioners should undertake pilots and evaluate the effectiveness of 'intensive recovery pods' (homely places of safety in the community) that are autism friendly, trauma informed and where the person and those supporting them feel safe.	If appropriately implemented, there may be a role for alternative accommodation/ intensive recovery pods for patients at times of acute crisis.	We are concerned that intensive recovery pods may end up becoming effectively community-based hospitals, without the safeguards of a hospital.

(Continued)

Table 1 (Continued)			
Number	Recommendation	Strengths	Weaknesses
12	The DHSC, NHS England and CQC should commit to funding and delivering interventions to reduce the use of solitary confinement and move people to the least restrictive setting and out of hospital as soon as possible.	We support the intentions of minimising use of seclusion and/or LTS and facilitating timely discharge.	The role of the discharge coordinator is defined as someone 'who enters solitary confinement to help monitor the implementation of their therapeutic plan and manage both their discharge out of hospital and their rehabilitation in the community'. This defines their role vaguely, as well as the required qualifications and experience to fulfil such a role. This risks creating ill-defined roles open to a high degree of interpretation. Furthermore, for detained patients, discharge approval ultimately lies with the responsible clinician. We would have concerns about a situation where anyone other than the responsible clinician has the final say on discharge without being accountable for this (i.e. being able to sign the relevant paperwork to discharge the patient from their section).
13	Anyone who has been in solitary confinement should be monitored for 2 years following discharge from hospital to ensure changes are sustainable and they are receiving good community support.	We agree that patients who have been placed in seclusion and/or LTS stand to benefit from ongoing monitoring post-discharge.	We would suggest that this time period of monitoring should be for a minimum of 5 years.
HOPE(S), Harness Opportunities Protective Enhance (System); LTS, long-term segregation; CQC, Care Quality Commission; ICb, integrated care board; DHSC, Department of Health and Social Care.			

Table 2 Definitions for key terms	
Term	Definition
Solitary confinement	'The confinement of prisoners for 22 h or more a day without meaningful human contact'. ⁶
Seclusion	'The supervised confinement and isolation of a patient, away from other patients, in an area from which the patient is prevented from leaving, where it is of immediate necessity for the purpose of the containment of severe behavioural disturbance which is likely to cause harm to others'. ⁷
Long-term segregation	'Where, in order to reduce a sustained risk of harm posed by the patient to others, which is a constant feature of their presentation, a multi-disciplinary review and a representative from the responsible commissioning authority determines that a patient should not be allowed to mix freely with other patients on the ward or unit on a long-term basis'. ⁷

The report rightly recognises the aetiological role of trauma in hospital admission, with further LTS/seclusion being potentially traumatic interventions in themselves. However, there is little evidence for the assertion that ‘trauma is usually at the root of the exclusions that eventually lead to hospital admission, and for too many people, to solitary confinement’.

There is good evidence of the bi-directional relationship of trauma and mental illness, and in many instances the role of the illness itself cannot be excluded; thus, LTS/seclusion should not be seen solely in isolation through the prism of trauma. It is worth pointing out that many other forms of restrictive practices exist to manage high-risk incidents, such as physical restraint, mechanical restraint and rapid tranquillisation, all of which can in theory predispose, precipitate or perpetuate trauma. Indeed, evidence from the adult psychiatry systematic review⁵ suggests that seclusion appears to be better accepted when compared with other coercive measures, such as forced medication and restraint. All of these interventions are balanced on risk analysis principles of affording immediate safety to the distressed individual and others. An understanding of the balance between short-term risk management and the longer-term harm in trauma perpetuation is needed, and a research call on this would have been welcome.

Various factors are considered when LTS/seclusion is used to manage extremely aggressive behaviour that poses a risk to others, including staff and fellow vulnerable patients. The Mental Health Act (MHA) Code of Practice definition⁷ states that if a patient’s constant feature is a sustained risk of harm posed to others, then they should not mix freely with other patients on the ward/unit on a long-term basis. If the risk to others is not ameliorated by other forms of treatment, including short periods in designated places of safety on the unit under seclusion policy, other patients or staff might be vulnerable to potentially serious injury or harm. Furthermore, if such incidents were to occur, this could compromise the chances of the patient being offered a service by community care providers and achieving suitable discharge from hospital.

The Nuffield Trust reported that in 2022, ‘2.1% of [NHS staff] respondents in mental health and learning disability Trusts said they had experienced violence from patients and the public more than 10 times in the past 12 months’.⁸ Although not directly related to LTS and seclusion issues, this raises concerns about other vulnerable patients and staff safety. Violence toward staff and other patients could put the treating clinicians in breach of the Code of Practice. Hence, the utilisation of LTS in these situations to manage potential risks is a difficult and nuanced clinical decision made by the multidisciplinary team.

If the report’s recommendations (Table 1) were implemented, it raises concerns of the management of patients who present with

severely aggressive behaviour when LTS and seclusion are not available options to manage risk. Perversely, this could lead to increased likelihood of using other restrictive practices such as restraint, psychotropic medication prescribing or even forseniscation.⁹

The assertion that LTS and/or seclusion has no therapeutic benefit for people with intellectual disability and/or autism might not be true for all cases. For example, some patients have sensory integration difficulties¹⁰ and the low-stimulus environment provided through LTS/seclusion can provide necessary and therapeutic reduction in sensory stimulation during intense distress (Appendix 1). It is anecdotally recognised in clinical circles that certain patients do escalate their behaviour to achieve the sensory relieve/solitude afforded by LTS, and sabotage efforts of reintegration – especially as current mainstream psychiatric units are poorly equipped for these needs.³ Further evidence is required to assert specific harms of LTS/seclusion.

Specifics of the report

Report Recommendation 3 states that ‘clinicians should be held accountable when they fail to follow these good practice guidelines’, without being clear as to how the clinicians would be held accountable and what the potential consequences would be. The report subsequently cites an example of such a failing being ‘found to have used punitive measures such as the withholding of section 17 Mental Health Act 1983 leave’. This statement implies that withholding Section 17 leave could be done with punitive intent. However, in clinical practice, Section 17 leave decisions should be made in accordance to the MHA Code of Practice,⁷ with full discussion and input from the multidisciplinary team. It is part of the robust treatment and risk management plan that has independent oversight. Any divergence from the MHA Code of Practice can be challenged at the level of the individual case in the already well-established clinical–legal framework. It is disappointing that the report appears to claim professional misconduct without basis by practicing clinicians. Professionals remain accountable with professional regulatory bodies, and if there are concerns about misconduct in an individual case, there should be a referral made to the relevant regulatory body. Additionally, in the case of patients detained under sections within Part 3 of the MHA (the forensic sections), it may be the Ministry of Justice who are effectively withholding permission to grant Section 17 leave.

The report also proposes that clinicians should be held accountable for ‘failure to develop a clinical environment that does not rely on enforced isolation in solitary confinement’. First, the need for seclusion or LTS may not be a consequence of the clinical environment. Indeed, the risks that led to isolation may have preceded their hospital admission. Second, admission to hospital may be the result of placement breakdown in the community (for example, because of physical and/or sexual aggression¹¹), or the lack of suitable community care. Furthermore, although the responsibility to create the therapeutic environments is a collective responsibility of clinicians, organisations and integrated health and social care systems, it depends fundamentally on the actions of funders who commission services in the community and hospitals. This statement in the report carries the risk of scapegoating clinicians for issues that are outside their locus of control. It invariably would discourage clinicians from working within hospital settings, leading to a loss of clinical expertise and worse outcomes for an already vulnerable patient group.

Recommendation 4 refers to a ‘redress scheme’ for everyone placed in seclusion or LTS. The Cambridge Dictionary¹² defines redress as ‘to put right a wrong or give payment for a wrong that has been done’. Such a scheme heavily implies that any patient being placed in LTS or seclusion has been wronged in some way,

despite healthcare professionals undertaking such practice to keep the patient and others safe. Furthermore, although a decision to place a patient in LTS/seclusion should never be taken lightly, both treatment approaches are legislatively codified,⁷ particularly to address the needs of high-risk patients with complex needs, where there are often no easy interventional options.

Recommendation 5 states that ‘solitary confinement for people with learning disabilities and/or autistic people should become “never events” for children and young people under 18 years of age, where it does not meet the minimum standards for adults, and when it lasts longer than 15 days’. NHS England defines never events as ‘serious incidents that are entirely preventable because guidance or safety recommendations providing strong systemic protective barriers are available at a national level and should have been implemented by all healthcare providers’.¹³ We would suggest that LTS and seclusion are not entirely preventable, and there are circumstances where the risk to the patient and those around them are far greater if these approaches are not used in a timely manner. Additionally, the rationale for a young person being placed in LTS and seclusion being a never event and this not being the case for adults appears to be ideological rather than evidence based.

Recommendation 8 states that ‘family members and advocates should be able to visit those in solitary confinement at any time of day or night if they consider it necessary, in the environment in which they are living.’ In principle this is a reasonable expectation. However, some caveats need to be considered. First, this should be subject to the wishes of the patient themselves, with their wishes respected, provided the patient has capacity in relation to this specific decision. Second, this could place an unrealistic demand on services to comply, and could be profoundly disruptive for fellow patients and possibly to the individual themselves. Furthermore, it fails to recognise circumstances whereby the patient being seen by their family may not be in their best interests, such as where they have difficult relationships with their family, where the patient themselves may not want family visits, and in secure settings where there may be a policy in place for family visits to take place outside the patient area to protect both patients and families.

Recommendation 13 states that ‘anyone who has been in solitary confinement should be monitored for 2 years following discharge from hospital to ensure changes are sustainable and they are receiving good community support.’ It is our view that all patients should be monitored regularly after discharge and their care package tailored to their current circumstances. Although those on LTS/seclusion would be more vulnerable, the suggested duration of monitoring post-discharge is arbitrary. An additional concern we have is that commissioners may expect the person to have lower support needs after 2 years, leading potentially to a reduced package of care and subsequent risk of deterioration in their mental health, well-being and corresponding risks. Bespoke placements may also result in patients living on their own, effectively continuing to live in the conditions of LTS/seclusion but without the same safeguards in place within in-patient settings. Often, where people are managed well in the community post-discharge, it is because they have individualised packages of care specific to their needs.^{14,15}

Other related aspects

It is unclear how the membership of the oversight panel was derived. It would be reasonable to expect the membership to be drawn from various professional stakeholder bodies, with a significant proportion being currently practicing expert clinicians, particularly psychiatrists from across the UK, to give relevant insight and perspectives to current practical challenges and conundrums on this issue.

Rates of behavioural incidents and risk scores for people with intellectual disabilities are higher than those without intellectual disabilities in psychiatric in-patient units.¹⁶ It is interesting to note that this is not the result of this population being unfairly treated. Research has shown that those people with intellectual disabilities with similar offence histories and higher risk levels are, at present, being diverted away from the criminal justice system, with resultant shorter lengths of stay.¹⁶ It is unclear how the proposed changes could affect these trends.

There is also a lack of acknowledgement of the challenges faced by healthcare professionals working with some people with intellectual disability and/or autism in in-patient settings, and the physical and psychological injuries sustained by them when supporting patients with complex needs.¹⁷ LTS and seclusion also needs to be seen in the context of rising staff injuries, poor staff retention and increasing need acuity of patients.

The voices and preferences of people with intellectual disability and/or autism themselves does not appear to feature prominently in the report. A case report on a patient 'Mr Wonderful' is discussed, but the detail is scant, with the report authors writing that 'there is a long story about what happened to get Mr Wonderful back into his home and community but what is important is that he was a person who was thought to be 'too difficult' to live in his community and the opposite was proved to be the case'. An individual case report does not represent the diversity of experiences of the concerned group (see Appendix 1 for an alternative case study perspective). However, context is critical, and further insights of the 'long story about what happened' would have been useful when considering effective approaches of transitioning successfully to a community setting.

The report additionally relies on individual cases with respect to the healthcare professionals experience, where one senior psychiatry trainee reported not having examples of effective admissions (Report Annex B). Clearly one trainee's experience is not necessarily representative, and it is unclear how many other psychiatrists were interviewed and if a suitable research methodology was followed to gain an unbiased view. There is strong evidence in literature of what good in-patient care looks like for people with intellectual disability and/or autism.^{18,19} It is another matter that there has been a focused, sustained, but poorly evidenced push toward closing specialist in-patient intellectual disability beds despite contrary evidence.⁴ Further, there has been ongoing debate in England and Wales for the reform of the MHA for people with intellectual disability and/or autism, which also has potential unintended consequences.^{20,21} There are also ongoing concerns of complex and vulnerable individuals needing to be discharged from hospitals being placed inappropriately outside of their local area because of a lack of suitable services in their home neighbourhood.^{22,23} Given the complexity of this vulnerable population, they would be at higher risk to be moved from hospital settings to community without due consideration of their long-term best interest.

It is worth noting that geographic issues, nature of hospital settings, patient characteristics, staffing levels and many other features would be potential confounding variables to the report's recommendations. It would have helped if the report had balanced the available evidence and these key associated areas with its findings.

Reflections on how to improve the current state of affairs

Baroness Hollins' report is emotive, as it appeals to people's values. As clinicians, we are driven by our values, which are supportive of upholding the human rights of our patients. We acknowledge that LTS and seclusion represent an infringement of specific human

rights. However, there needs to be an accurate representation of positively managing the balance of human rights infringements against clinical benefits and risk of harm.

LTS and seclusion are used only in extreme circumstances for a tiny proportion of in-patients. The measures are heavily monitored, and the aim is to minimise its use if it is unavoidable because of the risk of imminent harm to the patient and others in the vicinity.

LTS and seclusion needs to be viewed in context with other restrictive interventions, as it is often used to reduce use of restraint/physical/chemical intervention for the patient.²⁴ Restraint is the riskiest of all restrictive interventions, with risk of severe physical health consequences, including death.²⁴ Seclusion and LTS is the response to the most severe behaviours, and if seclusion or LTS is not implemented, the patient or others could be at exceptionally high risk.²⁴



In the cases of both LTS and seclusion, we need to better understand the characteristics and needs of patients that are subject to these restrictive practices, including whether such practices are consistent with the patient's own preferences (e.g. for some patients, withdrawal of staff during seclusion may be helpful for them, whereas others may find this highly distressing).²⁴ Such patient preferences could be documented in advance statements, in addition to recognising that restrictive practices will represent just one component of a multifaceted care plan.²⁴

High-quality support should be available in such circumstances, including appropriately experienced and trained staff, facilities should be appropriate, access to television, occupational therapy and leisure activities, etc. Evidence-based tools such as the Health of the Nation Outcome Scales for People with Learning Disabilities should be considered to guide the management plan.^{18,25} Clinicians need to be supported to provide the best possible care to those requiring specialist clinical settings and engage their valuable experience to help inform service planning for the future. Ensuring best practice requires consideration of research evidence, patient and carer perspectives and the clinical experience of those working in specialist settings.

We would welcome robust research to help delineate the role of LTS and seclusion in clinical practice, including comparisons of the relative merits and risks of alternative approaches. A possible model might be to look at the studies reviewed by Chieze et al² and see if any could be modified suitably to examine people with intellectual disability and/or autism.

Although a report into LTS and seclusion involving people with intellectual disability and/or autism is welcome, we have serious reservations regarding the methodology used to derive the report findings and the subsequent recommendations. Implementing the recommendations within the report might cause harm to vulnerable patients and their families, who we serve, and may have a significant detrimental impact on clinical services.

Our care of this most vulnerable group in society should be underpinned by evidence-based medicine and not ideologically driven opinion. In the USA, an ideologically driven policy to close mental health asylums, where abuses had occurred, was not matched by alternative, evidence-based community care. The consequences are now being seen, with chronic neglect of the severely mentally ill and more people with mental illness being in prisons than in psychiatric hospitals.²⁶ We cannot let that happen to people with intellectual disability and/or autism in the UK. The answer to poor institutional care is not to denigrate clinicians, who mainly would be psychiatrists or necessarily to close institutions. It is to establish a balance of good community care, good institutional care when necessary, inspect and scrutinise both rigorously, and base all care on a research-led, evidence-based approach.

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Appendix 1

A counter-narrative case study of LTS written by our co-author (expert by experience), the mother of a person with intellectual disabilities, is shared with her consent and has been anonymised.

'My heart breaks'! How many times did I feel this incredibly strong emotion, when coming out of endless meetings called to discuss the

future of my daughter. I always knew that there could be hope for her, given the correct support. Experts through experience would advocate a fuller life for her – clubs, cinema, frequent outings – to broaden her horizons. They could not see that their expectation of life is not necessarily right for every single member of our community. Some need much less in order to be happy. My daughter is now middle aged. She has been in residential care since late childhood. She suffers from a rare syndrome. She has an intellectual disability. She can be violent, will self-harm, is incredibly difficult to work with and requires expert care. She can also be great company and has a wonderful sense of humour. She moved from residential school into residential care. She has absconded, been arrested on more than one occasion, called the emergency services and was constantly at loggerheads with her fellow residents. Over the years, she has moved from one residential setting to another. She was medicated frequently, and rarely got on with her peers. In recent years she would try to find quiet areas where she could do her 'work' away from others. It was obvious that she preferred her own company. Her possessions were stolen or damaged, and this would result in frequent meltdowns, often resulting in restraint, forced isolation and strong medication. She would always gravitate to staff – especially male staff. She would form crushes on them, become jealous and highly resent the time they spent with fellow residents, and the whole spiral would begin again. She eventually found herself sectioned under the Mental Health Act. She has spent the past decade or so going in and out of hospital. Occasional providers were identified and tried, but her needs were so great that she would return to hospital. My recommendations on caring for her (i.e. in her own space) were rarely heeded. Every new provider 'knew better'. Finally, on her return to a specialist intellectual disability hospital 2 years ago, where she was away from the other patients to begin with, it was decided to leave her in her own space – with support. She had spent a short time there some months before and they had seen the difficulty she had on the ward. A programme of activities was planned. She has access to an advocate, a tutor, and does cooking and art regularly. She has community access provided, and I visit and take her out once a month. She is looked after by an experienced, lovely team of female staff. There are obviously a few interactions with men, but they are not her regular carers. The change in her is dramatic. She is calmer, can concentrate on her activities for longer and is so happy in herself. She is good company and has a fantastic rapport with her staff. This is not to say she is 'cured' of her difficulties. That will never happen. They still emerge. They are managed by a team who understand her well.

I fully support her LTS living arrangement. It is what suits her and brings out the best in her. For such an arrangement to be called 'solitary confinement' is harsh and cruel. It shows little understanding of the different needs of people. LTS is not for everyone, but for those few whose lives have been changed for the better, it is something to always be considered, as it can have real and special benefits. I realise that I do not spend every day worrying anymore.

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