Please cite the Published Version

Quinn, Alexis, Cavanagh, Dawn E, Kilcoyne, Jennifer, Haines-Delmont, Alina, Ryan, Sara, Lodge, Keri-Michèle, Bradley, Elspeth, Shalev, Sharon, Lamb, Norman, Hassiotis, Angela, Memmott, Ann, Banks, Roger, Pellicano, Elizabeth and Pavlopoulou, Georgia (2025) Long-term segregation and seclusion for people with an intellectual disability and/or autism in hospitals: critique of the current state of affairs: commentary, Quinn et al. The British Journal of Psychiatry. pp. 1-3. ISSN 0007-1250

DOI: https://doi.org/10.1192/bjp.2025.53

Publisher: Cambridge University Press

Version: Accepted Version

Data Access Statement: Data availability is not applicable to this article as no new data were created or analysed in this study.

Title: Long-term segregation and seclusion for people with an intellectual disability and/or autism in hospitals: a critique of the current state of affairs: Commentary, Quinn, et al.

Authors: Quinn, Alexis (1), Cavanagh, Dawn. E. Orcid (2), Kilcoyne, Jennifer (1, 3), Haines-Delmont, Alina Orcid identifier 0000-0001-6989-0943 (2)., Ryan, Sara (2), Lodge, Keri-Michèle (4), Bradley, Elspeth (5), Shalev, Sharon Orcid identifier (6), Lamb, Norman (7), Hassiotis, Angela, (8, 9), Memmott, Ann (10), Banks, Roger (11), Pellicano, Elizabeth (12), Pavlopoulou, Georgia* 13,14).

***Corresponding Author**: Georgia Pavlopoulou: Group for Research in Relationships in Neurodiversity (GRRAND), Department of Clinical, Education and Health Psychology, Division of Psychology &Language Sciences, Faculty of Brain Sciences, University College London, London, UK. EMAIL: georgia.pavlopoulou@ucl.ac.uk

Acknowledgements: The authors thank Fiona Anderson and Wendy Ashdown (parent experts by experience) for sharing their insights, and thank Wendy Ashdown for providing the image used.

Affiliations:

(1) Restraint Reduction Network, London, UK.

(2) Manchester Metropolitan University, Manchester, UK.

(3) Mersey Care NHS Foundation Trust, UK.

(4) Leeds and York Partnership NHS Foundation Trust, Leeds, UK.

(5) Department of Psychiatry, University of Toronto, Canada.

(6) Research Associate Centre for Criminology, University of Oxford.

(7) South London and Maudsley NHS Foundation Trust, London, UK.

(8) University College London Division of Psychiatry, London, UK.

(9) Camden Intellectual Disability Service, London, UK: North Central London, Integrated Care Board.

(10) Independent autism research consultant, UK.

(11) Associate Non-executive Director, North Staffordshire Combined Healthcare NHS Trust, UK.

(12) University College London, London, UK.

(13) Group for Research in Relationships in Neurodiversity (GRRAND), Department of Clinical, Education and Health Psychology, Division of Psychology & Language Sciences, Faculty of Brain Sciences, University College London, London, UK.

(14) Anna Freud Centre, London, UK.

Declaration of interests:

AQ was a member of Baroness Sheila Hollins Oversight Panel into Long Term Segregation (LTS), is a current member of the Care Quality Commission Oversight Panel on ICETRs and part of the National HOPE(S) Oversight Group focusing on the reduction of LTS. AQ is autistic and was forcibly isolated when an inpatient. AQ manages the Restraint Reduction Network (RRN).

DC is autistic and the founder of the campaign group, Stolen Lives. Her son, who has a learning disability, autism, epilepsy and ADHD, was forcibly isolated when an inpatient.

JK is Clinical Director for the Centre of Perfect Care and was previously a member of Baroness Sheila Hollins Oversight Panel into Long Term Segregation, and is a current member of the CQC Oversight Panel on ICETRs. She is the specialist advisor for reducing restraint in England for the RRN and co- author of the HOPE(S) clinical model to reduce LTS. She works on a consultancy basis for the World Health Organisation on the quality rights programme.

KL is a consultant in the psychiatry of intellectual disability and a sibling carer expert by experience.

EB is a psychiatrist and psychotherapist for people with intellectual disabilities. EB is Mental Health Lead, Canadian Consensus Guidelines for the Primary Care of Adults with Intellectual and Developmental Disabilities, Surrey Place, and Lead on the trauma-informed tools for implementation.

SS is an Independent Consultant at SolitaryConfinement.org

NL was former Minister of State for the Department for Health, is Chair of South London and Maudsley NHS Foundation Trust, Patron of the Restraint Reduction Network, Chair of the National HOPE(S) Oversight Group focusing on the reduction of LTS, Vice President of the National Autistic Society and an adviser to Kooth.

AH is a consultant in the psychiatry of intellectual disability and member of the editorial board of the British Journal of Psychiatry Open.

AM is an independent research consultant working with the National Development Team for Inclusion, advising NHS mental health care review clinical teams on research matters, and is autistic.

RB is a Psychiatrist in Intellectual Disability retired from Clinical Practice. Fellow of RCPsych, Honorary Fellow of RCGP, Fellow of Institute of Psychotherapy and Disability. Former National Clinical Director for Learning Disability and Autism, NHSEngland. Independent

Consultant to WHO Europe Quality Rights Programme. Trustee of the Association for Psychodynamic Practice and Counselling in Organisational Settings (APPCIOS)

EP is Professor of Autism Research, funded by the Australian Research Council.

GP is funded by MRC/UKRI to research autism and ADHD mental health and is working on NHS England programmes to train and upskill the workforce in autistic mental health and experience sensitive approaches to adapt evidence based practice. Georgia is Director of the National Autism Trainer Programme at Anna Freud.

Word count with revisions: 1000 (excluding image caption)

Tromans et al. [1] critique Hollins' [2] conceptual definitions of long-term segregation (LTS) and seclusion, and findings on their effects on autistic people and/or people with intellectual disability (ID). We refute their arguments that minimise and negate the current situation, and reassert that enforced isolation is a harmful, rights-restricting practice which has no place in contemporary mental health care.

Enforced isolation breaches disabled people's human rights and is prohibited in many countries. Solitary confinement in prisons is the most punitive and harmful intervention bar the death penalty [3]. The law is clear – restrictive interventions must be justified, proportionate, least restrictive and humane. However, Hollins [2] is just the latest of multiple national reports to unequivocally demonstrate this is simply not the case [2, 3]. Tromans et al.'s [1] assertion that *"enforced isolation cannot always be avoided"* is indicative of organisational cultures that support and excuse its use as a 'last resort', often consequent to staff perceptions of disability, resulting in greater prevalence [4, 5].

The phenomenon of enforced isolation and terminology

Hollins [2] found LTS was difficult to quantify. Staff often use it unknowingly, under less pejorative descriptors, e.g., "care away from others (CAFO)", "living alone" and "long-term seclusion", without adequate safeguards or reduction strategies. However, regardless of the term used, people's experience was of *enforced isolation from meaningful human contact* which is consistent with the definition and experience associated with the term "solitary confinement". Tromans et al. [1] reject this term, arguing that regular contact with healthcare professionals constitutes meaningful human contact. Yet, Hollins [2] found that direct, meaningful social, emotional and sensory contact was severely moderated and/or denied. For example, communication was frequently obstructed by doors, glass, and/or mediated through hatches and/or electronic devices. These factors, amongst others, acted as barriers to safe and therapeutic emotional connection for people that were distressed.

Tromans et al.'s [1] suggestion that Hollins [2] includes bespoke single occupancy housing, where a person has agency and control over when they leave, and who enters their space as enforced isolation, is misleading. Clearly, this does not meet the definition of "enforced". However, Hollins' report [2] includes hospital-based bespoke, single occupancy accommodation where force *is* enacted to maintain isolation recognising that these settings are vulnerable to becoming closed cultures, warranting greater supportive oversight.

Hollins' [2] assertion that isolation has no therapeutic benefit is evidence-based, and the suggestion that social contact is crucial to normal human development is hardly contentious. The report's findings are in keeping with consistent robust evidence spanning decades and sectors [3-6]. Tromans et al. [1] criticise Hollins' methodology, in which independent chairs (mainly psychiatrists) of multidisciplinary panels reviewed 191 episodes of LTS in depth, troublingly dismissing their carefully documented encounters and the experiences of the people involved.

Isolation is not a therapeutic alternative to inappropriate inpatient wards

Autistic people and people with ID do not sit outside of core human values and characteristics. The anecdotes offered by Tromans et al. [1] - that "certain patients" escalate their behaviour to sabotage reintegration because they prefer solitude - do not account for normal, human traumatic reactions to isolation, attempts to ward off its harmful effects, or the impact of power differentials between patients and carers, and health professionals. Reactions to isolation are known to include perceptual distortions, paranoia, psychosis, sensory hypersensitivity, anxiety, depression, self-injury, action-oriented coping and insomnia [6].

Ward environments may be difficult for some, however Tromans et al. [1] perpetuate the outdated stereotype that autistic people prefer their own company and like enforced isolation because it is less stimulating. However, solitary confinement is not solitude [6]. Any potential benefits [7] come at a high physical and psychological cost, and should not need to be realised through forcible isolation. Isolation is simply not legally justifiable on this basis. Additionally, even in the *best* cases of enforced isolation (where people were better able to control their social and sensory environment), the absence of normal, direct social and emotional connection had deleterious effects [2]. Tromans et al. [1] cite Chieze et al.'s [7] systematic review of 14 studies involving enforced isolation, yet this overwhelmingly details its adverse consequences, including high rates of post-traumatic stress disorder. Chieze et al., [7] like Hollins [2], suggested enforced isolation should be avoided and therapeutic relationships prioritised.

The need to re- and un-think as professionals

A further challenge by Tromans et al.[1] is that LTS is not experienced punitively. However, people are often isolated because they are perceived as having a behavioural disturbance and being at a sustained risk of harm, which may be understood as a constant feature of their presentation. As such, Hollins [2] found many patients attributed their isolation to their distress which communicated procedurally and sensorially their experience of being deserving of a cold and objectless space (image1).

Image 1. An autistic person's graphic representation of *deserving* their time in what they call solitary confinement, from Hollins'[2] recommendations. The person is under review by Independent Care and Treatment Reviews. (https://www.gov.uk/government/publications/independent-care-education-and-treatment-reviews)

Claims are made by Tromans et al. [1] about patients' experiences as if their own testimony is not to be trusted. This 'othering' of people who have experienced solitary confinement - suggesting they *like* having their neurobiological needs for connection frustrated - and that it is therapeutic, is arguably inhumane and constitutes epistemic violence. Like trauma, solitary confinement is not located in how others understand the event, but how it is experienced by the person - the inside out perspective [8]. Our social and biological imperative is connection, and enforcing isolation on any human is fundamentally traumatising. Systemic change is required to end LTS, and co-produced/delivered psychiatric curricula, particularly in the context of trauma-informed and neuro-diversity informed care, could support relational safety and restraint reduction [8, 9]. However, a framework of intensive support comprising consistent and collaborative practice leadership is essential, while listening to, learning from and understanding patients is foregrounded [9].

In conclusion, we are alarmed by the tone, content and defensiveness of Tromans et al. 's paper [1], and are deeply concerned about what it signifies for the care of current and future patients. We reiterate the urgent need to work collectively and constructively towards ending human rights abuses and improving support for people who are highly distressed.

References

1. Tromans SJ, Sawhney I, Odiyoor M, de Villiers J, McCarthy J, Boer H, Alexander R, Courtenay K, Wallace S, Gangadharan S, Roy A. Long-term segregation and seclusion for people with an intellectual disability and/or autism in hospitals: critique of the current state of affairs. The British Journal of Psychiatry. 2024:1-8.

2. Baroness Hollins' final report: My heart breaks – Solitary confinement in hospital has no therapeutic benefit for people with a learning disability and autistic people. London: Department of Health and Social Care; 2023 November. https://www.gov.uk/government/publications/independent-care-education-and-treatment-reviews-final-report-2023/baroness-hollins-final-report-my-heart-breaks-solitary-confinement-in-hospital-has-no-therapeutic-benefit-for-people-with-a-learning-disability-an).

3. Out of sight - who cares? Restraint, segregation and seclusion review. Progress report. London (UK): Care Quality Commission; 2022 March. https://www.cqc.org.uk/sites/default/files/20220325_rssreview-progress-march_print.pdf

4. De Benedictis L, Dumais A, Sieu N, Mailhot MP, Létourneau G, Tran MA, Stikarovska I, Bilodeau M, Brunelle S, Côté G, Lesage AD. Staff perceptions and organizational factors as predictors of seclusion and restraint on psychiatric wards. Psychiatric Services. 2011 May; 62(5): 484-91.

5. Webber LS, Richardson B, Lambrick F. Individual and organisational factors associated with the use of seclusion in disability services. Journal of Intellectual and Developmental Disability. 2014 October 2; 39(4): 315-22.

6. Haney C. Chapter 8: Solitary confinement, loneliness and psychological harm. In Lobel J, Smith PS, editors. Solitary confinement: Effects, practices, and pathways toward reform. Oxford (UK): Oxford University Press; 2019 November, p.129-152.

7. Chieze M, Hurst S, Kaiser S, Sentissi O. Effects of seclusion and restraint in adult psychiatry: a systematic review. Frontiers in psychiatry. 2019 July 16;10:491.

8. Bradley E, Korossy M. Chapter 5. Trauma in people with intellectual disability: recognition and intervention. In Branford D, Gangadharan SK, Barrett M. Alexander, RT. The Frith Prescribing Guidelines for People with Intellectual Disability. Branford D, Gangadharan SK, Barrett M. Alexander, RT, editors. The Frith prescribing guidelines for people with intellectual disability. (4th Edition). Cambridge (UK): Cambridge University Press; 2024 November, p. 61-73.

9. Quinn A, Wood A, Lodge KM, Hollins S. Listening to the experts: person-centred approaches to supporting autistic people and people with an intellectual disability in the mental health system. BJPsych Advances. 2023 Sep;29(5):308-17.