HOPE(S) EVALUATION

Final Report

“...what would I want for my son? I want HOPE(S).”
– Participant 45

Evaluation of the National HOPE(S) Programme to end long-term segregation (LTS) for children and young people, autistic adults and/or adults with a learning disability in inpatient hospital settings

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Manchester
Metropolitan
University

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“You forget the world, and the world forgets you.

Reality becomes even more distorted, and you forget how to have conversations and what the world is. Loneliness cripples you but you don’t think you deserve people, and you know the real world doesn’t want people like you. You rot alone and the world moves on, but you stay the terrified teenager that was first put in LTS, but you will never be the same again.

The horrors you see in the experience don’t just isolate you physically but separate you from humanity in a way you’ll never get back. You’re so desperate for conversations that you chat to AI, and pretend that you’re their friend, but you don’t have friends.”

-Unnamed individual with lived-experience (non-participant).

Consent was obtained to use this quote in the report

Acknowledgements

Special thanks to all our research participants, from people with lived experience and family members, to HOPE(S) and Respond practitioners, clinical staff and other healthcare professionals, commissioners and regulators who have taken the time to share their experiences and views about HOPE(S) and, more generally about long-term segregation - we would not have been able to produce this report without your input. Thank you, My Life My Choice for helping us reach out to the amazing people who have shared their experiences of restrictive practices and long-term segregation and their hopes for the future.

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We value your feedback!

We would like to know how this report has changed your thoughts and/or practice.

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Key abbreviations and terms

LTS	Long-term segregation, defined as "…a situation 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." (Department of Health, 2015)
CQC	Care Quality Commission
NHS	National Health Service
NHSE	National Health Service England
Lived experience	These are individuals who have been subjected to restrictive practices, including but not limited to long-term segregation in inpatient hospital settings.
Family member	These are usually individuals who are close to/care for someone with lived experience. This includes family members and friends.
Professionals	This includes any staff such as practitioners working in and across settings who were supported through the National HOPE(S) programme, e.g., nurses, psychologists, psychiatrists, speech and language and occupational therapists, ward managers, service manages or providers, case managers, commissioners and/or regulators.

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- Fradley, K., Rajan, D. G., & Haines-Delmont, A. (2025). *Evaluation of the National HOPE(S) Programme to end long-term segregation (LTS) for children and young people, autistic adults and/or adults with learning a disability in inpatient hospital settings*. Final Report. Manchester Metropolitan University.

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We are interested to know whether this report impacts on thinking around LTS, practice, policy, future research and initiatives. If you do use this report or findings from it, please acknowledge it as such in your presentations, documents etc. Thank you!

Evaluation of the National HOPE(S) Programme to end long-term segregation (LTS) for children and young people, autistic adults and/or adults with a learning disability in inpatient hospital settings

1. Overview

Manchester Metropolitan University (MMU) was commissioned by Mersey Care NHS Foundation Trust to undertake an independent research evaluation of the National HOPE(S) programme using a clinical model designed to reduce the use of long-term segregation (LTS) for children and young people, autistic adults, and adults with a learning disability. Funded by NHS England's Learning Disability and Autism Programme, the HOPE(S) national rollout concluded on 31st March 2025. This implementation and outcome evaluation represents the first large-scale, mixed-methods research study to systematically examine the impact of LTS in mental health settings and evaluate a dedicated intervention designed to reduce and prevent its use.

The National HOPE(S) programme adopts a dynamic, trauma-informed and human rights-based model of care. The model seeks to challenge restrictive, risk-averse practices and promote compassionate, least-restrictive, person-centred alternatives that restore dignity, voice and agency to those most affected by institutionalised care.

This report serves three core purposes: (1) To describe how the evaluation was conducted, including the procedures, methodologies, and ethical principles underpinning the study; (2) To present the key findings emerging from a comprehensive mixed-methods design, drawing on qualitative, quantitative, and routinely collected clinical data; and (3) To offer evidence-informed recommendations for the future of policy, practice, and research aimed at ending LTS and improving outcomes for children and young people as well as autistic adults and adults with learning disabilities.

Central to the evaluation were in-depth interviews and focus groups with 73 key stakeholders including individuals with lived experience, family members, clinical staff, those delivering the intervention, commissioners, regulators and system leaders, providing a rich narrative account of the harms of LTS and the perceived impact of the National HOPE(S) programme. These qualitative insights were complemented by outcome data gathered by service providers and HOPE(S)/Respond practitioners between May 2022 and March 2025, including: (1) Clinical data for 122 individuals supported by the HOPE(S) programme; (2) Questionnaire data from 11 family members who received trauma-informed therapy; and (3) Survey responses from 388 professionals engaged in HOPE(S) training and implementation.

Throughout, the evaluation has sought not only to document outcomes, but to elevate the voices of people with lived experience, especially family members sharing their experience and that of their loved one, embedding co-production at each stage — from design and data collection to analysis and recommendations. The result is a robust and multi-layered account of how LTS is experienced, how it can be challenged, and what it takes to create a system where hope, rights, and recovery are possible.

2. Background

The use of restrictive practices for people with mental health conditions, a learning disability or autistic individuals in mental health settings has significant adverse effects on the individual, their family, care providers and organisations. Whilst their intended use is to protect people from harm, they are not always used as a last resort (Brophy et al., 2016), due to trauma-uninformed and fearful staff (Hennessy et al., 2023; Power et al., 2020; Sweeney et al., 2018) and/or unsuitable environments (Oostermeijer et al., 2021). Much attention has been directed towards the reduction of seclusion and restraint, but there is far less focus on understanding and addressing the use of long-term segregation (LTS) — a practice that can result in prolonged and profound human rights violations.

2.1 What is 'long-term segregation'?

Broadly, LTS is a form of restrictive practice used to prevent or reduce the likelihood of harm by a patient to others on a long-term basis. Patients in LTS have limited, or no interaction with other patients and peers, but are allowed to interact with professionals such as clinical staff teams. With regards to mental health services, the UK Mental Health Act (MHA) Code of Practice (2015) defines LTS as:

> *"…a situation 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."* (Department of Health, 2015).

2.2 What is known about the extent and impact of LTS in inpatient hospital settings?

According to the Mental Health Services Dataset (MHSDS) between 2021 and 2022, 554 people in NHS funded secondary mental health, learning disabilities and autism services were placed in segregation (NHS Digital, 2025). Emerging evidence and inspection reports from advocacy organisations (Mencap, 2021; National Autism Society, 2020) and research studies (Belayneh et al., 2024; Chieze et al., 2019; Jones et al., 2021), show that LTS is associated with: (i) decline in physical and mental health; (ii) loss of sensory input, social contact and daily living skills; (iii) feelings of shame, humiliation, powerlessness and institutional trauma; (iv) human rights violations, including denial of access to fresh air, privacy, personal care, and family contact.

LTS is often implemented in environments ill-suited for therapeutic recovery — with unclean accommodation, minimal stimulation, and isolation lasting months or even years. In extreme cases, individuals have remained in segregation for over a decade.

In summary, restrictive practices, such as LTS, may increase the risk of clinical practices that infringe upon the individual's human-rights (Joyce, 2020). There are also concerns about the use of physical interventions and overuse of medication, poor environment and treatment, unnecessary periods of LTS and, possibly unjustified restrictions on family contact and privacy.

2.3 National scrutiny and system failures

The impact of LTS has entered the public consciousness largely through media exposés, including the BBC Panorama investigations into Winterbourne View (2011), Whorlton Hall (2019) and Edenfield Centre (2022). These reports revealed ongoing abuse, neglect, and systemic failures to safeguard the rights of people in institutional settings, particularly autistic people and those with learning disabilities (Richards, 2020).

In response, national reviews and reforms were initiated. Positive and Proactive Care (Department of Health, 2014) called for a reduction in restrictive practices, stating that LTS should be used only in exceptional circumstances, and for the shortest possible time. In 2019, Baroness Hollins was appointed to lead an independent Oversight Panel to review the care of people in LTS. Her interim and final reports (Hollins, 2021, 2023) highlighted: (i) rare examples of good practice; (ii) widespread failure to provide person-centred, trauma-informed care; and (iii) systemic denial of meaningful relationships, resulting in what was described as "social death".

The Care Quality Commission (CQC) echoed these concerns in Out of Sight – Who Cares? (Care Quality Commission, 2020) identifying poor leadership, closed cultures, and a lack of appropriate staff training as key barriers to safe, high-quality care. This includes retelling Bethany's story of unjustified and excessive use of restrictive practices which stopped following a media campaign. The report identified that poor leadership and culture were a barrier to patients receiving high quality care. Staff disclosed that they felt undertrained and lacked appropriate knowledge of alternative modes of communication, e.g., picture symbols or Makaton. As part of the legal response, the Health and Care Act (2022) introduced mandatory training for health and social care providers in autism and learning disability, aiming to address the knowledge and skill gaps that contribute to inappropriate care and overuse of restrictive practices.

However, the latest CQC (2022b) report into the experiences of being in hospital for people with a learning disability and autistic people (*Who I am Matters*) clearly indicates that improvement is still too slow. Health inequalities continue to be identified in routine practice as well as poor practices, including overly restrictive care and human rights breaches. This includes people not being involved in the decision making process regarding their care planning; services not making appropriate reasonable adjustments to meet people's individual needs; staff lacking the skills to enable them to communicate effectively to meet these needs; or staff lacking the knowledge to understand the role of age, race and sexual orientation for people diagnosed with a learning disability or autistic people (Care Quality Commission, 2022b).

More recently, Baroness Hollins' (2023) final report highlighted the serious and now long-standing concern around the use of LTS whereby individuals in LTS are described as 'forgotten'. The report again highlights the systemic issues that may cause poor practices of LTS, e.g., professionals not meeting the needs of these individuals nor providing trauma-informed care. As result, individuals in LTS are denied meaningful relationships with others, including with professionals, which can result in such severe consequences that it is described as 'social death' (Hollins, 2023). The greatest impact of the report presented by Hollins is that the Department of Health and Social Care recognise that LTS can be devastating highlighting that there is a need to raise awareness and take action (Department of Health and Social Care, 2023).

2.4 Policy response and the National HOPE(S) Programme

In recognition of the need for urgent and sustained reform, NHS England committed, through the Long-Term Plan (2019), to reducing the use of inappropriate inpatient care and improving community support for autistic people and people with learning disabilities. As part of this strategy, NHS England funded a series of national initiatives focused on transforming care for individuals in LTS.

The National HOPE(S) Collaborative, led by Mersey Care NHS Foundation Trust, was one of the programmes funded to address these systemic failures. HOPE(S) was designed to provide a dynamic, human rights-based model of care to reduce the use of LTS through relational, trauma-informed, and least-restrictive practices. This evaluation explores the national rollout of HOPE(S), its impact, and what it reveals about the broader system of care.

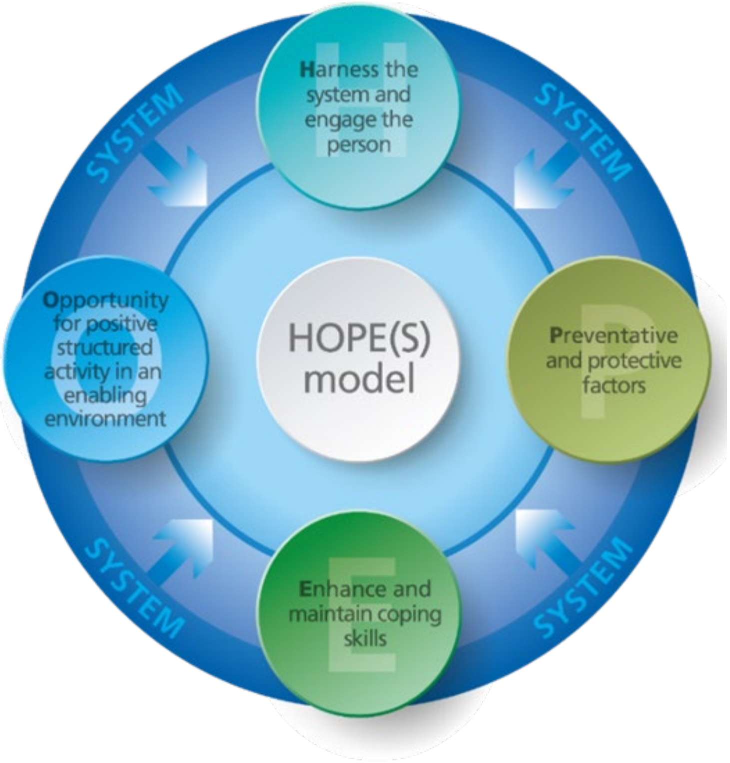
2.5 The National HOPE(S) NHS England Collaborative

2.5.1 Introducing a new model of care

The National HOPE(S) Programme was built on a clinical model of care known as the HOPE(S) model (Kilcoyne & Angus), which was originally developed by Mersey Care NHS Foundation Trust, a large mental health and physical health organisation in the North-West of England, to reduce LTS for adults in high secure settings. The HOPE(S) model is based on a philosophy of person centred, human rights-based care, which includes being unconditionally and relentlessly positive. It allows clinical teams and the person in segregation to understand the significant barriers and systemic issues maintaining their circumstance. The HOPE(S) model aims to end or reduce time spent in LTS, improve quality of life and personal experiences, support physical health outcomes, increase family involvement, reduce other restrictive practices and length of stay, support appropriate forward planning and discharge and also change clinical practice to a more human rights-based culture of care.

The HOPE(S) model (Kilcoyne & Angus) implements three key components to reduce or end LTS: (1) the HOPE(S) training, (2) the Barriers to Change Checklist (BCC) and (3) intervention by the HOPE(S) practitioners for the person and their staff team. HOPE(S) training includes 2-day clinical teams training and HOPE(S) awareness training. The aim of the training is to raise awareness of the negative impact of LTS through evidence-based literature, case studies and reflective practice, as well as provide staff with an understanding as to what the HOPE(S) model is and what it can offer. The training is facilitated by HOPE(S) practitioners. They support clinical teams to implement the model through practice leadership, advocating for least restrictive practices and encouraging staff to create opportunities to build meaningful relationships, promote meaningful activities and fresh air for those in LTS. The Barriers to Change Checklist (BCC) is a tool used by practitioners, clinical teams and the person in LTS to identify factors that interfere with someone moving out of LTS. The BCC offers a framework for teams to understand dynamic risk factors associated with LTS and help them develop an implementation plan that enables a targeted positive approach for the person in LTS. Four main domains have been identified from research, a thematic analysis of clinical practice and the literature which contribute to and/or act as barriers to moving out of LTS in services and these are assessed and specifically targeted by the BCC (***Figure 1***).

Figure 1. Overview of the HOPE(S) model



System factors: Understanding staff & systemic responses to working with the person in LTS, and the dynamic relationship between individual and the organisation. For example, the impact of cycles of behaviour and LTS have on the culture of care.

Environmental factors: Context of constraints/demands presented by the environment - not only the social and physical structures, but also the opportunities available for the person.

Risk factors: Levels of risk the person presents when distressed and impact on their care and staff confidence in working with them.

Individual factors: Specific to the person in LTS. Such as distressed behaviours/difficulties that led to the LTS in the first place & difficulties developed as a response to harmful effects of LTS.

2.5.2 The implementation of the National HOPE(S) programme

In 2021 the National HOPE(S) programme - ***hereby referred to as HOPE(S)*** - was funded to implement the model across England for autistic people, and/or people with a learning disability, and all children and young people in LTS, regardless of diagnosis. Service delivery started in May 2022 due to funding arrangements and recruitment delays (mainly due to Covid-19 organisational staffing issues) and was ceased on 31st March 2025. In collaboration with NHS England the programme developed a prioritisation criterion for HOPE(S) intervention to ensure those people in LTS experiencing greater levels of restriction were prioritised for support. NHSE regional leads in collaboration with HOPE(S) practitioners from the region met regularly to review referrals and agree prioritisation. The prioritisation criteria consisted of the following key areas; are there safety concerns, does the person have access to fresh air and exercise in an outside space, is the person at risk of escalating up the secure pathway and is the person's human rights being infringed upon or breached. Where NHSE regional leads had safety concerns, people had lack of access to fresh air and exercise in an outside space, the people were at risk of escalating up the secure pathway and their human rights infringed upon or breached, these people were prioritised for HOPE(S) support.

Since its first referral in May 2022, HOPE(S) has been a dynamic and evolving programme based on the feedback from those engaged with the programme and the ongoing research evaluation; with over 2,000 HOPE(S) clinical guides (HOPE(S) model, 2023) distributed across England. From the onset, the demand to provide HOPE(S) for people in LTS was greater than the capacity available within the programme. The programme thus developed an additional level of intervention in the form of consultancy support to enable those individuals and their clinical teams to receive support from the programme. Two levels of support were offered and throughout delivering the programme many people receiving support have moved between intensive support and consultancy support depending on clinical need (***Table 1*** and ***Figure 2***).

Table 1. HOPE(S) programme: two levels of support according to clinical need

	Intensive support	Consultancy Support
Engagement	• Engage with person and assess the salient issues relevant to long-term segregation • Connect with the family / carers, clinical and ward team, advocacy, and wider stakeholders	• Engage with person and assess the salient issues relevant to long-term segregation • Connect with the family / carers, clinical and ward team, advocacy, and wider stakeholders
Complete Barriers to Change Checklist (BCC)	• Facilitate the completion of the BCC with the person and clinical team • Address any urgent human rights / quality of life issues • Generate 3 SMART key intervention targets	• Facilitate the completion of the BCC with the person and clinical team • Address any urgent human rights / quality of life issues • Generate 3 SMART key intervention targets
Delivery	• Intensive relational and therapeutic work with the person in LTS • Train clinical and ward teams in the HOPE(S) model • Support the teams through coaching, practice leadership, reflective practice, and clinical supervision to achieve the key intervention objectives • Train wider networks including future community providers	• Train clinical and ward teams in the HOPE(S) model • Support the teams through reflective practice and clinical supervision to achieve the key intervention objectives
Transition	• Monitor progress through experiential narrative and outcome measures • Develop infrastructure to maintain transition and progress	• Monitor progress through experiential narrative and outcome measures (not including physical health and other quality of life measures)

Figure 2. Overview of the implementation of HOPE(S) (May 2022 - March 2025)

17 HOPE(S) Practitioners nationally

HOPE(S) has been rolled out to **40** NHS commissioned organisations including

68

sites

Implemented across seven regions in England:

- North-East and Yorkshire
- North-West
- Midlands
- East
- London
- South East
- South West

122

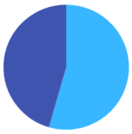
people have commenced HOPE(S)

39

integrated care boards (ICBs) made referrals since May 2022

Over 2,000

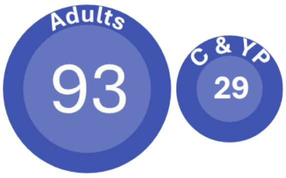
HOPE(S) clinical guides have been distributed across the system



49% have received intensive support

68% have received consultancy support

HOPE(S) has supported people in adult and CYP services



Out of the adults:
27 dual diagnosis
34 autistic adults
29 with a learning disability
1 no diagnosis
1 unknown

1,685
staff completed the HOPE(S) 2-day training

2,184
staff completed the HOPE(S) awareness training

20 families were referred to RESPOND

16 families accepted and received therapy

* The data presented here is based on the 122 individuals whom the research team received data for by 17th March 2025. It is important to briefly note that by 31st March 2025, 125 individuals were supported by HOPE(S) and 85 were out of LTS.

** Males include trans males and females include trans females.

*** Some individuals from the cohort received both consultancy and intensive support.

2.6 Respond therapy service

Since 2022, Respond worked collaboratively with HOPE(S) to provide support the families of those in LTS. Respond is a national charity who specialise in providing services (including therapy) to people with learning disabilities, autistic people, or both, who have experienced abuse, violence, or trauma (https://respond.org.uk). Respond was commissioned by HOPE(S), complementing HOPE(S) interventions by delivering trauma informed therapy to those families who wished to engage with the aim to better understand and lessen the effect of complex trauma on themselves and their loved one. They achieved this by:

i. providing independent trauma support for families and carers with a psychotherapist from Respond, either online or in person.
ii. offering a relational approach that places the specific individual experience of the family members at its centre and the development of the relationship with the therapist as an integral aspect of the therapeutic process.
iii. enabling those that access therapy to be properly heard and understood.

Families who have a loved one in LTS were referred to Respond by HOPE(S) practitioners. Once referred, pending an assessment to ensure therapy was appropriate, families were allocated a therapist and were offered weekly sessions for one year (the equivalent to 44 sessions). Additional sessions beyond this were subject to review. As of August 2024, 20 families were referred and 16 families received services from Respond.

2.7 The HOPE(S) family peer support forum

Interim findings from the research evaluation (Haines-Delmont et al., 2024), as well as feedback from families who had a loved one in LTS have pointed to the need for additional support for family members. As a result, a HOPE(S) family peer support forum was introduced in 2024. While this is an initiative developed and facilitated by HOPE(S) practitioners, it is a peer support family-driven forum for those who have children, siblings or friends in LTS coming together to listen to and support each other. The forum currently meets once a month providing a safe open space where people can share their experiences to help stand against the isolating and stigmatising effects of LTS. The forum is also a platform to celebrate progress, and share hopes for the future.

3. Aims and objectives

This report presents the overall findings of the research evaluating the implementation of the National HOPE(S) programme in England, covering the period May 2022 to March 2025. Manchester Metropolitan University (MMU) has been commissioned to produce independent evidence-based reports, presentations and papers capturing experiences and outputs linked to the introduction of HOPE(S). Interim findings reported in 2024 have already been used to inform future developments and changes within and beyond the programme (Haines-Delmont et al., 2024). It is hoped that the findings and recommendations presented here will be accessed and used by key stakeholders to continue to improve practice in this area and, most importantly, the quality of life of individuals in LTS and their families.

The overall aim of the evaluation was to explore experiences and accounts of key stakeholders involved in HOPE(S) as well as to measure changes with regards to key outcomes for people in LTS, families, professionals and services following the introduction of HOPE(S).

Specific objectives included:

- To explore the perceived impact, benefits and challenges regarding the implementation of HOPE(S) for a wide range of stakeholders including family members of individuals currently or previously in LTS, people with lived experience of LTS or other forms of restrictive practices, clinical staff involved or engaging with HOPE(S), HOPE(S) and Respond practitioners, and other stakeholders such as commissioners/regional managers and policy makers or regulators;
- To describe the cohort of individuals who have received support through HOPE(S) up until 17th March 2025 and highlight the number of individuals who were out of LTS by that time;
- To assess the potential impact of HOPE(S) with regards to key health outcomes for people in LTS (e.g., quality of life and physical health), access to meaningful activities, and safety (e.g., use of restrictive practices);
- To assess the potential impact of HOPE(S) on professionals’ quality of life (QoL) and on family functioning; and,
- To identify and agree on key findings, challenges, lessons learnt and best way to improve practice, including the co-production of recommendations.

METHODS

SECTION

- Design and procedure
- Measures
- Participants
- Analysis

4. Methodology

A mixed methods design was used to address these objectives, including:

i. Qualitative in depth semi-structured interviews, focus groups and self-completion questionnaires with **73 key stakeholders** including families of individuals in LTS, individuals with lived experience of LTS and/or restrictive practices, clinical staff, HOPE(S) and Respond practitioners, service or regional managers, commissioners and regulators); and
ii. Secondary analysis of routine clinical data collected by service providers and key outcome measures collected by HOPE(S)/Respond practitioners for (i) a cohort of **122 individuals** who have received support through HOPE(S); **11 family members** who have engaged with therapy provided by Respond; and **388 professionals** (e.g., clinical staff, therapists) who have engaged with HOPE(S).
i. In addition, the following evidence was obtained (with consent) to strengthen the quantitative and qualitative data above, e.g., statements and photographs from family members and people with lived experience; and qualitative case studies provided by HOPE(S) practitioners.

Co-production/sense-checking sessions with people with lived experience, family members and professionals took place throughout the evaluation to validate the results and co-produce qualitative themes and recommendations for change. Patient and public involvement (PPIE) was incorporated from the early stages of the evaluation, to ensure the study design and approaches to data collection were accessible and appropriate to this population.

4.1 Qualitative study

4.1.1 Design and procedure

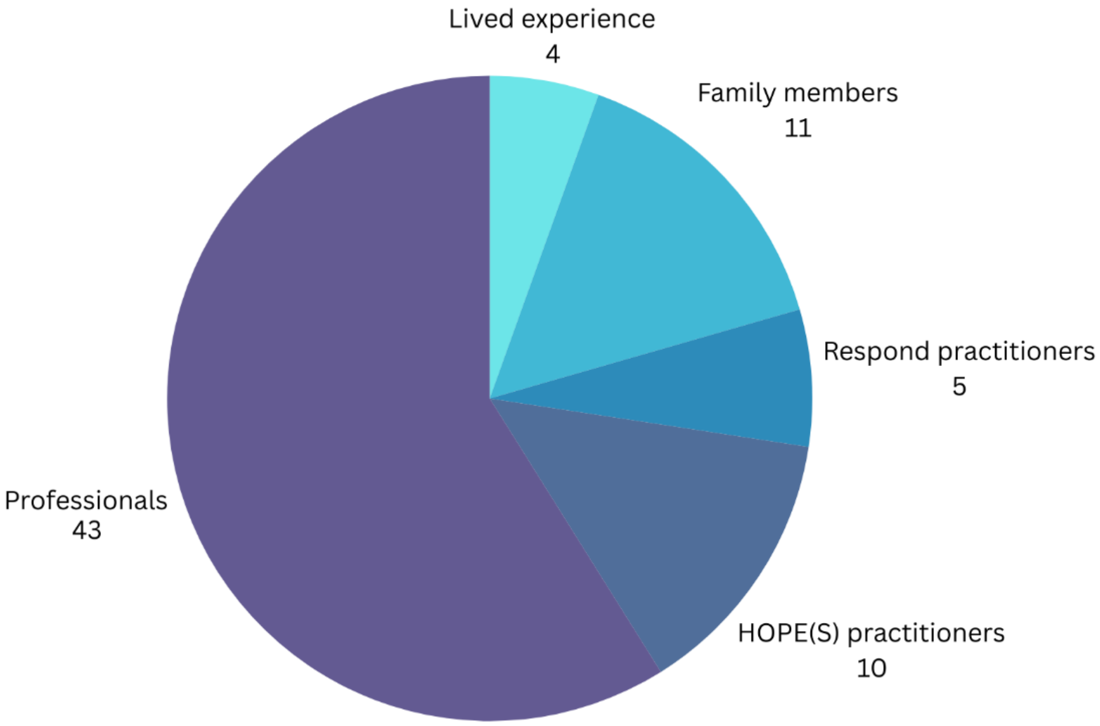
A mixture of interviews, focus groups and self-completed questionnaires were conducted between July 2023 and January 2025 with 73 individuals with lived experience, family members of individuals currently or previously in LTS, HOPE(S) practitioners, Respond Practitioners as well as clinical staff who have engaged in HOPE(S), regional managers/commissioners and regulators. For details regarding the sample population, see ***Figure 3*** below.

All interviews and focus groups were conducted online by independent researchers at MMU ('JL', 'KG', 'AHD', and 'KF') using Microsoft Teams, with the exception of a focus group with people with lived experience that was conducted face to face. Data collection was overseen and supervised by the study PI, an experienced methodologist and researcher in the area of coercive practices for people with mental health conditions and other psychosocial difficulties. There were two rounds of data collection. The first round of data collection was conducted between 19th July 2023 to 1st January 2024 to capture initial outcomes regarding HOPE(S) and to identify emerging benefits, good practice and implementation issues (to inform the conduct of the final report, as well as ongoing practice). The second round of data was conducted between 2nd April 2024 and 31st January 2025 to capture further developments, including new practice such as the establishment of the HOPE(S) family peer support forum; to improve the recruitment uptake of professionals (clinical staff and commissioners); and to provide those interviewed during round one a chance to participate in a follow up interview or a focus group if they felt would benefit from doing so. All participation was subject to informed consent.

4.1.2 Participants

All participants were recruited by the research team at MMU using volunteer sampling. Information about participation and how to contact MMU was provided to people who had experience of the National HOPE(S) programme by HOPE(S) or Respond practitioners. In addition, MMU had a recruitment table at the National HOPE(S) conference in May 2024. All eligible participants were asked to read a participation information sheet and a consent form. Different versions of the participation information sheet were created to tailor the information for each type of participant (family member, person with lived experience of LTS and/or restrictive practices, professionals). All participants were required to provide consent either through signing the consent form or by providing verbal consent to the statements presented on the consent form. Data was not included nor analysed in this report if consent was not given. To ensure anonymity, all participants were given a participant number/code instead of using their names and this was used in this report when reporting quotes from their data.

Figure 3. Sample population: qualitative study



'Professionals' included clinical staff such as practitioners working in the settings supported through the HOPE(S) programme including nurses, psychologists, speech and language therapists, occupational therapists, psychiatrists, ward managers, case managers, commissioners and/or regulators. Therefore, this includes all staff either employed and working in the NHS or private inpatient, outpatient and/or community settings who have engaged or been involved with HOPE(S). Out of the 43 professionals participating in the qualitative study, 30 were clinical staff, 10 were commissioners or regulators, and three were from community or family services or providers.

Out of 11 family members participating in the qualitative study, 10 were mothers and one was a sibling of an individual in LTS. Family members were recruited by HOPE(S) or Respond practitioners. All participants, especially families and Respond practitioners, were invited to share their experience again to ensure that their narrative is captured in this report. Two Respond therapists and three family members participated more than once. Researchers felt that each occasion improved the quality of the data and representation of these groups in a sample which contained a large proportion of clinical staff.

4.1.3 Interview guide

Semi-structured interview guides were used by the interviewers; these were tailored to the type of participant interviewed. For example, family members were asked to share their thoughts and feelings about their loved one's journey into hospital and LTS; views about HOPE(S) and the therapy from Respond (where applicable); benefits and challenges and ideas for improvement. Respond therapists were asked about their role in relation to HOPE(S), specifics with regards to Respond therapy and engaging with families, key benefits, and challenges. HOPE(S) practitioners were asked to share their views and experiences about HOPE(S), anything from rationale for LTS, specifics to do with their role, good practice, challenges, and ideas on how to improve or enable sustainable practice. In round two, interview guides for family members were adapted to include questions to capture their experience of the HOPE(S) family peer support forum and their loved one journey into (and potentially) out of LTS, in more detail. All participants were provided a concise set of example questions prior to the interview through email (alongside the participation information sheet and the consent form) to ensure that they were fully informed of the type of questions that would be asked during the interview (or focus group), as well as to give them time to reflect beforehand, in case they found this beneficial.

4.1.4 Thematic analysis

Recordings were transcribed by *Type it Write*, a transcription company who had a contract with MMU and followed the data protection and confidentiality rules as agreed in the protocol and the ethical approval. All transcripts were imported into NVivo 14 (Lumivero, 2023) for reading, coding, and analysis. For the purpose of this report, reflexive thematic analysis (Braun & Clarke, 2021; Braun et al., 2023) was undertaken by KF, a post-doctoral research associate with previous experience analysing qualitative data for successful peer-reviewed publications (Fradley et al., 2024). Samples of the transcripts were coded by multiple researchers involved in the project, including AHD. For more information and details on the data analysis process, peer debriefing and audit trials see 'Appendix: Qualitative analysis and audit trails'.

4.1.5 Sense checking/co-production sessions

Sense checking was used at various stages due to the large quantity and diversity of the data. Four sessions were conducted in total between 7th February and 19th March 2025. The first sense checking session was conducted to discuss the themes generated from the family members data only. The decision to undergo sense checking for the family members data was to ensure that the analysis accurately portrayed their experience. Sense checking was performed between KF, AHD and, by a family member with someone in LTS and who was not a participant in the study. It was felt that the impact of LTS needed to be reported first to help contextualise how, or to what degree, the HOPE(S) might address this.

The second sense checking session was conducted with an individual who has lived experience of LTS (and seclusion) and who was not a participant in the study. The preliminary themes for the evaluation of the HOPE(S) project for the whole sample were reviewed and discussed. It was agreed that the language used in the emerging themes needed to be reviewed; also, the language around 'risk' (including risk aversion, 'positive risk taking') needed to be carefully considered in the report, as this can have negative connections for those with lived experience; in their view, this language perpetuates a culture (in practice and academia) based on fear and risk, rather than rights and recovery. This feedback was considered and acknowledged, where appropriate, in this report.

The third sense checking session was conducted for emerging recommendations with two mental health care professionals who were not participants in the study. The recommendations for the report were revised based on their feedback.

A final sense checking session was conducted with a large team, i.e., the HOPE(S) National Steering Group. Here, findings and some recommendations were presented to a diverse audience (individuals with lived experience, family members, NHSE, Advocacy, CQC, ICB representatives, independent charity groups, service providers, HOPE(S) practitioners, Respond practitioners) and feedback or comments were taken into account (especially with regards to limitations to the data and lessons learnt).

4.2 Quantitative study

The MMU team received data from Mersey Care NHS Foundation Trust regarding the cohort of individuals who have received support through HOPE(S). Data collection was overseen by the HOPE(S) clinical business manager and the study PI. Clinical outcome data such as start and end date of long-term segregation, use of restrictive practices and engagement in meaningful activity were (routinely) recorded in contemporaneous clinical notes on electronic patient record systems. These data were shared by provider organisations before being categorised and recorded by HOPE(S) practitioners in an anonymised format. Provider organisations agreed to the sharing of clinical outcomes data for the purposes of this evaluation covered by the Data Protection Impact Assessment (DPIA) between NHSE and Mersey Care NHS Foundation Trust by signing the Memorandum of Understanding (MoU) between their organisation and Mersey Care NHS Foundation Trust. The transfer to and use of data by MMU was covered by data protection impact assessments and research ethics approval (IRAS project ID: 319279; REC reference: 23/SS/0044). Data collection for the quantitative study started 3rd May 2022 and ended on 17th March 2025.

4.2.1 Outcome measures

Quality of life (QoL)

Data was only required to be collected from individuals receiving intensive support, yet some consultancy data was also collected and included in this report. Four QoL measures were proposed and HOPE(S) practitioners selected the most suitable measure for the individual they were supporting; this depended on the individual's age and diagnosis and ability. Data was collected across multiple time-points. The time points included in this report were: within 4 weeks of HOPE(S) commencing (Time 1)/(T1), between 1-3 months of HOPE(S) commencing (Time 2)/(T2), and between 4-6 months of HOPE(S) commencing (Time 3)/(T3)[1].

i. YQOL-SF (Youth Quality of Life-Short Form)

The YQOL-SF is a valid and reliable 16 item measure which assesses quality of life of individuals between 11 and 18 years old (Patrick et al., 2002). Example items include: '[I] feel good about

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[1] Time points beyond time 3 were not included because numbers were too small.

myself' and '[I] look forward to the future'. The tool has an 11-point Likert scale; higher scores indicate better quality of life. A total score was created for each individual by summing together and averaging the scores.

ii. Mini-MANS-LD (Mini Maslow Assessment of Needs Scale for Learning Disabilities)

The Mini-MANS-LD is an adapted nine-item accessible assessment instrument is based on the Maslow Assessment of Needs Scale (MANS) (Skirrow & Perry, 2009). The Mini-MANS-LD is designed to reflect Maslow's hierarchy of needs covering self-reported satisfaction with environment, safety, social relationships, esteem, and self-actualization, as well as an item of overall life satisfaction (Raczka et al., 2020). The Mini-MANS-LD was adapted to assess quality of life for those with learning disabilities. Example items include: 'Are you happy with how you spend your time?' and 'Do you try to hurt yourself?'. The tool has a five-point Likert-scale, using a pictorial as well as verbal scale. Higher scores indicate worse quality of life. A total score was created by summing together the individual scores.

iii. MANS-AS (The Maslow Assessment of Needs Scale - Asperger's Syndrome)

The MANS-LD is an adapted 19 item accessible assessment instrument based on Maslow's hierarchy of Needs Scale (Skirrow & Perry, 2009). The MANS-AS is designed to reflect Maslow's Hierarchy of Human Needs (Maslow & Lewis, 1987) and has been adapted to assess quality of life of autistic individuals. Example items include: 'I feel good about myself' and 'I feel accepted by other people'. The tool has a five-point Likert scale based on how much the person agrees with each statement. Higher scores indicate better quality of life. A total score was created by summing together the individual scores.

vi. HOPE(S) Outcome Tool (HOT)

HOT was developed by speech and language therapists working on HOPE(S) who recognised the need for a tailored tool more specific to the needs of the individuals in LTS (Brackley & Carr, 2022). The tool was used only where the above validated tools were deemed not appropriate, for example, where people were identified with significant communication difficulties, attentional difficulties, a moderate learning disability or struggled with face-to-face conversations because of perceived demand. The HOT uses a simple scale with 3 options (e.g., "it's okay", "it's not okay", or "I don't know") which makes concepts that are abstract more understandable using picture support or adjusting the language. Visual tools and talking mats are used to help focus attention and can reduce perceived demand in 1:1 interaction. All HOPE(S) practitioners have received adequate training on how to use this tool. Higher total score indicates higher quality of life. A total score was created by summing together the individual scores.

Access to fresh air and engagement in meaningful activities

Data was only required to be collected from individuals receiving intensive support, yet some consultancy data was also collected and included in this report. Firstly, clinical teams were asked to record the days where the individual had access to fresh air. Fresh air refers to time spent in outdoor spaces, including accessing the community. Secondly, clinical teams were asked to record the number of meaningful activities which refers to activities which are important to the individual to have a healthier and improved quality of life. The definition of a 'meaningful activity' was decided collaboratively with the individual. This could include: (i) physical activity (exercise in gym etc.,) (ii) therapeutic intervention (sessions with therapists, well-being group etc.,), (iii) family and friends contact, (vi) personal care (bath, haircut etc.,), (v) community/off site leave, (vi) building independence skills (such as going shopping or cooking),

(vii) education (used mostly for the children and young people supported), and (v) other activity (phone calls, ICT sessions etc.,). Data was collected at two time-points; Time 1 (T1)/pre-HOPE(S) refers to data collected for between 1 to 7 months (an average of 2 months) prior to HOPE(S), and Time 2 (T2)/post-HOPE(S)) refers to between less than a month to 30 months (an average of 10 months) since commencing HOPE(S). Days where the individual had access to fresh air and the number of meaningful activities, as separate outcomes, were assessed by the total number per month[2].

Use of restrictive practices

Data was only required to be collected from individuals receiving intensive support, yet some consultancy data was also collected and included in this report. Use of restrictive practices was collected by service providers. Restrictive practices are interventions aimed at constraining an individual's freedom to move when they are perceived as causing harm to themselves or others (Department of Health, 2015). These include the incidents of mechanical restraint, physical restraint, rapid tranquillisation (with breakdown of intramuscular and oral) and seclusion. The following definitions were used for data collection:

- '*Mechanical restraint'* was defined as to 'the enforced use of mechanical aids such as belts, cuffs and restraints to forcibly control a patient's movement for the prime purpose of behavioural control'.
- '*Physical restraint'* was defined as 'any direct physical contract where the intervener's intentions is to prevent, restrict, or subdue movement of the body, or part of the body of another' (Department of Health, 2015). Physical restraint includes the following positions: prone (patient is chest down), supine (patient is held on their back), side standing, seated, kneeling or as a restricted escort.
- '*Chemical restraint'* was defined as 'the use of medication which is prescribed and administered (whether orally or by injection) for the purpose of controlling or subduing disturbed/violent behaviour, where it is not prescribed for the treatment of a formally identified physical or mental illness'. Data for PRN was deemed unreliable due to a service provider recording, thus was not included in this report.
- '*Seclusion*' was defined as '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' (Department of Health, 2015).

Data was collected pre and post HOPE(S) commencing support. 'Pre' data was collected between 0-15 months (average of 7 months) prior to HOPE(S) (T1); and 'post' refers to data after HOPE(S) commencing until the end of the intervention or end of data collection for the study (17th March 2025) (T2). At T2, data was collected between 1-28 months (an average of 10 months). Use of restrictive practices (including seclusion) was assessed by the average number of their use per month.

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[2] Per month was calculated for the following outcomes: access to fresh air (in number of days), number of meaningful activities, number of incidences where restrictive practices were used and whether physical health checks were performed once a month. It is important to note that number of months may vary between individuals due to differences in the number of months they have received HOPE(S) support.

Physical health checks

Data was only collected for those who received intensive HOPE(S) support (n = 60) by clinical staff as to when, in dates, physical health checks (including plans and reviews) were carried out for the individuals receiving HOPE(S) support. For analysis, we identified whether the individual had received a physical health check at least once per month for the duration of receiving HOPE(S) support. Data was only collected since the start of the HOPE(S) intervention.

Barriers to Change Checklist (BCC)

Data was required to be collected for all individuals who received HOPE(S) support regardless of type (intensive or consultancy). Barriers to Change Checklists (BCCs) were completed by clinical staff teams. Although clinical teams were asked to complete the BCC within four weeks of HOPE(S) involvement, teams were required to undertake the HOPE(S) training before completing the BCC. It is therefore possible that not all clinical teams completed the BCC within four weeks as they have yet to complete the required training. The BCC is a 36-item tool to help clinical teams identify the barriers which may be preventing someone moving out of LTS. Professionals completing the BCC must have had the HOPE(S) 2-day clinical training. Example items include: 'Is there a graded reintegration in place?' and 'Has [person's name] significant incidents been analysed in detail?'. Responses are 'yes' or 'no' to all items; higher scores indicate more barriers to moving out of LTS. There are four domains to the BCC, each indicating a type of barrier which may be preventing someone moving out of LTS: 'engagement and system factors', 'opportunities and environment', 'preventing risk', and 'individual'.

The completion of the BCC triggers the identification of key intervention targets, which are goals set by clinical staff teams to help individuals move out of LTS. Data was collected as to what were the key intervention targets (from the team's SMART intervention plan) and whether they were met. The data as to whether key intervention targets were met were included in this report (no other data).

Family functioning (for family members receiving Respond therapy): SCORE-15

Systematic Clinical Outcomes and Routine Evaluation (SCORE-15) is a 15-item measure to assess family functioning engaged with therapy (Hamilton et al., 2015). This data was collected by the Respond practitioners to measure change in family functioning in those who engaged with their service. Example items include: 'things always seem to go wrong for my family', 'it feels miserable in our family' and 'we trust each other'. The SCORE-15 uses a 6-point Likert scale. A total score was created by reversing all the relevant items and summing together individuals scores; higher scores indicate worse family functioning. Data was collected at the during the first session (T1) and either in the middle or at the end of therapy (T2); ranging between 7 and 20 months (an average of 9 months) following data collected at T1.

Quality of life of clinical staff: ProQOL

The Professionals Quality Of Life (ProQOL) is a 30-item measure to assess professionals' quality of life (Stamm, 2010). 'Professionals' refers to individuals in 'helping' professions at an individual, community, national or international level; this includes professionals such as healthcare workers, teachers, social workers and firefighters. The ProQOL assesses quality of life through three components: job-satisfaction (compassion satisfaction); burnout; and work-related or vicarious trauma (secondary traumatic stress). Total score for each of the three sub-factors (compassion satisfaction, burnout and secondary traumatic stress) is created by summing together the scores from the relevant items (Stamm, 2010). Professionals, i.e., clinical staff who engaged with HOPE(S), data was collected within 4 weeks of HOPE(S) commencing

(T1) and then between 3 and 15 months (an average of 5 months) following T1 (T2). All staff of individuals who received support from HOPE(S) were asked to complete the ProQOL regardless of the type of support received.

A summary for completion of measures included in this report is included in ***Table 2*** below:

Table 2. Number of participants who completed measures (including data across multiple time points* where appropriate)

Outcome measure	***T1 n***	***T2 n***	***T3 n***
Quality of life: YQOL-SF**	4	1	-
Quality of life: MANS-AS**	5	2	3
Quality of life: Mini-MANS-LD**	15	9	3
Quality of life: HOT**	7	3	2
Access to fresh air**	60	57	-
Engagement in meaning activities**	61	56	-
Mechanical restraint**	59	60	-
Physical restraint**	58	60	-
Chemical restraint**	57	60	-
Seclusion**	60	59	-
Physical health checks**	51	-	-
Barriers to Change Checklist	108	-	-
SCORE-15	11	8	-
ProQOL: Compassion satisfaction	376	65	-
ProQOL: Burnout	379	68	-
ProQOL: Secondary traumatic stress	377	68	-

* For data collected at multiple times points, these timeframes differed for each of the measures presented:

(i) For quality of life, T1 refers to the baseline taken within the first four weeks of HOPE(S) commencing, T2 refers to 2-4 months since commencing HOPE(S); T3 refers to 5-7 months since commencing HOPE(S).

(ii) For access to fresh air and engagement in meaningful activities, T1 data refers to data collected for between 1 to 7 months (an average of 2 months) prior to HOPE(S), and T2 data refers to between less than a month to 30 months (an average of 10 months) since commencing HOPE(S);

(iii) For type of restrictive practice, T1 data was collected between 0-15 months before HOPE(S) (an average of 7 months) and T2 data was collected between 1-28 months (an average of 10 months) since commencing HOPE(S);

(iv) For physical health checks and the Barriers to change checklist, this was only collected following the start of the HOPE(S) intervention.

(v) For family functioning (SCORE-15), data was collected during the first session (T1) and either in the middle or at the end of therapy (T2); ranging between 7 and 20 months (an average of 9 months) following data collected at T1.

(vi) For staff/professional quality of life, T1 refers to a baseline taken within the first four weeks of HOPE(S) commencing and T2 refers to data collected 4-14 months (an average of 5 months) since commencing HOPE(S).

**Data was only required for individuals who were receiving HOPE(S) intensive support, but in a few cases, data from those receiving consultancy support was also collected and analysed. However, for physical health checks, data was only collected for those receiving intensive support.

4.2.2 Statistical analyses

Before analysis, the quantitative patient clinical data was delivered to the research team in the form of pseudo-anonymised Excel spreadsheets. Pseudo-anonymisation of the data involved stripping it of any identifiable information such as: the names of individuals who are engaged with the HOPE(S), family members/carers, clinical care staff/professionals; their date of birth (DOB), address, email, or phone number; their job titles; the names of participating NHS trusts, hospitals, or units. The data collected were entered into SPSS software version 29 (2023) for all statistical analysis. The dataset underwent a data cleaning process to address the data entry errors, recoding, missing values, and outliers.

Regarding the analysis, descriptive statistics (n, %) were firstly performed to determine how many individuals supported through HOPE(S) have ended LTS as of 17th March 2025. This includes identifying how many individuals have moved back into their community straight from LTS. Descriptive statistics (M, SD, and range) were performed to measure the how long individuals were in LTS before HOPE(S) and until LTS ended (days and months). Reasons as to why individuals have not moved out of LTS were also included in this report.

Secondly, descriptive statistics were performed (as described below) for all the outcome measures (apart from SCORE-15). For family functioning (SCORE-15), the cut-off for clinical or reliable improvement in therapy over time was used following Miller et al.'s (2023) recommendation, i.e. if an individual's score lowered by 9 points and crosses the score of 40 (known as the threshold) then family functioning 'significantly improved'. If an individual's score lowered by 9 points, and does not cross the threshold, then their family functioning has 'reliably improved'. The number of those with no change, significant or reliable improvement in family functioning is reported.

Descriptive statistics (m, SD and range) was performed for the BCC, quality of life outcomes, access to fresh air, engagement in meaningful activities and use of restrictive practices (restraint and seclusion). The mean and standard deviation for each of the sub-scales was calculated for the BCCs completed during the first 4 weeks of HOPE(S) commencing and overall, to identify the key barriers to moving out of LTS. The number and percentage of key intervention targets which were successfully achieved is also reported.

For the physical health checks, the number and percentage of those who had received physical health checks monthly for the duration of HOPE(S) was calculated. It is important to note that for some individuals who received intensive support they moved from, or into consultancy support and therefore, this data is missing for these months.

Paired t-tests were performed if the sample size was accepted to determine if there was a change in quality of life (individual and professionals) following the implementation of HOPE(S). Additionally, paired t-tests were performed (if the sample size was acceptable) to determine if there was a difference in access to fresh air, engagement in meaningful activities and use of restrictive practices (restraint and seclusion) between pre and post HOPE(S) commencing. Additionally, assumptions were tested (Shapiro-Wilks test of normality).

4.3 Ethical approval

Ethical approval for this study was obtained from MMU (the sponsor for this research) (EthOS ID: 46401), the South-East Scotland Research Ethics Committee (10th May 2023) and the Health Research Authority (16th May 2023) (IRAS Project: 319279). Any amendments to the protocol were approved prior to implementing them.

QUALITATIVE

RESULTS SECTION

- Themes and sub-themes
- Co-production

5. Qualitative thematic analysis: evaluating the perceived impact and the implementation of HOPE(S)

The following section presents the results from the first study based on the reflexive thematic analysis of qualitative data. Five themes and twenty sub-themes were identified, capturing the vastness and richness of the data collected (***Figure 4***).

Figure 4. Themes and sub-themes capturing perceptions of LTS and the impact of HOPE(S)

Theme 1

LTS has a devastating impact on people and their families

- Neglected basic human rights and quality of life
- Hopelessness, fear and trauma
- Dehumanisation
- Fighting the system
- Isolation

Theme 2

HOPE(S) likely leads to better care and positive culture change

- Becoming 'unstuck'
- Change in general practice
- Pushing back against systemic barriers

Theme 3

HOPE(S) can improve the quality of life of people in LTS as well as family members and staff

- Building trust and hope though meaningful connections
- Enjoying a meaningful life
- Validated experiences through the trauma-informed Respond service
- Isolation reduced through HOPE(S) peer-support family forum
- Staff's confidence and morale improved

Theme 4

There were challenges that impeded the success of HOPE(S)

- Lack of shared understanding and clarity as to what LTS is in practice
- Pushing back against closed cultures
- Working in isolation
- Training uptake

Theme 5

HOPE(S) should continue and expand beyond its original purpose

- Proactive as well as reactive (prevention focus)
- Better communication between families and staff is needed
- Accessible to all individuals in LTS, disregarding of diagnosis and setting

5.1 Theme 1: LTS has a devastating impact on patients and family members

There was a strong consensus that LTS has a devastating impact on the individual in LTS (n = 71). Those with lived experience of restrictive practices describe being in LTS as a horrible and stressful experience which "makes you more angry and more distressed" (participant 64, lived experience). They felt that their experience and environment during their time in LTS was "traumatic", "overwhelming and anxiety-provoking". Consequently, LTS was perceived to have impacted both the families and staff involved.

5.1.1. Neglected basic human rights and quality of life

Those with lived experience described how their physical and mental health deteriorated as clinical teams neglected their basic human-rights.

> *"I think you're very much ignored considering you're in a place where you're being supervised 24/7, you're still ignored quite a lot or a lot of the time it's just negative comments being thrown at you. So, considering you're a mental health hospital, you'd think they would understand mental health but if anything, they're very far from it. Obviously considering they've had all this training and everything else, a lot of them barely know anything. That sounds a bit harsh, but you will get a lot of comments which would then make you worse. I think I had one, she went on to be a manager which I wasn't happy about. She told me that if I did want to die, I would take a stronger overdose." (participant 64, lived experience).*

> *"...it made me more wound up because you're already feeling out of control, and I was already in that position because of other comments that were made, and I didn't know how to deal with the stress so I'd take it out on myself. Because I couldn't self-harm by cutting, which is what I used to do, I would then bang my head. The staff wanted to intervene but were actually told by their manager to just leave it and just sit there and basically watch." (participant 64, lived experience)*

> *"...he had said to her, or the team had said to her 'What can we do? What do you need? what can we do for you?' And she said, 'I just want a hug' and they were like, 'You never touch people'. So, I said, 'What about her human rights?'" (participant 9, HOPE(S) practitioner).*

For individuals in LTS, enforced isolation meant a lack of meaningful human connection, compassion and empathy from some clinical teams or staff, especially during times of severe distress. This included a lack of physical human contact. Also, individuals in LTS were often denied basic amenities and clinical staff were described as not meeting their needs. Individuals with lived experience felt that support was unavailable, and staff were too busy to (meaningfully) engage with them. Hurtful comments were common by certain clinical staff, which contributed to their distress. Additionally, they expressed that when they were in LTS they deeply missed their families (including family pets) as well as the activities they used to enjoy and that were meaningful to them, such as going to the park and listening to music. There was a strong consensus that LTS likely led to a culture that focused more on 'risk'[3] management rather than a balance with a human-right based approach.

The neglection of a human-rights approach to care was described to have led to worse outcomes, including poorer quality of life, for individuals in LTS.

> *"So, she's been officially in long term segregation since [date], not walking, not talking and she's now not eating hardly anything in about five or six weeks. She's lost so much weight." (participant 20, family member).*
>
> *"Their quality of life, I would say, is challenged. Limited access to personal items, limited access to family, limited or no access to fresh air…" (participant 22, professional: commissioner).*
>
> *"At one point I said, please just let her die because it feels like you are just killing her anyway." (participant 18, family member).*

There was a strong consensus the individual's quality of life and symptoms had worsened whilst in LTS. In particular, the lack of quality of care and life was the source of desperation, devastation and frustration amongst family members. Family members described how they saw their loved one's mental and physical health deteriorate leading to greater mental health difficulties and distress. One family member recalled deeply regretting taking their loved one to hospital to seek care and treatment as they have witnessed their physical and mental health deteriorate in LTS (participant 21).

5.1.2. Hopelessness, fear and trauma

There was a common feeling of hopelessness across all the groups before HOPE(S).

> *"I think for some service users they might feel hopeless and are not particularly willing or not particularly in a position where they feel able to be hopeful enough that somebody else could come in and could help them." (participant 1, HOPE(S) practitioner).*
>
> *"I've certainly had patients who have felt hopeless and like there's nothing that's going to change about the situation." (participant 38, professional: clinical staff).*
>
> *"I have come across over and over and over again people stuck. And I don't mean just stuck in a room, I mean stuck in a place where there is no hope. There's no way out, it's intractable." (participant 33, professional: commissioner).*
>
> *"There was nothing I could do. You just feel hopeless." (participant 18, family member).*
>
> *"…they've tried their best. They don't know what else to do…" (participant 52, professional: clinical staff).*

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[3] We would like to acknowledge that the term 'risk' within this context can have negative connotations. During sense-checking authors were informed that phrases such as 'risk management', 'risk averse' and 'positive risk' could infer that the individual is the risk rather than poor clinical practices and environment as the risk. Future research and discussions are needed in this area to determine the best phrase to adopt going forward. For now, these terms will be avoided where possible and where not possible, as it is the language used by professionals, apostrophises will be used to acknowledge the latter. Direct quotes however will not be adapted.

All groups felt they lacked the ability or resources to stop the seemingly never-ending cycle of restrictive practices. Individuals in LTS seemingly gave up hope; believing that they would be constrained to a life of enforced isolation with little to no support, engagement in meaningful activities or human contact. Family members and staff found it difficult to see positive prospects for the individual's future if clinical practices remained as they were. One family member (participant 17) disclosed that their loved one lost so much hope that they attempted suicide to escape LTS.

Additionally, clinical teams felt stuck due to systemic barriers around moving someone out of LTS.

> *"Well, they're actually in long-term segregation. They don't have any clear exit plan. Their pathways are unclear. They have a lot of restrictions in place." (participant 22, professional: commissioner).*
>
> *"...there was a lot of challenges that we were facing on a daily basis and that was impacting on the team and we did feel stuck, but we also felt pressure from outside agencies that didn't understand the complexities and the harsh reality of facing assaults on a daily basis... If we do something wrong, the external professionals will hold us to account and it didn't allow for any growth or movement forward" (participant 57, professional: clinical staff).*

Clinical staffing teams became hopeless within a system that was perceived to be preventing people moving out of LTS. Clinical staff were fearful to make mistakes as they felt immense pressure and responsibility imposed by upper management and external bodies or policies. This is strongly expressed by a member of clinical staff who said, "you can't breathe" (participant 32). Simultaneously, many described how individuals were unnecessarily contained in LTS solely due to delays in hospital or community transfers, or in being discharged. Together, professionals felt that there were organisational processes and policies which act as systemic barriers keeping individuals in LTS for longer than necessary. It was felt amongst clinical teams and commissioners that moving someone out of LTS or ending the cycle of restrictive practices may not only fall on clinical teams but also the entire system.

Fear was often experienced alongside hopelessness amongst all the groups. Many described how LTS was a frightening experience for individuals in LTS and families were fearful for their loved one's lives.

> *"He was so frightened of being shut in there that he wanted the bed in the long-term isolation bit, in the bigger space. There was nothing in there [in the room]." (participant 19, family member).*
>
> *"The amount of times when we thought he was going to be dead." (participant 17, family member).*

For the individual in LTS, the environment of LTS was seen as frightening which lacks amenities and meaningful human contact. There were some cases where LTS was viewed as extremely dangerous likely leading to significant harm, or even death, for individuals in LTS. Family members expressed persistent worry for the care received, or lack thereof, in LTS. This was often accompanied with anticipating the worse when receiving calls from professionals or loved ones. The fear expressed here was justified by the traumatic events experienced by the individual in LTS and/or their family members. Individuals in LTS were described to be traumatised and re-traumatised by the system and by certain clinical staff. This includes safeguarding incidences where individuals witnessed traumatic events and/or they themselves were abused whilst in LTS.

> *"He was locked behind a door and the only interactions was through a hatch and still abuse, psychological and physical, took place." (participant 32, professional: clinical staff).*
>
> *"It just brought back so much trauma from [the hospital] where he was literally fed through a hatch for months on end and just medicated and left in his own faeces." (participant 17, family member).*
>
> *"And then they end up traumatised from being in hospital, then re-traumatised… it's a never-ending circle." (participant 22, professional: commissioner).*

It was felt that certain providers, staffing teams and/or clinical staff failed to protect the health, wellbeing and human-rights of the individual in LTS, leaving them vulnerable to neglect, harm and abuse. Re-traumatisation was also common during hospital transfers especially when individuals were forced to move back to hospitals where they were abused or neglected. Due to the traumatic experiences and/or poor practices by certain clinical teams or staff, individuals in LTS and families said they became mistrustful of clinical teams and the 'care'[4] system generally.

In contrast, clinical teams felt hopeless in a cycle of restrictive practices because they were often fearful for the safety of others and themselves.

> *"…it was very much organisationally fear-driven and team fear-driven. We don't want to open the door, we're not safe." (participant 57, professional: clinical staff).*
>
> *"… there is sometimes a fear and a worry about, "Am I going to get hurt, or is my colleague going to get hurt?" And absolutely, you can argue that that shouldn't dictate clinical decisions, but it has to be taken into consideration. Staff need to feel safe to look after somebody, I think." (participant 42, professional: clinical staff).*

Clinical staff are subjected to harm and exposed to traumatic events during their occupational duty, and this creates a sense of fear when supporting the individual in LTS. Clinical staff described incidences of physical aggression towards staff members leading to a sense of fear towards the individual in LTS. Often staff had been seriously injured; physical and sexual threats were also common. Across all groups, it was acknowledged that staff's fears may have also led to a cycle of restrictive practices as well as acts as a barrier for moving the person out of LTS.

> *"… you do find staff so traumatised that they just point blank surprised, "I'm not working on here if you're bringing that person out." …" (participant 3, HOPE(S) practitioner).*
>
> *"A lot of the time with people, there was this thought of there's so much risk there, is it worth it? Then people were too scared to even try." (participant 44, professional: clinical staff).*

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[4] Family members, who were interviewed, challenged the phrase 'care system' stating that it cannot be a system of 'care' where human-rights is neglected and there are incidences of abuse.

> *"It was a slippery slope to long-term segregation. We inherently knew it wasn't good, but we would almost like fear-driven and safety practice to use long-term segregation…" (participant 57, professional: clinical staff).*

Many clinical staff talked about the uncertainty as to how to support the individual whilst ensuring the safety of others and themselves. Staff described how their feelings of fear created reluctance to engage with the individual in LTS. Their fear seemingly played an important role in their decision making or 'risk' management, where clinical teams often outweighed their feeling of fear compared to the risk of harm of the use LTS to the individual. Clinical teams who felt hopeless or 'stuck' in this situation also described low morale and compassion fatigue as well as being burnt out due to the seemingly never-ending cycle of restrictive practices.

5.1.3. Dehumanisation

Many participants felt that individuals in LTS are often dehumanised by clinical teams or staff.

> *"…it dehumanises my gorgeous son" (participant 40, family member)*
>
> *"…but we almost sort of dehumanise the person" (participant 41, professional: commissioner)*
>
> *"…Then also you do find staff so traumatised that they just point blank surprised, "I'm not working on here if you're bringing that person out." The person becomes dehumanised…" (participant 3, HOPE(S) practitioner).*

Many described LTS as "serving a prison sentence" (Participant 5, HOPE(S) practitioner) where patients were viewed as criminals rather than vulnerable individuals seeking care; this was internalised by the patients themselves. See ***Figure 5.*** which provides an artistic representation of LTS from someone with lived experience which further supports this sub-theme.

> *"He went in as a happy go-lucky boy with a catatonic breakdown and he's now classified as a very dangerous person, and he thinks he's dangerous. He thinks he needs an Ironman suit to keep his arms and legs safe. He is completely destroyed as a human being." (participant 40, family member).*
>
> *"Then he did see it as a punishment and he'd say, oh I'm in trouble. He used to say am I in trouble again, am I going to seclusion? That's not what I wanted to hear because that's not what it was for. To me, seclusion and segregation was either to keep others safe or to keep him safe, not punishment but that's how it feels." (participant 29, professional: clinical staff).*
>
> *"And the problem we have in managing her now is she thinks she deserves to be punished and to suffer and does not want to come out of segregation particularly." (participant 30, professional: clinical staff).*

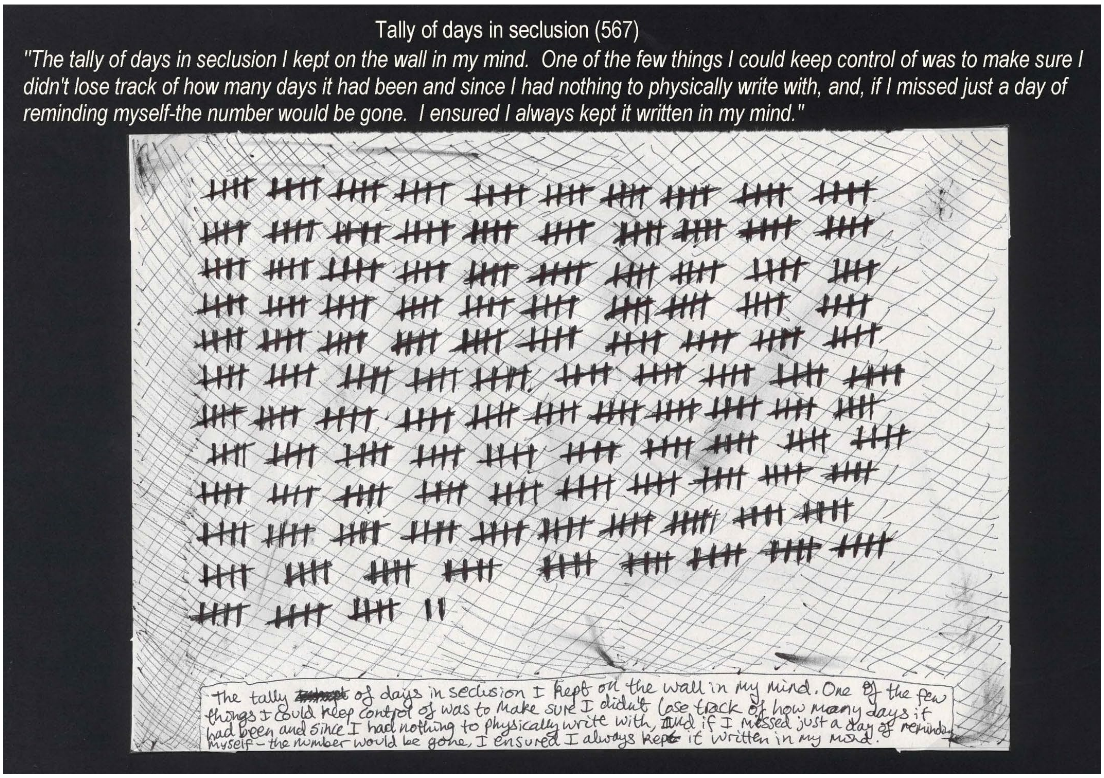
Many described how the dehumanisation of patients in LTS was likely due to the feelings of fear experience by clinical staff. Yet, the sense of fear is not only created through witnessing or experiencing a traumatic event but also in reputation as stories about serious incidences seem to echo across staffing teams and hospitals before individuals are transferred onto their ward. Participants described how individuals in LTS lose their sense of self overtime as they became dehumanised by clinical staff. They perceived themselves as dangerous people, just as clinical staff do, instead of seeing their own behaviours due to their distress. Individuals in LTS begin to fear that they will hurt others, and they may feel that they deserve to be in LTS. Hence, some individuals may self-isolate because they believe enforced isolation will protect others from themselves. This is devastating to family members as they feel that their loved one loses who they are whilst in LTS as they internalise the 'risk' narrative.

Participants felt that there was a need to raise awareness around how the environment and the system lead to increased distress in individuals in LTS which may lead to violence and behaviours that cause harm; rather than blaming the individuals for these behaviours and viewing them as criminals.

> *"In my eyes, he's definitely not a criminal. The system he's being forced to live in, unfortunately I feel created behaviours that have been challenging and as a result of that he's punished." (participant 17, family member).*
>
> *"...if you take someone out of their real social environment and you put them somewhere that's completely artificial then you're going to get this nasty feedback cycle of it's just re-traumatising a lot of the time. You get a very nasty vicious cycle of restriction. So, the person is distressed, so they act out, and so more restrictions are put in and you can't get the restrictions off." (participant 24, professional: clinical staff).*

Many participants felt that clinical staff were attributing behaviours incorrectly believing that the individual is intentionally acting aggressive towards staff due to their character, rather than due to their environment in LTS and/or their distress. One staff member (participant 35, staff) felt that individuals in LTS become more dangerous to care for, leading to more restrictive practices, such as LTS. Hence, participants feel that there seems to be a lack of understanding and awareness amongst certain clinical teams around the importance of the environment and meeting the needs of children and young people, autistic adults and/or adults diagnosed with a learning disability.

Figure 5. Artistic representation of LTS by someone with lived experience



Tally of days in seclusion (567)

"The tally of days in seclusion I kept on the wall in my mind. One of the few things I could keep control of was to make sure I didn't lose track of how many days it had been and since I had nothing to physically write with, and, if I missed just a day of reminding myself-the number would be gone. I ensured I always kept it written in my mind."

The tally ~~[illegible]~~ of days in seclusion I kept on the wall in my mind. One of the few things I could keep control of was to make sure I didn't lose track of how many days it had been and since I had nothing to physically write with, and if I missed just a day of reminding myself - the number would be gone, I ensured I always kept it written in my mind.

Note: Consent has been obtained to use this figure in this report.

5.1.4. *Fighting the system*

Family members said that, whilst having a loved one in LTS is not easy, it is the system itself which made their experience worse or traumatic. Family members who tried to get their loved one support and appropriate care for their difficulties described this process as "incredibly difficult" (participant 18, family member), negative and/or traumatic.

> *"There were times when I was on the phone breaking my heart to professionals saying, "Please can you just help him? Please can you just get him out? I can't take no more." So, I always knew that I would need to talk to somebody after I came out of this." (participants 16, family member).*
>
> *"Now, we wish we [had] never taken him in the hospital. We regret taking him [to] hospital. They did not help. Maybe they can't help. They say [they will help] and then they take time. They take long time. They don't treat straight away. They don't." (participant 21, family member).*

They said that they lacked support as carers[5], services for loved ones were non-existent and that family members often felt let down and felt helpless as the system could not or did not support or help them. Family members felt desperation to not only get care, but for the hospital to do something about their care. As a result, many families describe fighting the system to improve their loved one's care.

> *"... they've had to fight for their loved one who's in care to be, whatever it is that they need, whether it's to have the abuse that's happened recognised or to be moved or to change the care that they're receiving because they don't feel like it's been adequate or whatever it is. But there's often that real sense of there's been a long fight." (participant 14, Respond practitioner).*
>
> *"It's just been a constant battle to fight, fight, fight." (participant 15, family member).*
>
> *"We've been fighting and fighting for my sister to have some psychology input and all they said is a hospital setting is not the place to have that." (participant 20, family member).*

Some family members disclosed they felt guilty for not being able to support and advocate for their loved one better whilst they were in LTS; one participant labelled this feeling as "mum guilt" (participant 12, Respond practitioner).

However, many participants said that, despite their strong desire to be a part of their loved one's care, family members often are pushed out of their loved one's care by professionals.

> *"So, we're carers but we're not carers. We have been castrated. It's a vicious, horrific system." (participant 40, family member).*
>
> *"All I want is an update on how my daughter is, please." (participant 18, family member).*

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[5] It is important to note that some family members did not feel that they were carers or that were 'caring' for their loved one. This term was only used here to refer to those who do describe themselves as carers. Direct quotes are not adapted.

> *"We begged them. We said, "Please, we've all had such a horrific experience there, please don't send her back," but they did." (participant 20, family member).*

Some family members described difficulties in navigating a hostile system. Disagreements and conflict were common between family members and professionals. This was further corroborated by those with lived experience who said that "even with my parents, they wouldn't listen to them" (participant 67). Family members often felt not heard by professionals leaving them to feel powerless lacking the resources, capacity or authority to get their loved one adequate care, further adding to the feeling of helplessness about the situation.

Additionally, there was a common perception that professionals blamed family members for worsening their loved one's care and/or condition whilst they were in LTS.

> *"...I think that's what I've seen quite a bit, that families get positioned as the ones causing the trauma in the loved one because of how they're behaving or interacting... I mean I still find it just hugely amazing and shocking that professionals find families, in my experience anyway, such a threat or that families have to be kept out. So I do think there is a lot of blame on parents, mums, that they are the cause of this individual's distress or anxiety and therefore they must be out of the picture rather than actually working together to support the person..." (Participant 12, Respond practitioner).*

> *"You look at the culture of any institution and is it welcoming of families or does it blame and shame. Gosh, I mean I could give you lots of examples where hospitals have raised safeguarding against family members in a really punitive, aggressive way. It's so unhelpful..." (participant 53, HOPE(S) practitioner).*

Many participants described how some professionals and providers were seemingly hostile and accusatory towards family members; perhaps unemphatic to their distress. Some family members described how they were threatened by professionals and providers who subsequently stopped visitation. In such cases, family members described how there was a power imbalance which made them feel defeated at times; further adding to feeling powerless.

5.1.5. Isolation

Family members described their experience as deeply isolating and felt they were marginalised by society.

> *"I found incredibly isolating. People don't know how to talk to me. If I do tell people, and I don't tell people very often, then I think, "I will do this," but almost you can see them running away from me so it's very isolating." (participant 18, family member).*

> *"...it's almost like they were on an island in this huge desert and other family and other friends were pushed way out." (participant 13, Respond practitioner).*

> *"...thinking about the early years and the trauma that can be experienced from having a child with disabilities and the challenges it brings in our society, in how marginalised families can become and how isolated, this happens throughout, again feeling isolated and marginalised." (participant 12, Respond practitioner)*

> *"They're made to feel very isolated with their feelings that they're troublemakers or they're the ones causing the issue." (participant 12, Respond practitioner)*

Family members often felt alone in their experience; both in relation to having a loved one in LTS and navigating a potentially hostile system. They talked about a lack of understanding from others who do not share the experience leading to them to grow tiresome in attempting to educate others about the issues that surround LTS and their fight. ‘Others’ included extended family and friends as well as professionals. Family members felt shame, frustration and detachment from others who were unemphatic of, or pass judgement on, their situation; this further added to feelings of blame and isolation about their situation.

Additionally, family members stated the location of the hospital led to isolating their loved one away from familial support and visitations. They talk of emotional and financial challenges when trying to visit their loved one in hospital, especially where this was located far from home. In some cases, visiting their loved one was not possible at all due to the hospital being too far away from home.

5.2 Theme 2: HOPE(S) likely leads to better quality of care and positive culture change

The majority of participants said that their experience of HOPE(S) as a whole had a positive impact on the individual’s care as well as a change in the mindset and culture amongst staffing teams. Many described how HOPE(S): helped staff practices; led to a more positive culture amongst teams; and, helped to address some of the systemic barriers. Simultaneously, when asked which component they wished to keep going forward, they described that the whole programme (or model) was needed rather than just one or two components to ensure the success of HOPE(S).

> *“I think it's really difficult to kind of salami slice bits of HOPE(S) off. I think it would be really difficult to do that. I mean you need practitioners. The barrier to change checklist I think is important. The staff training is important. I don't see how there are areas which you could slice off really from my perspective… if people are serious about getting people out of LTS and reducing LTS, then I think it's going to be difficult to get that change leaving it just to MDTs, given that practice around LTS is so vastly different across the country, I just don't see how that will be done without having a specialist service providing that input.” (participant 38, professional: clinical staff).*

5.1.1. Becoming ‘unstuck’

Many believed that HOPE(S) led to a positive change in staff practice which was perceived to have reduced restrictive practices, including the use of LTS. Professionals described how HOPE(S) enabled them to become solution focused and feel ‘unstuck’ compared to being fear-driven or unable to see suitable and safe alternatives to restrictive practices.

> *“… we couldn't see a way out and HOPE(S) for us provided us with a way out, some solution-focused instead of fear-driven.” (participant 57, professional: clinical staff).*

> *“HOPE(S) being able to have a framework to engage with that real lockdown, this patient is so dangerous we can’t unlock the door because she will kill staff and for HOPE(S) to go into that and to begin to unlock it and to free up the team even before the move is, I have to take my hat off to that level of clinical intervention really.” (participant 72, professional: commissioner).*

> *“I think that gave us potential to give kind of lots of hope and people can move out of that kind of situation.” (participant 24, professional: clinical staff).*

> *"…But I think it just made it more cohesive for the team to try and action the tasks and it wasn't just, I did the training and I was trying to push it and when I wasn't on shift, nobody else was also doing it, because they'd all done the training. It was everybody's responsibility to bring that forward." (participant 23, professional: clinical staff).*

Many talked about an improvement clinical staff's perceived competence in supporting individuals in LTS and becoming advocates for least restrictive practices. Clinical staff felt more knowledgeable and felt better equipped at supporting the individual when distressed; this improved their perceived capacity to stop the seemingly never-ending cycle of restrictive practices and fear. Hence, HOPE(S) gave clinical staff hope about the future for the individual in their care. Moreover, many described how HOPE(S) helped to motivate and unify the team by sharing the common goal of ending LTS for the individual.

For many clinical staff, they talked about the various components of HOPE(S) and how they contributed to becoming 'unstuck'. Firstly, the training helped staff to understand the new model of care, the role of the HOPE(S) practitioner, as well as the impact of LTS for individuals in their care.

They talked how it raised their awareness about the impact of LTS on patients and gave them time to reflect on their practices. There were, however, some difficulties in seeing how HOPE(S) would be implemented in practice, which was addressed by the inclusion of HOPE(S) practitioners who were role models and led the approach.

> *"…it was good training. Obviously, we got the training at the beginning which looks at the model and the vision and things like that. It's sometimes hard to understand in that moment before you've tried to implement it how it's going to be implemented." (Participants 25, professional: clinical staff)*

The importance of the HOPE(S) practitioner for the implementation of the model in practice was mentioned the most.

> *"I think for me, the unique thing about HOPE(S) is the fact that they are on the ground. So, you've got people like me who garble on and say what you should be doing but I don't get in there, get stuck in and do it. Whereas the HOPE(S) work with individual staff members and I know that the staff have actually said that they really, really appreciated that because a lot of them are at the end of their tether. They've tried their best." (participant 50, family member).*
>
> *"But that support has also been really helpful because it lays another foundation that it's not just a chalkboard exercise where we're going to teach you how to do this and then we're going to leave you alone." (participant 28, professional: clinical staff).*
>
> *"So, I think some of it is about a team seeing that someone else is helping, is holding their hand, is standing alongside them." (Participant 57, professional: clinical staff).*

The adaptability and flexibility of their approach was believed to be key in the success of HOPE(S), e.g., providing practice leadership and/or intensive support. Many of the staff members who viewed the HOPE(S) positively stated that practice leadership was most useful in understanding and implementing the model in practice. Through practice leadership staff became motivated and confident in creating opportunities to build meaningful connections and relationships with the patient; staff became solution focused rather than fear driven. Staff members who found practice leadership useful felt understood and supported by the HOPE(S) practitioner; they were viewed as being “very hands-on” (participants 24 and 38, staff) in facilitating the implementation of the model.

Additionally, many said that the interpersonal skills of the HOPE(S) practitioner played an important role in the implementation of the model. This was especially talked about by clinical staff who for some described their initial interactions with the HOPE(S) practitioner as being poor. Here, staff described that during their initial interaction (with the HOPE(S) practitioner) they felt blamed, not understood, and accused of poor practices. In these cases, clinical staff described how as a team they became more defensive and less engaged with the programme. For others, they described how the HOPE(S) practitioner approached the teams with openness and empathy, which made staff feel supported and understood.

Lastly, the BCC was helpful because staff were able to focus on ‘quick wins’ or short-term attainable goals.

> *“So, the goal setting was really effective, I thought, as well, because all the small wins were big wins as well.” (participant 26, professional: clinical staff).*
>
> *“I think a really useful tool to focus people on what needs to happen and break it down. I think the thing that I really like about the HOPE(S) approach has been that were as it all feels really overwhelming when you’ve got someone in long-term segregation, how on earth do you end it. But actually, breaking it down using the Barriers to Change Checklist to the steps, what's this, what's the smallest thing that you can actually do and achieve.” (participant 24, professional: clinical staff).*

When feeling overwhelmed, clinical teams found the BCC helpful because it focuses on smaller more attainable goals. This seemingly helped clinical staff to feel more in control about the situation and feel more competent in reducing restrictive practices where possible. Clinical staff stated that the BCC was useful to maintain the essence of HOPE(S) in the absence of practitioners. In a few cases, the BCC was useful for staff when attempting to implement the model throughout their team; whom many had not completed the HOPE(S) training. They stated that the BCC enabled them to educate others and advocate for least restrictive practices amongst the team. Hence, growing the essence of HOPE(S) without the presence of a practitioner.

However, some highlighted possible concerns about the implementation of the BCC. It was expressed that it takes time to formulate goals which may be a burden of staff who have an already high and demanding workload. Also, the quality of the BCC may depend on who completes it.

5.1.2. Change in general practice

Staff described how HOPE(S) led to change in their mindset about their approach to care, including a trauma-informed and human-right based approach to care.

> *“…it supported the staff to see okay, this could be a trauma response from him that’s happened at his previous hospital. Therefore, we need to avoid that at all costs and we need to make this a fresh start for him.” (participant 29, professional: clinical staff).*
>
> *“…you had to remember that you weren't working with what you see, it's what's going on underneath and what, you know.” (participant 34, professional: clinical staff).*

Many participants described a change in the use of language around the individuals and during their care plans or reviews. This was believed to be helpful when advocating for least restrictive practices within their clinical practice generally. There was also a strive to further understand the individual, rather than through a dehumanising lens, to prevent distress and possible re-traumatisation. In some cases, clinical staff stated how HOPE(S) improved their practice generally as they saw the impact and benefits of a more dignifying and compassionate approach to care, improving their communication and relationship with other patients.

Many felt that the HOPE(S) training was useful at helping to begin that culture change. Clinical staff felt positive and motivated to implement HOPE(S).

> *"...I think I would have gone to that training every week. It was so good. We just came away... I think going in to it we were a bit like, oh what's this going to be and when we came away, we were like HOPE(S) champions, we're going to do this and... it was just really positive. I think the videos and things that are shown within the training as well, is really quite eye opening." (participants 23, professional: clinical staff).*

However, many participants recognised that changing an ingrained culture takes time as it "doesn't happen overnight" (participant 73, *professional: commissioner).*

> *"...there is a sense of urgency and a recognition of the negative impact of being in seclusion and restrictive practice. I see that those have been kind of absorbed, those principles, despite the resistance." (participant 31, professional: clinical staff).*

> *"It's a long journey to unravel that and get people to think in a different way." (participant 33, professional: commissioner).*

It takes time for staff to change their thinking and practice. While some staff were resistant to embracing the HOPE(S) philosophy and approach, they changed their views over time when they started to see that the approach was working.

5.1.3. Pushing back against system barriers

The HOPE(S) practitioner was viewed as an 'external' overseer of the care received by the individual in LTS when advocating for least restrictive practices.

> *"...but there was a lot of pushback. This is where the HOPE(S) practitioner and it was down to the HOPE(S) practitioner, not the HOPE(S) model, was able to knock heads together..." (participant 57, professional: clinical staff).*

> *"The medics were really pushing back against it, but I think because [HOPE(S) practitioner] knew a lot of people, she was going above everybody's head. She was going to the directors and had it not been for that, we would have really struggled, so for us, it was brilliant having that." (participant 23, professional: clinical staff).*

> *"HOPE(S) also have a lot of clout because of being completely independent which gives them a level of authority and autonomy around how they do things." (participant 21, family member).*

> *"I think it's like having the model and having it be external people gives it a bit more clout, doesn't it, than if it's just your own team saying it I think. So yes, really, really helpful for us." (participant 50, professional: clinical staff).*

> *“The problem is, there’s no mediator between the local authority, the ICB, and the private hospital. But the HOPE(S) team would step in and say, “Hold on you guys, let’s get this all done. Let’s get this training sorted out. This is going to happen.” (participant 35, professional: clinical staff).*

HOPE(S) practitioners were viewed as having a wealth of experience as well as the effective interpersonal skills to successfully manage and pushback against systemic and environmental barriers. Despite the fact that practitioners themselves often felt they lacked power, HOPE(S) practitioners were viewed by others to have more power because they were ‘external’ or independent. It was believed that their independency enabled them to challenge staff (including senior and management staff), advocate for least restrictive practices and, to drive a sense of urgency to improve care; two key things that families and some clinical staff felt they could not achieve by themselves. Simultaneously, commissioners found it useful as practitioners were thought of as trusted persons who had valuable insights and perspectives about the quality of clinical practice occurring in hospitals, including private settings. Staff employed in private hospitals felt that the independent, but NHS based role of HOPE(S) practitioners was useful as they represented the NHS in these settings (“when you send the HOPE(S) team in, you’re sending the NHS in… So, it’s like having a commissioner day-to-day really” - *participant 35, professional: clinical staff*).

Many staff also reported that the inclusion of an external staff who was knowledgeable about the person in LTS was extremely useful during hospital transfers. Many described how hospital transfers were often traumatic and distressing for the individual, family members and staff involved. HOPE(S) practitioners were involved, or at least tried to be involved, in the logistics of the transition to support staff and to prevent the individual becoming distressed during the transfer. Often their involvement was perceived to have led to a stress-free transfer. Additionally, staff reported that the HOPE(S) practitioners were able to offer a detailed history of the patient upon their transition to a new provider which was useful in reducing the risk of re-traumatisation. HOPE(S) was commended for its ability to support transfer to another service as well as in continuing their work upon transfer (i.e., continuing to build trust and hope for the individual and support the new staffing team).

5.3 Theme 3: HOPE(S) can improve the quality of life of individuals in LTS as well as family members and staff

There was consensus (n = 71) that HOPE(S) leads to positive outcomes for the individual in LTS, the families and professionals supporting individuals in LTS. See ***Case study 1.*** which presents ‘Carly’s’ (pseudonym) story as an individual with lived experience whose quality of life improved through HOPE(S).

5.3.1. Building trust and hope though meaningful connections

HOPE(S) was believed to have led to deep and meaningful human connections between the individual in LTS and the HOPE(S) practitioner through relationship-based care, practice leadership and/or intensive support. This meaningful connection and building of trust seemingly gave people in LTS hope again overtime.

> *“…slowly he was able to build up trust in [loved one]” (participant 18, family member)*

> *“That was showing her that because the general message that she gets told all the time is that you’re a monster, nobody wants to be around you and that couldn’t be further from the truth. But for him to go in, that didn’t just show her that one, he was confident,*

> *two, he trusted her and knew that she wasn't a monster…" (participant 20, family member)*
>
> *"We feel [loved one] has finally started to gain some trust." (participant 21, family member)*
>
> *"That was a lot of it, was actually spending time with him and building up that trusting relationship…" (participant 7, HOPE(S) practitioner).*

Many said that building a strong bond with the individuals was the most important aspect of the role of a HOPE(S) practitioner. They were driven to build a trusting relationship with the individual in LTS who, for some, did not have anyone else including family and friends. HOPE(S) practitioners described simply talking and communicating with the individual as well as understanding the individuals' needs and past institutional trauma. Also, practitioners recognised the dehumanising impact of LTS on the individual's self-identity. They described helping the individual to think differently about themselves and their self-narrative: "I've had to explicitly say to people, *'I trust you'* when there is a feeling that nobody trusts you and you're this dangerous person" (participant 1, HOPE(S) practitioner).

Simultaneously, staff also described how the implementation of HOPE(S) lead to an improvement in their relationship with, and outlook of, the individual in LTS.

> *"The HOPE(S) model transformed the way clinical teams thought about individuals." (participant 45, professional: commissioner).*
>
> *"It started with the shift, instead of being fearful of the gentleman, how to be caring, how to look after him, how to enable him." (participant 53, professional: clinical staff)*
>
> *"…it also showed the staff that she's not like a lion, you can actually build a relationship with her." (participant 20, family member).*

There was a shift towards humanising the individual in LTS. Clinical staff were less likely to view the individual as a dangerous person, but rather someone who is in distress and may find it difficult to communicate their thoughts and feelings. In return, clinical staff described themselves feeling less fearful of the individual. Also, clinical staff said that they were better able to understand the individual as well as their needs; this helped staff to provide person-cantered care for that individual.

Over time, the individual in LTS began to be more trustful and hopeful for their future as they felt humanised. One family member describes how their loved one - whom prior to HOPE(S) unfortunately did not wish to live anymore - is now seemingly hopeful for their future and wishes to move out of hospital; and stated that "my daughter is only alive today because of HOPE(S)" (Participant 18, family member).

5.3.2. Enjoying a meaningful life

HOPE(S) was believed to have improved the quality of life of individuals in LTS, reducing restrictive practices, and in many cases ending LTS. This includes individuals in LTS feeling safe enough to be themselves again.

> *"…it was really positive because they made such a shift in [loved ones] mood because the staff were more present." (participant 16, family member).*

> *"...I can see a genuine smile now, he's smiling all the time and I can his sense of humour, his mischief is coming back..." (participant 15, family member).*
>
> *"...So [loved one] is doing far more than she did in the last couple of years now which is fantastic." (participant 18, family member).*

Although building trust took time and there were setbacks, this enabled individuals to engage in meaningful activities, get fresh air, reduce restrictive practices, engage in the community and often move out of LTS. Many described individuals having a better quality of life as individual was seemingly happier and showing fewer signs of distress. Many described how aggression and distress reduced amongst the individuals and how as a result they were subjected to less, or no restrictions. Many also stated that many of the individuals previously in LTS were now able to freely visit or are now living in the community. Additionally, family members believed their loved one became more like themselves again as they gained back their identity, humour, and sense of agency because of HOPE(S).

Improving the quality of life of individuals in LTS also had a knock-on effect on family members as they themselves felt better.

> *"His staff are amazing, I can relax that he's not going to get hurt, that's a big thing for me and [another family member], that he's cared for and he's not going to get hurt, that's the main one for me." (participant 15, family member).*
>
> *"Hope is what it means to us. So, the fact that they go in, they work there, it's all about least restrictive. It's about working with the person, the individual. They're amazing." (participant 17, family member)*
>
> *"So, there's often a pattern of if my loved one's having a good day, I'm having a good day..." (participant 12, Respond practitioner).*

Due to HOPE(S), family members were less concerned and fearful about their loved one's care. Many felt that they no longer had to fight the system as HOPE(S) practitioners were fighting on their behalf. Some were able to engage in therapy provided by Respond, because they were able to take the time to focus on themselves as opposed to constantly worrying and fighting for better care for their loved ones. Yet, many described that there was a interlink or interconnection between family members and their loved ones. Family members were happier when their loved ones were happier; and, when loved ones were having a bad day this negatively impacted family members.

5.3.3. Validated experiences through the trauma-informed Respond service

Those who have engaged[6] with the support and/or therapeutic interventions provided by Respond service found it helpful in addressing or managing the isolation and trauma brought forth by their experience of 'caring' for someone currently or previously in LTS.

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[6] It is important to state that a Respond practitioner (participant 11) said that some family members who were referred could not engage in the service because it does not currently offer weekend or evening support.

> *"...she's helped me understand my thoughts and my feelings around the things that have happened and to acknowledge that it's okay to feel the way I feel, but also putting in steps to try and overcome." (participant 16, family member).*

> *"So having the ability to speak to [Respond therapist] at Respond has helped me more than I realise right now, I think in a year or so. I recognise it has had value and it's made me more confident, able to deal with stuff." (participant 18, family member).*

> *"...when I've spoken to [RESPOND therapist] and got it off my chest and stuff and she really understands." (participant 15, family member).*

Family members felt their feelings were validated and felt heard by the therapist. Additionally, due to the specialised trauma-focused support, families felt that they were able to safely explore and understand their traumatic experience. This includes understanding how their experience has impacted their lives and how to address or manage these. Two family members (participant 19 and 20) stated that service provided by Respond was more suitable for them compared to previous therapies they had engaged with. They stated that they did not need to educate the therapist of the challenges they faced whilst caring for someone in LTS, nor the difficulties that comes from that challenge. Instead, they felt that Respond therapist understood and were empathetic to difficulties family members face when navigating a closed and/or hostile system.

Additionally, due to their level of understanding, the service provided by Respond may also empower family members in navigating the system more effectively.

> *"I think at the moment, as far as I understand it, our role very much is with the families and helping them voice what's gone on for them and also helping them to create some safety and some trust still with professionals because obviously professionals are still part of their lives, so helping their part in the relationship, the professionals, how they can do communication or move forwards with them." (participant 12, Respond practitioner)*

> *"Then with coming to Respond, our hopes are, as it is with all the families we work with, that families feel more empowered, they feel more able to engage with the network around them, that communication gets better..." (participant 11, Respond practitioner)*

It was felt that Respond provided family members a safe space to talk about and plan up-coming interactions with professionals; this includes debriefing sessions after interactions with staff. It was reported to help families try and navigate the system differently and more effectively to improve professionals' engagement with staff. However, Respond practitioners argue that more needs to be done to improve professionals engagement and communication with family members; believing that improving communication should not fall solely on the family member.

5.3.4. Isolation reduced through HOPE(S) peer-support family forum

The HOPE(S) peer-support family forum helped family members attending the sessions reduce their feelings of isolation.

> *"I feel I can almost talk about it in quite a lot of peace to me that there's so much shared experience that it's been very beneficial to me." (participant 18, family member).*

> *"I hate that there's other women and men going through this but I do get comfort from it… The whole experience is soul destroying but having other people going through it, it's disgusting but helpful." (participant 40, family member).*

Family members felt that it was helpful to have a group who not only understood how they were feeling but were empathic to what they were going through without passing judgement. As a result, family members felt that they were able to build strong emotional bonds with others whom they could safely and openly speak to about their experience, sharing thoughts and feelings about their loved one(s). This also includes sharing and celebrating the positives.

5.3.5. Staff's confidence and morale improved

Many believed that HOPE(S) improved clinical staff's confidence in their clinical practice.

> *"[the HOPE(S) practitioner] brings a level of insight and even competence. I think in these sessions there's so many professionals who just don't know how to support people with a learning disability and autism. They just lack the practical skills. So, the HOPE(S) worker, I think, taught them. There's been a lot of training. She's shown them. But I think it started with confidence. It started with the shift, instead of being fearful of the gentleman, how to be caring, how to look after him, how to enable him…" (participant 53, professional: clinical staff).*

> *"….the team seemed more confident in how they were describing his behaviours, how they were describing how you need to communicate with him, how they described the management of the environment he was in." (participant 22, professional: commissioner)*

> *"…staff are feeling more confident in working with people a little bit differently because they can see that there's different ways of interacting." (participant 28, professional: clinical staff).*

> *"…she gave us the confidence and the knowledge to try different things." (participant 34, professional: clinical staff).*

As staff no longer felt 'stuck' and hopeless, clinical teams described feeling empowered and confident in their practice. They felt a great sense of achievement seeing the positive impact of their work through implementing HOPE(S). This improved their job role satisfaction such as improved morale.

> *"…I was so proud of how our gentlemen had progressed, he was a different person from the person that came in. I'm just like proud of the team because we really made the effort and it was good to see that what we had done had worked." (participant 34, professional: clinical staff).*

> *"…I just think that there was a massive morale boost for the staff." (participant 23, professional: clinical staff).*

> *"…the staff enjoy it because, even though they're seeing him enjoying life, it affects the morale of the staff team as well, because they're getting out, they're not sat on a unit all day, stuck inside, so the staff love taking him out. If the staff can get him out all day, they would." (Participant 26, professional: clinical staff).*

Case study 1: Carly's story demonstrating improvements in their quality of life through HOPE(S)

Carly is a young woman who likes cooking, crafting and animals. She has a significant history of childhood trauma and was admitted to hospital after experiencing distress in the community. She moved into long term segregation which consisted of her being on a 15-bedded ward by herself. She displayed distressed behaviour every day and was regularly placed in a seclusion room. Carly was regularly placed in police handcuffs and she was soon referred to secure services.

Carly was very scared. She thought she was a bad person and said that she wanted to be "locked away". The frequency of the distressed behaviour also led to many of her clinical team feeling anxious and afraid to confidently work with her. Many staff soon refused to work directly with Carly leading to an unfamiliar agency team being called in to provide her day-to-day care.

In addition to providing HOPE(S) and condition-specific training, supporting the team with how to respond to distress behaviours and planning activities to do alongside her, two HOPE(S) practitioners worked directly with Carly and right away role modelled working in close proximity to her in a relaxed and respectful way. The HOPE(S) practitioners offered practice leadership, supervision and reflective practice to Carly's team. Staff soon reported that they were more confident in working alongside Carly which contributed to her being transferred to a non-secure hospital placement where she accessed external leave from hospital almost every day. She used her bicycle and went swimming to a pool in the community. Carly spontaneously said "*Thank you HOPE(S) for believing in me*". She is now co-producing her discharge plans.

Feedback from two newly qualified nurses reported that the input from HOPE(S) was "*life changing in shaping their professional practice*".

Theme 4: There were challenges that impeded the success of HOPE(S)

Although the majority of those interviewed felt HOPE(S) had a positive impact on patients, challenges to the implementation and success of HOPE(S) were also identified.

5.4.1. Lack of shared understanding and clarity as to what LTS is in practice

The majority of participants said that there was some confusion and/or a lack of shared language or understanding as to what is meant by 'LTS' and what it that may look like in practice.

> *"...The strange thing is though, that it could end up within community provision that looks exactly the same as hospital, but it's not [classed as] set long-term segregation anymore because we're in the community." (participant 57, professional: clinical staff).*

> *"...I think there's just so many different terms that they're using now. I wonder if that's some of the confusion with staff as well when it's getting called different things in different places." (participant 73, professional: commissioner).*

Some staff expressed confusion as to why the definition of LTS does not cover individuals outside of inpatient hospital settings who have similar restrictions in place. There was also perhaps some confusion regarding the difference between LTS and seclusion; especially, how to identify and differentiate these in practice. When asked why there may be some confusion around the term 'LTS', some participants believed that the definition of LTS is perhaps outdated and not specific for learning disability and autism services (participant 72, professional:

commissioner). There was also a speculation that different providers may have different interpretations of the definition proposed by Mental Health Act 1983 Code of Practice which may be leading to differences in the practice of LTS across providers.

The lack of shared understanding and clarity as to what LTS is, was described as a key barrier for some HOPE(S) practitioners in implementing the HOPE(S) model. There were disagreements between themselves and staff as to whether an individual was in LTS or not which led to delays in providing support for the individual in question.

> *"Because we're being stopped from doing things because we're getting into an unhelpful debate about long-term segregation when actually we just need to do the work." (participant 4, HOPE(S) practitioner).*

Additionally, there was a recognition that there were inaccuracies or omissions in the data which aims to identify, monitor and report on individuals in LTS.

> *"...there are systems in place, but my experience is that doesn't always work, so there are people who get missed off of that. And it relies on people feeding in, case managers feeding into the system reporting on it accurately and that being updated and that being fed to us. So, there is sort of an anxiety and a bit of a worry that we're not always making our triaging judgements based on the available pool of people in segregation. So, there is always a worry that you're missing somebody, or someone is segregation somewhere and you don't know about it." (participant 1, HOPE(S) practitioner).*

> *"The team said to her, "Why are you working with this patient? If you want to see someone who's really segregated, you should check this guy out..." (participant 8, HOPE(S) practitioner).*

These practitioners described that there were clear contradictions between the data and what is happening in practice. This has led to some confusion about the cohort of individuals supported by HOPE(S) practitioners which might have not necessarily been identified by commissioners. Moreover, many clinical staff, commissioners and HOPE(S) practitioners expressed concern that the prevalence of LTS is significantly underreported. This was described as serious unrecognised problem across the sector because this means there could be high number of individuals in LTS who not receiving appropriate care or support.

5.4.2. Pushing back against closed cultures

As with any new intervention challenging set way of working, especially given a long history of closed cultured within mental health settings, there was resistance to buying into and implementing HOPE(S). HOPE(S) practitioners reflected on their approach when meeting new clinical teams and being mindful as to how different teams may react to HOPE(S) initially.

> *"...suppose it's how staff teams embrace the HOPE(S) model as well. I suppose, if they're not really open to it, then you're not going to succeed, are you, really?" (participant 26, professional: clinical staff)*

> *"...we need to keep an open mind that that might not be because they have negative attitudes. It might just be that they're anxious and paralysed. So, it's around nurturing, making sure that the system within the service is a nurturing one. Open I think they call it, open and flexible safety culture and just a learning culture..." (participant 3, HOPE(S) practitioner).*

HOPE(S) practitioners described how over time they learnt how to better interact with staff to manage their expectations and address possible resistance to the programme. Early in the implementation of the programme feedback from clinical staff stated that they felt blamed, not understood and accused of poor practices by practitioners. HOPE(S) practitioners described how they reflected on this feedback and amended their approach to focus on building a good relationship with staff and staffing teams. The interpersonal skill of the practitioner was seen as crucial to building good relationships to create a safe environment to engage in difficult discussions, challenge current mindsets and practices, and empower staff, especially during the initial stages of introducing a new model of care.

However, there were examples of sustained disagreements and conflict between clinical teams and HOPE(S) practitioners.

> *"...there was some straight up resistance to the training as well as the model..." (participant 31, professional: clinical staff).*
>
> *"...whilst HOPE(S) relies on culture change within organisations and if then some cultures are more difficult to shift..." (participant 1, HOPE(S) practitioner)*
>
> *"...and then there's some providers where they've been quite closed to welcoming and working with HOPE(S). They've been quite negative in their views of what HOPE(S) was trying to deliver because it was going against principles of restrictive practices within secure settings." (participant 22, professional: commissioner).*

Closed cultures and resistance to the programme were stated as the main reasons behind the disagreements and conflict. Some resistant clinical staff, or teams were described as: having had poor initial interactions with the HOPE(S) practitioner; being defensive or in denial about the issues linked to LTS; viewing the individual in LTS as too dangerous; power dynamics and defensiveness of some professions; and/or HOPE(S) being viewed as optional amongst staff. Safety concerns, fear and trauma amongst staff were believed to have the biggest impact on the successful implementation of the model and it was reported HOPE(S) created the environment to think differently about risk. 'Risk aversion'[7] , referring here to fear-driven decision which infringes on individual's human-rights, was perceived as a key characteristic of closed cultures by participants.

Furthermore, some disagreements between the HOPE(S) practitioner and clinical staff/teams were because staff were unclear regarding the role of the HOPE(S) practitioner as well as their level of responsibility and accountability.

> *"...And who's going to be accountable for if something happens...because [HOPE(S) practitioner] is a part of the clinical team, that made it difficult of sort out who's making the decision here, who's going to be accountable? And who's actually taking the risk of making this decision?... how much do HOPE(S) make these decisions? Are they part of*

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[7] We would like to restate that, during sense checking, authors were informed that there is a need to acknowledge that the phrase 'risk aversion' can also have negative connotation for the individual in LTS as it infers that they are the risk, rather than poor clinical practices and environment. This term was used here because this is the phrase used by participants: including 'risk management', 'risk averse' as well as taking 'positive risks' through HOPE(S). Direct quotes were not adapted.

> *the team? And this is one of the things I'm going to bring up, you know, I still don't know if HOPE(S), are they part of the team, are they integrated in the team, are they external, just giving advice? I think that grey area would be one of my big parts of feedback. And one of the reasons why I think it hasn't worked as well as it could have done for us, on the ward" (participant 42, professional: clinical staff)*
>
> *"…if organisations take it on, but then the definition of the role needs to be really clear." (participant 36, HOPE(S) practitioner).*

Staff members stated that they were uncertain as to who was to be held accountable if, at times, incidents would occur due to the suggestion provided by the HOPE(S) practitioner. Clinical staff described fearing that there would be serious repercussions and that they would be held accountable.

In light of the challenges raised, there was a strong agreement that there is a need for HOPE(S) to have a clear "buy-in" from upper management.

> *"It often still feels like we have to work very hard as practitioners to engage organisations and it's a bit hit and miss again about whether or not they're really willing to work with you. Whilst we have executive engagement in the program often it might be a chief executive that signs it off doesn't really know what it is and never sees it again. Or you might have a senior clinical lead that sort of does something similar and is not really massively involved unless there is a big issue." (participant 1, HOPE(S) practitioner).*
>
> *"So although, lip service wise, it was yes, we're going to try HOPE(S), we're going to do this, we're going to do that, they didn't actually buy into it in any practical ways apart from saying the right things but actually they didn't really give that full support." (participant 2, HOPE(S) practitioner).*
>
> *"…There are a significant proportion who are very, very, very convinced of the situation they're in being the correct response to their circumstance, and that kind of resistance. The HOPE(S) system is predicated on training and developing a team to do these things rather than bringing in someone to do it for you, and those situations I think often leave the HOPE(S) practitioner stuck trying to enable a change for an individual without anyone standing behind them." (participant 33, professional: commissioner).*

Many stated that it was sometimes difficult to pushback against systemic barriers as senior and upper management did not understand the HOPE(S) programme or the model, leaving some practitioners feeling powerless at times. In addition to a clear Memorandum of Understanding (MoU), preparatory work and support from senior staff and upper management would be beneficial, especially to help HOPE(S) practitioners as they begin work with new staffing teams.

5.4.3. Working in isolation

HOPE(S) practitioners described difficulties associated with working in isolation, such as the high demand of the role and difficulties in maintaining positive culture change.

Firstly, the majority of HOPE(S) practitioners viewed the role as highly rewarding and positive; with some feeling empowered when able to pushback against system barriers and willing to continue to work in this role if they could. However, many HOPE(S) practitioners felt that their role was very demanding, despite only supporting a few individuals in LTS.

> *"How do you change that much wider system? I'm one person going in." (participant 3, HOPE(S) practitioner)*
>
> *"When those partners are themselves anxious, commissioners, case managers, whoever, the system, everybody retreats back into their own little group and we are, as HOPE(S) practitioners, we are alone." (participant 3, HOPE(S) practitioner).*
>
> *"I think what you realise is that it's a massive problem there. Just working on that one-to-one basis, it's just not enough to effect a significant change... I feel like there's not been a lot of strategic approach to how we work and it's been very much left. Most of it's been left to us to triage patients and then make a decision about whether we pick them up or not." (participants 6, HOPE(S) practitioner).*
>
> *"...often it's quite hard to find the time to affect change across the whole trust when you're only working with one person as well. And that's what we try to do but sometimes those doors aren't always open, or we don't always have the time because we're focusing on individuals." (participant 1, HOPE(S) practitioner)*

Working in isolation can make practitioners feel powerless and under pressure. They described feeling frustrated and demoralised when up against closed cultures, lack of buy-in from upper management and/or lack of engagement by clinical teams. Additionally, the role overtime grew in scope increasing the demand for the role. There were concerns, by some, that the role may have a risk of low morale and high burnout for HOPE(S) practitioners.

Secondly, it was expected that the initial implementation of HOPE(S) would be dependent on the HOPE(S) practitioners until change in practice and culture occurred in clinical teams. For some clinical staff and commissioners, it was believed that once the change had occurred there would no longer be a need for a HOPE(S) practitioner. On the contrary, many believed that it would not be possible to maintain a positive culture in the long-term without the presence of a HOPE(S) practitioner.

> *"But it's about keeping your foot on the gas in a sense. From a practitioner, my experience is that if I do that and walk away, where is the reassurance that things have been carried forward..." (participant 51, HOPE(S) practitioner).*
>
> *"So, when she's on holiday or annual leave or if there's an incident in the family, she can't be there. Those have been the times when things have dipped, which is really sad." (participant 17, family member)*
>
> *"So, even HOPE(S) practitioners are allowed to go on leave or be poorly and things like that and then we've lost... I think we've lost momentum when that's happened. As I say, I don't think that's a criticism of HOPE(S) or the HOPE(S) practitioner I think is the fact that no one here was willingly picking that up." (participant 24, professional: clinical staff)*

It was believed that the degree to which staff engaged (in the short and long term) with the programme was highly dependent on the ongoing presence and/or support from HOPE(S) practitioners, regardless of the benefits from training and practice leadership. It was felt that HOPE(S) practitioners had to continue to check-in on teams who may not have fully engaged with the programme. Others described concerns that staff would go back to their old ways of care if they were absent for a long time (while on annual leave or during long-term sick). Clinical staff also mention a lack of accountability during the HOPE(S) practitioner's absence resulting a loss of motivation to implement the model. Some staff felt uncertainty as to who is responsible for holding the team accountable when goals are not met or upholding the HOPE(S) model during the practitioner's absence.

Considering these concerns, the need for a higher number of HOPE(S) practitioners/national team and a strategic plan and oversight was emphasised. Many suggested employing two or even a team of practitioners might help mitigate against closed cultures; may be useful in managing the workload of complex cases; managing difficulties of working in isolation; and maintaining support during annual leave or long-term sickness.

5.4.4. *Training uptake*

Systemic staffing issues, such as a high staff turnover and workload, had a negative impact on the successful delivery of training to a meaningful number of staff in each service.

> *"I think our whole team didn't get to do it and that we had a reasonably high staff turnover so that by the time our HOPE(S) practitioner left us just very recently, not everyone had been through the training. So, some people would be citing principles or evidence kind of raised in the training that others would entirely understand." (participant 31, professional: clinical staff).*

> *"I think it probably was a feeling that staff didn't really know what HOPE(S) was about. And we tried to address that, but I don't think we were that successful. And I think actually, by that time, other things had happened and there were other difficulties. But I think it was hard to, it did make a difference that not everybody had done the training" (participant 42, professional: clinical staff).*

> *"I would say I don't think our medics did any of the training... So, there was barriers against ending the segregation. They didn't really understand it." (participant 23, professional: clinical staff).*

Systemic staffing issues impeded the successful implementation of HOPE(S) as staff members did not understand the programme (and model) or its purpose, which led to a communication breakdown within teams. Many participants believed that the training should be mandatory and accessible to all professionals, including upper management, to prevent the use of LTS and, where this is not possible, to improve care for individuals in LTS.

> *"I think that's everybody working around the person. I think that's your middle management. I think that's your chief execs. I think that's commissioners. I think everybody needs to be trained on it to understand it." (participant 56, professional: clinical staff).*

> *"Could it not just become mandatory training? You could say it's mandatory training for anybody that works in this sort of service" (participant 44, professional: clinical staff).*

5.4 Theme 5: HOPE(S) should continue and expand beyond its original purpose

Many of those interviewed reported that they desired the HOPE(S) programme to continue.

> *"I hope from this that we get to keep HOPE(S). I mean it would be, in my view, a complete and utter disaster if we didn't." (participant 52, HOPE(S) practitioner).*

> *"I just think the importance of the HOPE(S) team, it is not just around the training and their support to get somebody else. It's the ongoing training, it's ongoing support to*

> *providers like us who have still got complex people who have been traumatised, but also families." (participant 35, professional: clinical staff).*
>
> *"Knock down the hospitals, build new hospitals with the correct layout and put HOPE(S) in charge." (participant 18, family member).*
>
> *"...what would I want for my son? I want HOPE(S)." (participant 45, professional: commissioner).*

There were concerns raised that if HOPE(S) is not continued then more people would move into LTS, the problem will go unrecognised and, there would be a continuation of individuals in LTS who are subjected to poor care and/or abuse. There were also fears that without HOPE(S) individuals in LTS and their family members would continue to be unheard by professionals and feel powerless. Additionally, there was a strong desire to expand the HOPE(S) programme beyond its original purpose.

5.5.1. Proactive (prevention), as well as reactive intervention

There was consensus that the HOPE(S) programme should intervene earlier in an individual's care if they are exhibiting patterns of distress which may lead to the use of LTS.

> *"So I think there's a lot that HOPE(S) could do for prevention if we could do more prevention that might enable, there's something about the model of HOPE(S), not just the Barriers to Change, not the LTS bit. There's something about that model that if you could get in in an earlier way or you could train staff or whatever, maybe that might be the turning point to not allowing somebody to be into the hospital or even today might change some of the outcomes." (participant 57, professional: clinical staff).*
>
> *"The only drawback was that they had come so late in the process that [loved one] had regressed so much, their job was not going to be easy." (participant 21, family member).*
>
> *"We don't want it to be a reactive thing, do we. We want it to be proactive." (participant 3, HOPE(S) practitioner).*

It is believed that early intervention by HOPE(S) may reduce the risk of (re-) traumatisation and prevent a cycle of restrictive practices. A proactive HOPE(S) programme was welcomed on the basis that "*prevention is better than [a] cure*" *(participant 56, professional: clinical staff).*

Simultaneously, some felt that HOPE(S) could continue to provide support after ending LTS, or even post-discharge. One family member (participant 21) described that HOPE(S) succeeded in ending LTS for their loved one in their care, but the practitioner's hard work was not maintained; once HOPE(S) support had stopped this led to a deterioration in the quality of care received. Although not common, there were examples provided where the HOPE(S) practitioners continued to support individual once LTS had ended.

5.5.2. Better communication between families and staff is needed

In some cases, family members still did not feel heard by clinical staff.

> *"... but with HOPE(S) pushing it from a professional point of view, they listened more. That's always the problem. We'll give the same feedback, they won't listen but if somebody professional came in and said exactly the same as us, they'd listen." (participant 16, family member)*

It was believed that HOPE(S) practitioners were the best advocate for their loved one. Practitioners appeared to have more ‘weight’ and more likely to be listened to by staff. Respond practitioners highlighted that there is a need for more family advocacy within HOPE(S) or there is a need to improve the relationship between family and staff, potentially as part of HOPE(S) training. Some felt that HOPE(S) could do more to raise staff’s awareness of the difficulties and challenges experienced by family members within a potentially hostile system; and encourage staff to be more empathic and compassionate towards distressed family members.

5.5.3. Accessible to all individuals in LTS, disregarding of diagnosis and setting

There was a strong desire to expand the HOPE(S) programme to cover other settings and populations. For other settings, many believed that the HOPE(S) should be expanded to cover community services and be accessible to populations beyond autistic adults and/or individuals diagnosed with a learning disability.

> *“...we’ve got a lot of community services where people are in real dire long-term segregation situations, but it’s not recorded as LTS because they’re not in a hospital. I know our community services are crying out for help with that.” (participants 25, professional: clinical staff).*
>
> *“...I think there needs to be HOPE(S) in the community...” (participant 36, HOPE(S) practitioner).*
>
> *“Yeah. I definitely think this could be extended to every patient in this hospital, probably, with restrictions everywhere.” (participant 42, professional: clinical staff).*
>
> *“I’m very much, you know, an advocate of good learning disability care and HOPE(S) model does that. However, people with mental illness and personality disorder have been left behind in this. So, they’re not getting that. And if we’re talking about parity of esteem, then we could be rolling this out across.” (participant 45, professional: commissioner).*

Other examples where family members, staff and HOPE(S) practitioners believed the HOPE(S) programme could be expanded too includes: to cover other parts of the United Kingdom; to cover schools; and to continue to support the individual once staff were able to move the individual out of LTS or they were discharged. Therefore, many believed strongly that HOPE(S) could be applicable and transferable across different services and populations as a valid approach to supporting all clinical staff in reducing the use of, or ending LTS or other restrictive practices, regardless of the service, population, or location.

QUANTITATIVE

RESULTS SECTION

- Number of people who have moved out of LTS
- Access to fresh air and meaningful activities
- Use of restrictive practices
- Physical health checks
- Barriers to Change Checklist (BCC)
- Quality of life
- Family functioning

6. Quantitative findings

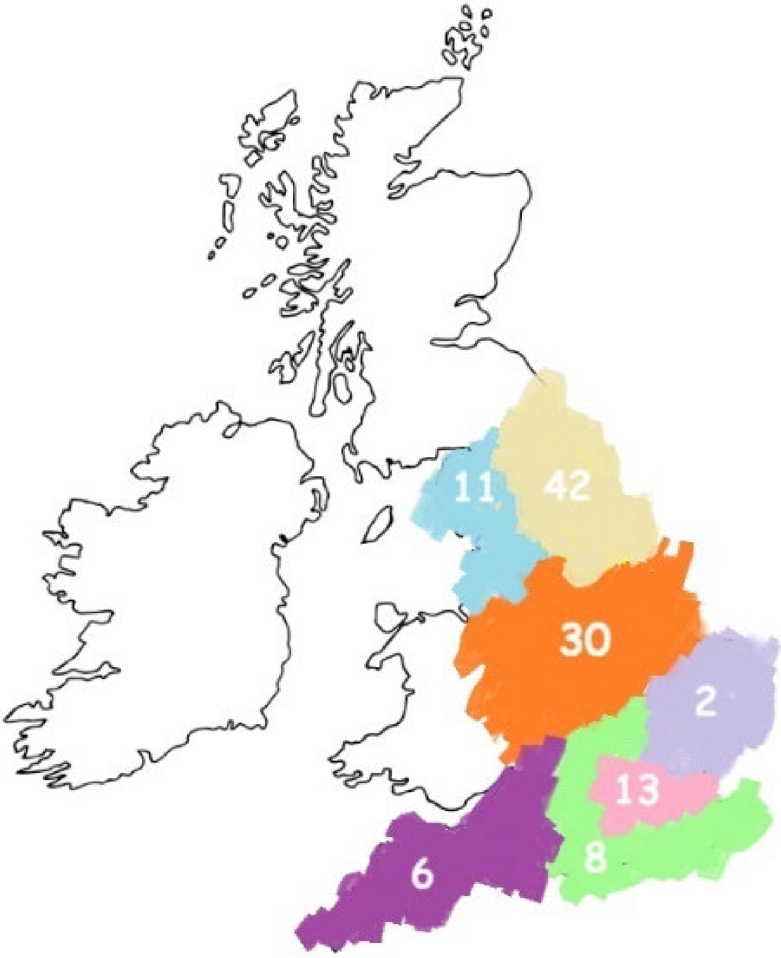
The following section presents the results from the second study: the analysis of the quantitative data.

6.1 Participants

6.1.1. Cohort of individuals receiving support through HOPE(S)

In total, data was available for 122 individuals who received support through HOPE(S) by 17th March 2025 (i.e., the cut-off date for data analysis for this report). The mean age of individuals was 27.73 (*SD* = 10.25), ranging from 12 to 61 years old. The majority were male (including trans male) (64.75%, n = 79), with 33.06% (n = 40) females (including trans female) and 1.64% (n = 2) non-binary. The majority of individuals were white (British, Irish, other) (81.15%, n = 99), with a small minority of mixed ethnicity (i.e., 'white and black', White and Asian'; 8.20%; n = 10), black (British, African, Caribbean, other; 5.73%; n = 7) and Asian (British, Indian, Pakistani, other; 4.10%; n = 5). ***Figure 6.*** provides a breakdown of the number of individuals supported by region, as reported by their initial region of referral. It is important to note that transfers were common and are not reported here. Nine of the individuals are across two regions and are not counted for.

Figure 6. Number of individuals supported by HOPE(S) across each region



6.1.2. *Family members who have received support through Respond and completed the SCORE-15*

Although data was collected for 11 family members, data for 8 family members were collected for the SCORE-15 at two time points. The majority were mothers (birth or adopted; n = 7) and one was a sibling. All participants reported that they were White (British, Irish or Other). The mean age was 51.25 (*SD* = 11.95) and ranged from 30 to 72 years old.

6.1.3. *Clinical staff who engaged with HOPE(S) and completed the ProQOL*

In total, 388 clinical staff completed the ProQOL, out of which, 64 completed this at two time points for compassion; and 68 completed this for burnout and secondary traumatic stress. The majority were nurses, with more than two thirds having completed the scale for compassion (65.63%, n = 42) and burnout and secondary traumatic stress at 64.06% (n = 41). The rest of the sample consisted of a wide range of roles including, but not limited to, occupational therapists, social workers and medics.

6.2. Individuals who have moved out of LTS under HOPE(S)

As of 17th March 2025, out of the 122 who commenced the HOPE(S) programme, 83 individuals moved out of LTS at least once[8]. Out of the 83 who have moved out at least once, 56.63% (n = 47) received consultancy support only; 12.05% (n = 10) received intensive support only; and 31.33% (n = 26) switched between consultancy and intensive support during their involvement with the HOPE(S) programme. Out of these, 24 were discharged straight into the community and 23 have remained out of LTS based on their latest follow-up data (up to six months).

Data available for 81 individuals (of the 83) shows that the average number of days in LTS since the start of HOPE(S) was 179 days (under 6 months) (5-706 days/0-23 months). Regarding length of stay in LTS, data available for 66 individuals (of the 83) shows that the average length of LTS before HOPE(S) support was 314 days (over 10 months) in the current provider (0-1788 days/0-59 months).

Out of the 83 individuals who moved out at least once, follow-up data was collected at three months for 70 individuals. Follow-up data at three months was not collected for 13 individuals because they moved out of LTS less than three months prior to the end of the evaluation period. Out of these, 66 had remained out of LTS. For 62 individuals for whom we had six months follow up data, 58 had remained out of LTS.

Reasons for those still in LTS included: still waiting to be discharged, commissioning issues, and requiring further support, as HOPE(S) support would have commenced working with them within the last three months.

Case study 2 presents Wayne's (pseudonym) journey from LTS to being discharged into community through the HOPE(S) programme.

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[8] Six people ended LTS once transferred to more secure services (five of these people had been referred and/or accepted prior to the programme engaging). It is of note however, a number of high secure referrals had been avoided due to involvement of HOPE(S) practitioners.
By the end of the programme on 31st March 2025 85 people have moved out of LTS at least once.
All data refers to the latest LTS episode recorded.

Case study 2: Wayne's journey from LTS to being discharged into community

Wayne is a young man that likes films, singing and sports. He is very sociable and a natural comedian. He is autistic, often demand avoidant and his daily life is very affected by Tourette's syndrome. After living in residential care homes for four years, he was admitted to hospital at 18 years old straight into a seclusion room. He remained in his seclusion room for 2 years. After this he moved out of seclusion but remained in long-term segregation for a further 7 years. Staff withdrew further and further away from Wayne in long-term segregation to the point where they only communicated via a small, double-glazed hatch window. Wayne found this alienation very difficult, and the situation caused him to show distressed behaviour as a response.

Wayne's care provider gave notice to end their involvement, at which point the HOPE(S) team was asked to support him and the system around him. The HOPE(S) practitioners worked with Wayne's team to provide training on using the HOPE(S) model and on understanding the impact of Tourette's and his demand avoidance. This was supported by them providing ongoing supervision and reflective practice to his team.

Wayne was very scared; thought he was a bad person and felt frustrated and ashamed of his tics and urges. HOPE(S) practitioners worked intensively with Wayne and role-modelled close, creative, fun and respectful interactions with him. He immediately noticed that they did not respond negatively to his tics and he said that he wanted everyone to do this. Wayne was empowered to jointly develop safety assessments and future plans. Intensive clinical practice leadership alongside the clinical team led to progress for Wayne to the point where he was going out to the community with his team. Wayne would say to passers by "See this everyone, this is progress!"

The HOPE(S) practitioners worked with Wayne, his mother, advocate, clinical team and commissioners over a long period of time to prepare him to live in his own home. After two and a half years of HOPE(S) support, Wayne was discharged from hospital to his new home. When he arrived and saw his new house, he cried and said he could not believe how nice it was.

His HOPE(S) practitioners trained the new staff team supporting him in the community and continued to support Wayne in the community to reduce the risk of social isolation. The success of the discharge has been the forging of partnerships between all agencies and their courage in commissioning a model of care that is different from the standard offer and that focuses on supporting Wayne's human rights.

Wayne passes on the message:
"For all of you still in hospital, you have to have hope."

6.3. Investigating quality of life, access to meaningful activities, use of restraint and seclusion, physical health checks, the BCC, and family functioning

6.3.1. Individuals' quality of life

The number of completed measures, mean (and standard deviation) were calculated for the four quality of life measures (YQOL-SF, MANS-AS, Mini-MANS-LD, and HOT) within 4 weeks of HOPE(S) commencing (Time 1), between 1- and 3-months following HOPE(S) (Time 2) and 4 to 6 months following HOPE(S) (Time 3). Summary statistics are included in ***Table 3***. The descriptive statistics for the mini-MANS-LD shows a positive trend with scores lowering across the three time points. This could suggest that, as HOPE(S) support carried on, this continued to improve the quality of life of individuals with a learning disability (as assessed through the mini-MANS-LD.

Due to small sample sizes, a paired t-test[9] was performed only for the mini-MANS-LD to determine if quality of life significantly changed between time 1 and time 2 (n = 9). Assumptions were also tested. Paired t-tests revealed a significant difference in mini-MANS-LD scores between time 1 and time 2 (t(8) = 3.32, *p* <.05; *Cohen's d*: 1.11). This suggests that individuals with a learning disability had better quality of life within three months since HOPE(S) commenced, compared to the first four weeks.

Table 3. Summary of the descriptive statistics for the quality-of-life measures

	Time 1		Time 2		Time 3	
Quality of life measure	n	M (SD)	n	M (SD)	n	M (SD)
YQOL-SF	4	40.75 (22.29)	1*	-	-	-
MANS-AS	5	53.80 (9.68)	2*	-	3	61 (12.17)
Mini-MANS-LD	15	22.27 (8.20)	9	17.56 (5.25)	3	14 (1.00)
HOPE(S) QoL	7	7.14 (3.58)	3	14.67 (1.16)	2*	-

Note: *Means not included because of small sample size

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[9] Due to violations in the normality assumption, Wilcox-test rank was also performed in addition to a paired samples t-test. Both tests revealed a significant difference.

Case study 3: Jamie’s story shows their improved quality of life and journey to being discharged

Before hospital, Jamie used to live with her family. She had friends and a fairly active life with some support from a personal assistant as she has a mild learning disability. After a significant bereavement, she began to self-harm and was admitted into a psychiatric inpatient ward for people with learning disabilities. This would be the first of several admissions to hospital over the coming years. In between each admission, Jamie lived in residential placements that broken down amidst allegations of abuse from staff toward her. During this period of her life she also developed non-epileptic seizures which professionals believe were due to prolonged and extreme stress. She had several admissions to general hospital as a result.

Soon Jamie’s care was being provided in long-term segregation. Her segregation consisted of her lying on a mattress on the floor in a corridor behind a locked door. She had no access to fresh air, natural light or free access to a bathroom. She would often have to wait for up to an hour to be supported by a team of staff to go to the toilet, which would often be too long to wait. As a result of these traumatic experiences her abilities to verbally communicate had deteriorated and she stopped eating and drinking.

After a referral to the National HOPE(S) programme, a HOPE(S) practitioner began to work with Jamie and the system around her. They involved the senior leadership team and raised safeguarding concerns related to how her segregation could be breaching her human rights, particularly Article 3 of the Human Rights Act (1998) which protects people from inhuman or degrading treatment. This right is absolute and must never be limited or restricted in any way.

The HOPE(S) practitioner trained approximately 50 staff members in the HOPE(S) model and human rights-based approaches. By taking a rights-based approach and engaging the wider system in safeguarding Jamie her mattress was moved out of a corridor into a bedroom to maintain her dignity and privacy. In this environment, the HOPE(S) practitioner worked with the team and provided practice leadership to support the staff team to work in close proximity with Jamie, providing her with more human contact and prosocial meaningful activities of choice.

Initially, many in the professional system saw Jamie as someone who should not be under their care as they believed she required another inpatient service, a more secure and restrictive service. Over the course of 18 months, the HOPE(S) practitioner worked to help them to picture Jamie as someone who could live in her own home, as she once did.

After many months of intensive work, Jamie was discharged to her own home where she continued to receive support from the HOPE(S) practitioner to help her settle in and train and support her new staff team.

Case Study 4. Asad's story which indicates improved quality of life through access to fresh air and meaningful activities

Background

Asad is a young autistic man with a learning disability who comes from a large supportive family. Before being admitted to hospital and into LTS, he was living in a care home where he suffered physical harm from professionals. He had been in LTS for 13 months before HOPE(S) intensive support commenced. While in LTS, he found out that his father had died.

Asad was fearful and mistrustful of professional carers and found it very difficult to tolerate them being near him or in his room. By the point that a HOPE(S) practitioner went to meet him for the first time, his world had become very small and desolate. He was spending much of his time lying on a mattress and smearing faeces with no meaningful activity including no fresh air. Despite their ongoing efforts, the hospital team caring for Asad felt stuck with how to move forward in supporting him.

Progress using the HOPE(S) model

Through applying the HOPE(S) clinical model of care, the team identified key intervention targets that focused on supporting Asad to feel safe enough to engage in meaningful activity to increase his quality of life.

After four weeks of HOPE(S) involvement, the team and HOPE(S) practitioner had successfully supported Asad to get fresh air and use section 17 leave to take a drive in a van. Despite feeling anxious, Asad was able to enjoy this and van rides were scheduled to take place at least every week. He went on over 40 more van rides that year.

After four months of HOPE(S) involvement, Asad began trampolining using a kick scooter around the garden on a regular basis too.

After five months, Asad and his team felt able to get out of the van and walk in the local park. Very significantly, in that month, Asad visited his father's grave for the first time. He then continued to visit his father's grave every month for the rest of the year.

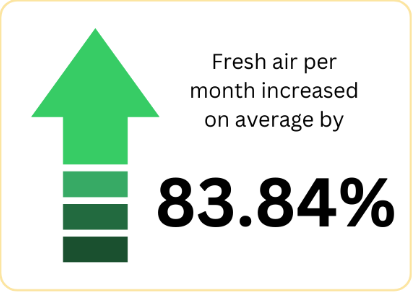
After six months, Asad and his team successfully began to visit the local community swimming pool for a swim.

After 10 months of intensive HOPE(S) support and collaborating to achieve key intervention targets, Asad and his team's feelings of safety had reached a place where his LTS could be ended.

After 12 months, 2 care providers had submitted proposals to care for Asad in the community.

6.3.2. *Fresh air and meaningful activity*

Fresh air: data was collected for 57 individuals before and after HOPE(S). Before HOPE(S), individuals had access to fresh air for an average of 7.82 days per month. This increased to 14.09 days per month since HOPE(S) commenced. Paired t-tests[10] revealed a significant difference in the average number of days an individual had access to fresh air per month (t(56) = 4.18, *p* <.001, *Cohen's d* = .55), indicating that HOPE(S) has potentially helped increase the number of days where an individual had access to fresh air by 6.27 days per month (83.84%[11]).



Meaningful activities: data was collected for 56 individuals both before and following HOPE(S). Before HOPE(S), an individual had engaged on average in 3.09 meaningful activities per month. This increased to 21.70 meaningful activities per month since HOPE(S) commenced, which is a statistically significant difference (t(55)= 5.79, *p* <.001, *Cohen's d* = .77; paired t-test[11]). This shows that that HOPE(S) has potentially helped increase number of meaningful activities by 18.61 (153.64%[12]) per month.

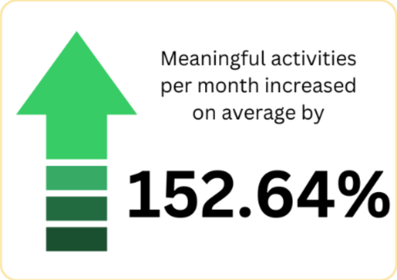


Table 4. provides an overview of the number (including percentage) for each type of meaningful activity. This table also includes the mean and standard deviation of the number of activities for the duration of HOPE(S) up to 17th March 2025.

Table 4. Summary descriptives by type of activity for the duration of HOPE(S)

	n (%)	Mean	SD
Building independence skills	2964 (22.77)	47.81	98.62
Community/off site leave	1385 (10.64)	22.34	44.74
Education*	967 (7.43)	15.6	88.53
Family and friends contact	783 (6.02)	12.63	32.18
Meaningful engagement**	1112 (8.54)	18.23	75.52
Personal care	1351 (10.38)	21.78	90.02
Physical activity	1398 (10.74)	22.55	57.06
Therapeutic intervention	3019 (23.19)	48.69	121.34
Other meaningful activity	38 (.29)	0.61	1.99

*Education: children and young people only.
**'Meaningful engagement' was reported at the start of data collection but was later remove as it was too ambiguous.
***There was an average of 13017 activities throughout the duration of HOPE(S).

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[10] Due to violations in the normality assumption, Wilcox-test rank was also performed in addition to a paired samples t-test. Both tests revealed a significant difference.

[11] The average percent change is calculated by first computing the percentage change between each consecutive pair or individuals, and then calculating the average of the percentage changes across all individuals.

6.3.3. *Use of restraint and seclusion*

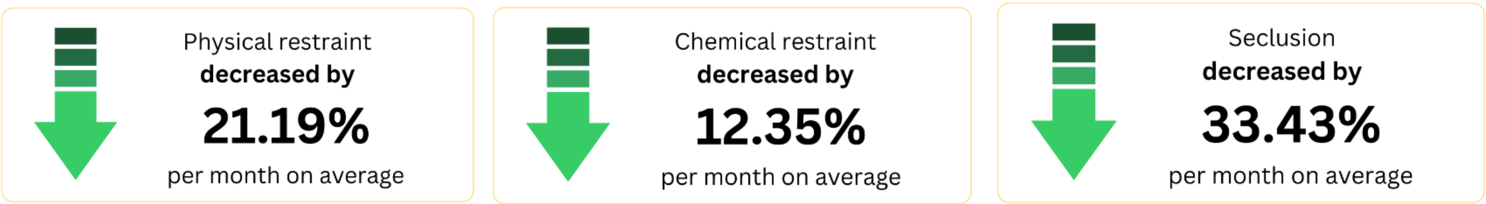
The number of individuals with both pre and post HOPE(S) data varied for each category of restrictive practice: 59 for mechanical restraint, 58 for physical restraint, 57 for chemical restraint[12] and 59 for seclusion. Descriptive statistics were performed for the number of reported times restraints (mechanical, physical or chemical) and seclusion were used (***Table 5 & Figure 7***).

Paired t-test[13] were performed to measure the difference in the use of restraints and seclusion between pre and post HOPE(S). Findings revealed a significant decrease in the mean number of reported physical and chemical restraint and seclusion per month following the introduction of HOPE(S) (t(57)= 2.73, *p* < .01, *Cohen's d* = .36; z = 2.01, *p* <.05, t(58)= 3.01, *p* <.01, *Cohen's d* = .39). The difference for the mean number of reported mechanical restraints used per month was not significant (t(58)= 1.17, *p* =.12). The findings demonstrate that HOPE(S) might have helped significantly reduce the use of physical and chemical restraints and seclusion, but not mechanical restraint. However, it is important to note that only 7 individuals were subjected to mechanical restraint prior to HOPE(S) and to better illustrate this, ***Case study 5*** presents Woody's story of reduced mechanical restraint through HOPE(S).

Table 5. Number of reported restraints and seclusion incidents per month pre and post HOPE(S)

	Pre HOPE(S)		Post HOPE(S)		
	Mean (SD)	Range	Mean (SD)	Range	Mean change
Mechanical	.34 (1.87)	0 – 13.36	.07 (.34)	0-2.56	-.27
Physical	14.62 (28.69)	0-153.67	6.03 (13.38)	0-69.67	-8.59
Chemical	2.02 (5.85)	0-30.67	.55 (2.63)	0-19.50	-2.53
Seclusion	.52 (1.09)	0-6	.22 (.62)	0-4	-.30

Figure 7. Percentage decrease for physical restraint, chemical restraint and seclusion per month on average[14]



Physical restraint
decreased by
21.19%
per month on average

Chemical restraint
decreased by
12.35%
per month on average

Seclusion
decreased by
33.43%
per month on average

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[12] Chemical restraint refers to rapid oral and intramuscular tranquilisation. PRN ('Pro re nata') use was removed because the data was deemed unreliable. Findings did not differ when PRN was included.

[13] Due to violations in the normality assumption, Wilcox-test rank was also performed in addition to a paired samples t-test. There was consistency across the tests apart from for chemical restraints whereby the non-parametric test indicated a significant difference at p = .045, whereas the paired t-test revealed a p value of .075. Due to violations in the normality assumption, the result from the Wilcox-test rank was reported here.

[14] Calculated by computing the percentage change between each consecutive pair or individuals, and then calculating the average of the percentage changes across all individuals.

Case study 5. Woody's story indicating reduced restrictive practices which improved his quality of life by eliminating the use of mechanical restraint

Woody is an autistic man with a moderate learning disability who is really good at football, has a fantastic memory and loves Disney films, music and hats. He is in his forties and has lived in environments away from others (including staff) for most of his life including periods of being cared for in periods of isolation as a child. Throughout his history of professional care, chemical, physical and mechanical restraint were regularly used.

When HOPE(S) practitioners first met Woody, he lived behind a locked door and staff mainly used a small hatch to interact with him and meet his basic needs. The National HOPE(S) programme worked with Woody and his team for 30 months, identifying and overcoming barriers to improving his human rights, quality of life and working towards long term segregation ending.

After completing a Barriers to Change Checklist, the team developed key intervention targets that initially focused on developing therapeutic trust and connection between staff and Woody that had been affected during and by his segregation. Alongside this, the HOPE(S) practitioners supported his staff team through interventions such as providing additional training specific to Woody's needs, formulation of his traumatic experiences, and offering reflective practice and supervision.

A key intervention target was developed to reduce the frequent use of mechanical restraint which was being used for close proximity interventions and when moving him to different areas. Woody's hands were bound using Soft Restraint Cuffs, a "tough" fabric alternative to metal handcuffs. Soft Restraint Belts were applied around Woody's torso, arms and legs and held by staff to support him to shuffle walk between parts of the hospital. In the three years before HOPE(S) practitioners worked with him, it was typical for Woody to be mechanically restrained 5 to 8 times per month, that is, 60 to nearly 100 times a year.
Woody and his staff team felt significant anxiety, and both had developed the belief that this was how his care needed to be. This had become formalised in a mechanical restraint care plan. Woody's HOPE(S) practitioner worked with his staff team and alongside the provider's physical intervention trainer to develop bespoke scenario-based training in how to care for him without using mechanical restraint. In the first few months, Woody's HOPE(S) practitioner worked closely with him and his team to successfully model close proximity interventions without the need for mechanical restraint.

Following collaborative decision making and significant practice leadership, HOPE(S) supported Woody's team to remove the mechanical restraint care plan. They committed to not using this practice and the subsequent reduction has been marked and sustained. At the time of writing, it has been 6 months since Woody has been mechanically restrained, with its practice now having been eliminated from his care. He is now less distressed in general and reports a better quality of life. The care his team offer looks completely different now, with them now able to sing and dance with him in close proximity, allowing them to continue to build trust in their relationships and work toward ending his LTS.

6.3.4. Physical health checks for people receiving intensive support

Out of 60 people who received HOPE(S) intensive support, data was collected for 51 individuals regarding their physical health checks (including care plan reviews). The number of individuals who received a physical health check at least once per month during HOPE(S) was 22 (43%). To be noted that a physical check was only contractually required to be recorded and monitored for intensive support cases, and only during the specific periods within which they were receiving that intensive support. Findings should therefore be interpreted with caution.

6.3.5. Barriers to Change Checklist (BCC)

Table 6 provides the number of completed BCCs, mean and standard deviation for the BCC sub-scales (‘engagement and system factors’, ‘opportunities and environmental’, ‘preventing risk’ and ‘individual’) within four weeks of HOPE(S) commencing, and all the completed BCCs. The biggest barriers to moving out of LTS were found to be ‘Engagement and system factors’.

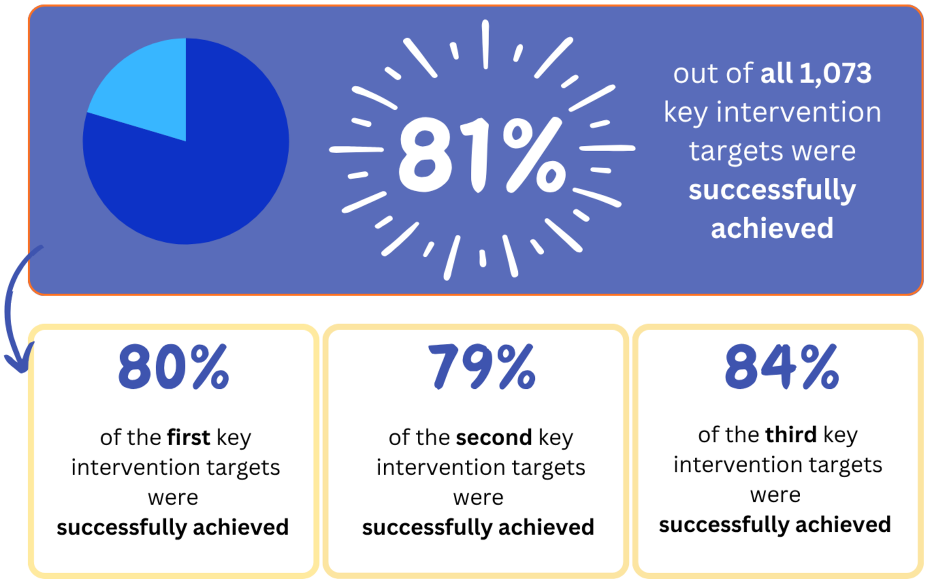
Table 6. Descriptive statistics for each of the BCC domains completed for the first four weeks as well as for all BCCs completed

	First four weeks BCC		All BCCs completed	
BCC sub-scores	n	M (SD)	n	M (SD)
Engagement and system factors	80	4.96 (1.87)	108	4.57 (1.64)
Opportunities and environment	80	4.04 (2.01)	108	3.60 (1.81)
Preventing risk	80	4.00 (2.12)	102	3.40 (1.77)
Individual	80	4.53 (2.14)	108	4.42 (1.87)

Note. ‘n’ refers to number of individuals who had completed BCCs; not the number of BCCs completed.

The completion of the BCC led to identifying three SMART key intervention targets. Intervention target 1 focused on where the most barriers are i.e., the highest scoring domain within the H,O,P,E sections of the checklist. Intervention target 2 focused on the issue that is most critical i.e., if not addressed segregation is unlikely to end. Intervention target 3 focused on a goal that can easily and quickly be achieved. ***Figure 8*** shows the high percentage of key interventions targets that were met. For all the intervention targets set between May 2022 to March 2025 (n = 1,073), 871 were successfully achieved; 270 out of 339 of the first key intervention targets and 252 out of 320 of the second intervention targets were achieved. Lastly, 349 out of 414 of the third key intervention targets were achieved.

Figure 8. Percentage of intervention targets which were successfully achieved



6.3.6. *Family functioning*

There was data for 8 family members for the SCORE-15 at least twice, i.e., at the start of receiving Respond therapy (Time 1) and, between 5 months to 19 months later (Time 2). At Time 1, the scores ranged between 15 to 52 and at Time 2, the scores ranged 27 to 51. According to the criteria for clinical improvement by Miller et al., (2023), there was no clinical or reliable change, as measured via the SCORE-15. This suggests that there was likely no improvement in family functioning for the family members who accessed therapy through Respond.

6.3.7. *Quality of life of clinical staff*

The number of staff who completed the compassion satisfaction sub-scale for the ProQol measure at two time points was 64. Paired samples t-test[15] revealed that clinical staff had significantly improved compassion satisfaction following involvement of HOPE(S) ($M = 38.13$; $SD = 6.99$) to time 2 ($M = 40.31$; $SD = 5.48$; $t(63) = 4.20$, $p < .001$, *Cohen's* $d = .53$). This suggests HOPE(S) might have led to greater feelings of work-related contentedness, fulfilment and gratification amongst clinical staff.

The number of staff who completed the burnout sub-scale for the ProQol measure at two time points was 68. Paired samples t-test[10] revealed that clinical staff had significantly less burnout, as a component of compassion fatigue following involvement of HOPE(S) ($M = 24.66$; $SD = 5.45$) to time 2 ($M = 22.28$; $SD = 5.02$; $t(67) = 3.39$, $p < .001$, *Cohen's* $d = .57$). This suggests HOPE(S) might have led to reduced feelings of work-related emotional exhaustion, frustration and anger amongst clinical staff.

The number of staff who completed the secondary traumatic staff sub-scale for the ProQol measure at two time points was 68. Paired samples t-test[10] revealed that clinical staff had significantly lower secondary traumatic stress, as a component of compassion fatigue following involvement of HOPE(S) ($M = 22.47$; $SD = 5.95$) to time 2 ($M = 19.93$; $SD = 6.17$; $t(67) = 4.11$, $p < .001$, *Cohen's* $d = .39$). This suggests HOPE(S) might have led to reduced feelings of work-related trauma and fear amongst clinical staff.

Figure 9. Summary of the ProQOL findings

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[15] Due to known violations in the normality assumption, which were not considered to be severe, a Wilcoxon Signed Ranks Test was also performed but the findings did not differ to the paired-samples t-test. Therefore, the paired samples t-test was reported here.

DISCUSSION

SECTION

- Overview of findings
- Discussion
- Strengths and limitations
- Closing remarks

7. Discussion

This report summarises the findings from the independent evaluation of the National HOPE(S) Programme to end long-term segregation (LTS) for children and young people, autistic adults and people with a learning disability in inpatient mental health settings. Using a comprehensive mixed-methods design, the study drew on a large and diverse dataset, including: qualitative interviews and focus groups with 73 key stakeholders (people with lived experience, family members, clinical staff, HOPE(S) and Respond practitioners, commissioners); clinical and outcome data for 122 individuals supported through HOPE(S); self-report data from 8 family members who engaged with trauma-informed therapy via Respond and from 388 professionals involved in the HOPE(S) programme.

To our knowledge, this is the first national implementation and outcome evaluation to provide empirical evidence from families and individuals with lived experience of LTS in the UK, alongside measurable outcomes for individuals, families and professionals following a systemic, human rights-based intervention. The evaluation not only addresses a critical gap in the literature, but also amplifies existing calls for change by drawing on deeply personal and often distressing narratives. Central to the design was the co-production and sense-checking of findings with people with lived experience, ensuring that their voices were not only heard, but instrumental in shaping the study’s conclusions and recommendations.

7.1. The devastating impact of LTS on individuals and families: quantitative and qualitative evidence

The findings from this evaluation offer a stark confirmation of what people with lived experience, families, and advocacy organisations have long described: long-term segregation (LTS) is profoundly harmful, both to the individuals subjected to it and to those who care about them. Across multiple outcome domains, the evidence shows that individuals in LTS face significantly compromised quality of life, heightened risks to their physical and mental health, and a significant erosion of their rights, dignity and autonomy.

Quantitative and qualitative data reveal low levels of access to fresh air and engagement in meaningful activities (including therapeutic interventions) at baseline; key markers of basic rights and quality of care. In many cases, individuals were found to have limited or no access to outside space/fresh air, irregular physical health checks, and restricted access to even the most fundamental personal care and hygiene. These findings echo concerns long raised by organisations such as Mencap, the National Autistic Society, and the Care Quality Commission (Care Quality Commission, 2020; Mencap, 2021; National Autism Society, 2020), and now formally recognised in Baroness Hollins' (2023) final report, which describes LTS as a form of 'social death' for those affected.

Furthermore, a small but troubling number of individuals in LTS had safeguarding concerns logged, including allegations of abuse and neglect while in segregation. These reports highlight not only the clinical and institutional failures associated with LTS, but also the extent to which it undermines the principles of therapeutic care.

The psychological and emotional toll of LTS also extends beyond the individual. This is the first study to extensively document the impact on family members, many of whom described persistent trauma, helplessness, and isolation. Families reported feeling excluded from care planning, disbelieved by professionals, and stigmatised by association. The quantitative findings on family functioning (via SCORE-15) suggest that improvements were limited; likely reflecting the depth and duration of trauma experienced by families over many years of being silenced or marginalised by services.

These findings lend empirical weight to a growing national consensus that LTS is not only ineffective but deeply harmful. Rather than containing risk, it often creates new and enduring harm, compounding trauma and undermining recovery. In doing so, this study contradicts some of the arguments provided by Tromans and colleagues (2025) in their critique of the state of affairs, but it adds to and strengthens existing critiques of restrictive practices in the literature (Belayneh et al., 2024; Chieze et al., 2019; Jones et al., 2021; Meehan et al., 2004; Quinn et al., 2025) and supports urgent calls for rights-based reform articulated in national policy and oversight frameworks. There was very limited evidence (2/73 participants in the qualitative study) to suggest that LTS was beneficial for some individuals and that it can be used as a 'least restrictive' practice. We argue that, where LTS is used (given very special circumstances), this should be for a brief period of time and, more importantly, the rights and quality of life of individuals in LTS should be prioritised.

7.2. Positive outcomes: the Impact of HOPE(S) on individuals, families, and staff

This evaluation provides compelling evidence that the HOPE(S) programme delivered meaningful and measurable improvements in the lives of individuals in long-term segregation (LTS), their families, and the staff supporting them. Despite implementation challenges in some settings, the data indicate that HOPE(S) has been a transformative intervention, not only in terms of outcomes, but in shifting culture and expectations across services.

Across the evaluation period, 68.03% of individuals (n=83) supported by HOPE(S) were able to leave LTS at least once (by 17th March 2025). Given that the HOPE(S) team continue to work with many of the remaining individuals to end their LTS. This is a remarkable achievement, given the entrenched nature of these placements. Importantly, almost a third of those who exited LTS were discharged back to their communities, a clear indication of HOPE(S)'s ability to enable not only movement out of restrictive settings, but meaningful reintegration and progression along care pathways. These findings align with the programme's commitment to rights-based, person-centred discharge planning, and challenge the long-held assumption that such transitions are unattainable for this population.

Quantitative outcome data further support the impact of HOPE(S) in key areas. Significant improvements in quality of life were observed using the Mini-MANS-LD, with supporting case studies and qualitative testimony indicating that these gains were not abstract metrics but reflected lived improvements, i.e., greater autonomy, re-engagement with meaningful activities, and renewed personal identity. Access to fresh air improved markedly, from an average of nearly 9 days per month to 14 days, while engagement in meaningful activity per month more than doubled (a 153.64% increase). Activities included not only therapeutic interventions, but critical aspects of self-care, community connection, and family contact, all of which are recognised protective factors for emotional wellbeing and recovery (Coulombe & Krzesni, 2019; Klussman et al., 2020; Lucock et al., 2011; Sharma, 2021).

In parallel, the results point to substantial reductions in restrictive practices following the introduction of HOPE(S), particularly in the use of physical restraint, chemical restraint, and seclusion. These reductions demonstrate that change is possible even in high-risk, complex care environments and that relational, rights-based approaches can support safety and dignity without reliance on coercion. The data also point to prioritisation of physical health checks and reviews during HOPE(S), addressing long-standing concerns about health inequalities in this population (Care Quality Commission, 2022b).

Taken together, these findings show that HOPE(S) is not merely a model of best practice; it is a viable, scalable solution to one of the most entrenched forms of institutional harm in UK healthcare. The programme's focus on individualised, relational care and its attention to systemic barriers (rather than pathologising individuals) are critical to its success. Moreover, the reported improvements were not temporary or superficial; rather, they signalled deep shifts in experience, identity, and trajectory for many people previously considered 'stuck'.

7.3. Enhancing staff wellbeing and practice: HOPE(S) as a catalyst for cultural change

The evaluation also found clear and significant benefits of the HOPE(S) programme for the wellbeing, confidence, and professional fulfilment of staff working in inpatient settings. Quantitative findings showed notable improvements in compassion satisfaction, alongside reductions in burnout and secondary traumatic stress, as measured by the ProQOL tool. These changes suggest that HOPE(S) has the potential not only to improve the immediate quality of care, but also to contribute to longer-term cultural change and workforce sustainability. Lower levels of staff distress may reduce turnover, sick leave, and absenteeism, all of which carry significant operational and economic costs for mental health services.

These quantitative improvements were powerfully echoed in the qualitative data. Many staff spoke candidly about the moral and emotional strain of working in environments where LTS was routinely used. They described feeling "stuck", unsupported, and afraid, both for their own safety and for the wellbeing of the people they were meant to care for. HOPE(S) offered them an alternative framework, grounded in rights-based and relational care, and supported by ongoing coaching and practice leadership.

The HOPE(S) programme helped shift staff perspectives from what they refer to as 'risk aversion' and containment to confidence in relational, trauma-informed practice. Staff reported that HOPE(S) enabled them to re-engage with their core professional values, i.e., compassion, empathy, and connection, which had often been overshadowed by fear and institutional inertia. This aligns with wider findings in the literature that show how restrictive practices not only harm individuals subjected to them, but also diminish staff morale and increase the risk of moral injury (Rowsell et al., 2024).

Importantly, these cultural shifts translated into tangible improvements in practice. Staff described building more meaningful relationships with individuals in LTS, understanding their needs and distress more deeply, and becoming more effective advocates for their rights. As staff began to see the person, not just the perceived risk, they also reported feeling more hopeful, skilled, and supported in their roles. These improvements were often described as mutually reinforcing: as individuals' quality of life improved, so too did the professionals' satisfaction and wellbeing of those around them.

In this way, HOPE(S) appears to have functioned as a mechanism for whole-system change, breaking cycles of fear and stagnation by equipping staff with the tools, frameworks, and emotional support they needed to provide better care. The relational turn supported by HOPE(S) benefited not only the individuals in LTS and their families, but also reinvigorated the workforce responsible for their care.

7.4. Implementing HOPE(S): the role of training, practice leadership and practitioners in driving change

The positive impact of HOPE(S) on individuals in LTS, their families, and clinical teams was strongly linked to the programme's multi-component design. Qualitative findings consistently highlighted that HOPE(S) training, practice leadership, and the role of the practitioners were each integral and interdependent elements that enabled the model to be implemented effectively and with meaningful impact.

The HOPE(S) training component was widely valued for raising awareness of the harms of LTS, promoting a human rights-based approach, and helping staff reframe behaviours through a trauma-informed lens. Staff noted that the training was most effective when it was followed up with practice leadership and real-time modelling by HOPE(S) practitioners, highlighting the need for practical, relational implementation of the model rather than a didactic approach.

The practice leadership role of HOPE(S) practitioners was seen as vital for sustaining cultural and behavioural change. Their "hands-on" support helped clinical teams transition from fear-based, 'risk-averse' practices to more confident and compassionate care. Staff described practitioners as standing alongside them, especially during moments of crisis or moral injury, which instilled hope and encouraged relational risk-taking. This modelling of trauma-informed and rights-based care was essential for building staff confidence and unifying teams around the goal of ending LTS.

Moreover, HOPE(S) practitioners were often viewed as critical catalysts for change within closed, hierarchical, or siloed systems. Their independent but NHS-affiliated role gave them credibility and freedom to challenge entrenched practices, advocate for the least restrictive options, and bring coherence to fractured commissioning pathways. Staff and families alike appreciated the sense of momentum and urgency that practitioners brought, describing them as trusted, relentless, and influential in navigating systems and advocating for the person in LTS. In particular, practitioners were seen as essential in supporting transitions out of LTS, with many staff attributing smooth and trauma-reducing hospital transfers to their continuity and relational knowledge. Their presence during these critical transitions helped reduce distress and re-traumatisation and ensured that gains made through HOPE(S) were not lost when individuals moved to new settings.

Importantly, the success of HOPE(S) was not attributed to any single component. Participants emphasised that it was the integration of training, tools like the Barriers to Change Checklist (BCC), and practitioner-led implementation that led to sustainable change. These findings strongly support existing evidence that multi-component interventions are more effective in reducing restrictive practices and transforming organisational culture (Daguman et al., 2024). For commissioners and systems leaders, this reinforces that sustaining the HOPE(S) model (or similar initiatives to reduce LTS/restrictive practices) requires ongoing investment in its full architecture: not only the tools or training, but also the people who drive and embody the model in practice.

7.5. Positive benefits of HOPE(S) for families: restoring voice, hope and connection

The evaluation revealed that the perceived impact of HOPE(S) extended beyond individuals in LTS to significantly benefit their families. Family members described a renewed sense of hope, emotional safety and trust, as they observed their loved ones begin to engage meaningfully with HOPE(S) practitioners. For many, this was the first time in years they felt professionals were advocating alongside them, rather than questioning or marginalising their role. This relief from advocacy fatigue and systemic mistrust aligns with longstanding concerns about how families of individuals in restrictive settings are often excluded or blamed (Care Quality Commission, 2020; Hollins, 2021). The HOPE(S) model's relational and rights-based approach provided an alternative narrative, one where families were seen as partners, not problems.

In particular, the Respond therapy service offered trauma-informed support that families found more accessible and validating than prior engagements with mental health services. Families appreciated not needing to 'educate the therapist', which is a recurring burden in therapy for carers of autistic children or children with learning disabilities (Tournier et al., 2021). This is consistent with wider calls to embed relational practice and specialist trauma-informed support for families affected by restrictive practices (Lenehan & Geraghty, 2017).

The HOPE(S) family peer support forum further tackled stigma and isolation, creating a rare space where parents and carers could connect with others who 'just understood'. Peer-led models of support are increasingly recognised internationally as powerful tools for reducing isolation experienced by caregivers navigating healthcare systems as well as enabling mutual empowerment and promoting better quality of life (Rackham & Morgan, 2017; Tari-Keresztes et al., 2024). This is the first study to support the later for family members of individuals in LTS.

Together, these findings suggest that HOPE(S) functions not only as an intervention for reducing LTS, but also as a family-centred model that actively supports the emotional, relational, and advocacy needs of those most deeply affected by long-term segregation. These family outcomes are not peripheral but core to understanding the wider systemic impact of the programme. In line with rights-based frameworks and the NHS Long Term Plan (2019), this holistic approach, supporting both individuals and their families is crucial to transforming care and reducing reliance on restrictive practices.

7.6. Improving and sustaining the HOPE(S) programme: from intervention to system transformation

While this evaluation highlights the clear impact of HOPE(S), it also identifies areas for development to maximise and sustain the programme's benefits. Stakeholders consistently emphasised the need for HOPE(S) to move beyond its current role in responding to entrenched segregation, towards a more preventative, system-wide model that identifies and addresses the precursors to long-term segregation (LTS) before they take hold. This means embedding HOPE(S) earlier in the care pathway, i.e., working collaboratively with services to identify individuals at risk of entering LTS and intervening before isolation becomes institutionalised.

Participants called for shared understanding and clearer definitions of LTS across all levels of professional practice. Current ambiguity creates inconsistency in how segregation is used and recorded, with some professionals unaware they are implementing LTS in practice. This aligns with national concerns about the "invisibility" of LTS in clinical decision-making and data systems (Care Quality Commission, 2019; Hollins, 2023).

The development of structured tools or screening mechanisms to assess the likelihood of a person being moved into LTS could support earlier intervention. While tools exist for predicting seclusion (e.g. Hilton et al., 2019), there remains a gap in predictive frameworks for LTS, particularly for children and young people, autistic individuals and people with a learning disability. HOPE(S) could play a key role in shaping and piloting such tools, using its existing Barriers to Change framework as a foundation for more proactive, preventative approaches.

There is also strong potential for the adaptation and expansion of HOPE(S) beyond the current inpatient remit. Respondents expressed interest in adapting the model to community services, residential care, education settings, and forensic pathways, as well as for wider populations, including individuals with a mental health condition. This resonates with calls in the literature for rights-based, trauma-informed approaches in other institutional environments where restrictive practices are still routinely used (e.g. Baker et al., 2022; Butterworth et al., 2022; Conway, 2019). The core principles of HOPE(S), i.e., relational practice, reflective supervision, and trauma-responsive support are highly transferrable, with potential for wider system benefit if adapted sensitively to context.

Yet the sustainability and fidelity of HOPE(S) are contingent on deeper systemic change. As the evaluation revealed, the model is often implemented in the midst of “closed” or broken cultures, where staff feel demoralised, unsupported, and fearful of repercussions. These environments, characterised by poor communication, defensiveness and risk-averse decision-making (Care Quality Commission, (2022a), can erode even the most robust interventions. Where HOPE(S) was introduced without the support of senior leadership or strategic alignment with organisational values, HOPE(S) practitioners reported low uptake, resistance, and personal demoralisation.

To embed HOPE(S) meaningfully, the model requires not only local enthusiasm, but structural buy-in from senior leaders, including NHS Trust boards, service providers and commissioners. Culture change in healthcare depends on more than good intentions; it requires a strategic vision, sustained leadership and psychologically safe spaces for professionals to challenge harmful norms and innovate. Senior leadership must create the conditions for HOPE(S) to thrive: by endorsing its values, aligning it with operational strategy, and embedding it within quality assurance and commissioning frameworks (Care Quality Commission, 2022a; Tate et al., 2023).

The findings from this report strongly suggest that the power of HOPE(S) lies not only in what it does, but in what it disrupts: entrenched cycles of fear, dehumanisation, and siloed working. To improve and sustain the programme, those surrounding the individual in LTS and the structures and cultures within which they live must change. The burden of transformation should not fall on individuals or families, but on the systems and services that have, for too long, failed to uphold their rights.

7.7. Strengths and limitations of this study

This evaluation represents the first large-scale, mixed-methods investigation into both the impact of long-term segregation (LTS) and the effectiveness of the HOPE(S) national programme designed to reduce it. By integrating quantitative outcomes with in-depth qualitative insights, the study provides a rich and meaningful picture of how LTS affects individuals and families, and how HOPE(S) may offer a practical and rights-based alternative. Nonetheless, as with any complex real-world evaluation, there are important limitations that must be acknowledged.

A key limitation is the use of a single-group pre-post design, which constraints the ability to draw definitive conclusions about the causal effects of HOPE(S). This design is known to have low internal validity due to the absence of a control group and potential confounding variables, especially the inability to isolate the impact of HOPE(S) when other interventions might have taken place at the same time (e.g., Senior Intervenors Project[16]). Nevertheless, the pre-post design offers high external validity and was selected purposefully to align with ethical principles and the rights-based ethos of the HOPE(S) programme. In the context of working with autistic individuals and people with a learning disability (whom may have a history of systemic exclusion), it was neither feasible nor ethically justifiable to withhold potentially beneficial interventions or to randomise participants (Craig et al., 2008; Nicholson et al., 2013).

This design also allowed for the tracking of within-person change, which is particularly valuable in populations with highly individualised needs and outcomes. It was easier to embed within routine data collection processes, thereby reducing participant burden and facilitating inclusive, co-produced research. While gold standard designs such as pragmatic or cluster randomised controlled trials (RCTs) were considered, they were not viable due to: ethical concerns about withholding intervention; small, heterogeneous populations; and the practical challenges of implementing tightly controlled trials in volatile, high-risk settings.

To enhance the rigour of the study, the evaluation was strengthened through rich qualitative enquiry and repeated measures where possible. The qualitative components offered critical insights into the mechanisms of change, implementation contexts, and perceived outcomes; thereby addressing gaps left by quantitative data and mitigating some of the limitations inherent to the design. These qualitative narratives were particularly important in highlighting experiences and impacts that may otherwise have been missed, including the subtleties of cultural change, relational repair, and system-level barriers.

Other limitations to the data should also be considered. Quantitative measures related to quality of life, meaningful activity, and restrictive practices were difficult to capture consistently across sites. While the Mini-MANS-LD provided a structured assessment of quality of life, it has not been validated for individuals in LTS, raising questions about its suitability in this context. The HOPE(S) Outcome Tool (HOT), developed for use when other measures were not appropriate, also lacks formal psychometric validation. There remains a pressing need to review and refine outcome measures to ensure they are sensitive, inclusive, and appropriate for this population. Lack of follow-up is also a limitation, as it would be valuable to know if individuals' quality of life and circumstances have changed 6-12 months post intervention.

Additionally, the true scale of LTS may be underestimated in this report. Qualitative data suggest that some individuals may be subject to LTS without being formally recognised as such, highlighting gaps in awareness, recording, and accountability. This raises serious concerns about hidden harm and the systemic invisibility of people in these circumstances.

The qualitative sample was diverse and representative across stakeholder groups, but professionals made up the largest proportion of participants. Although the research team took care to co-produce and sense-check findings with people with lived experience and families, there is a risk that the voices of individuals with experience of LTS may have been

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[16] More detail about the Senior Intervenors Project can be found here: https://www.england.nhs.uk/learning-disabilities/about/reducing-long-term-segregation/. Authors believe that this may have only impacted a small proportion of individuals receiving the HOPE(S) intervention (n = 7), however this has not been verified.

overshadowed. Future work must continue to prioritise direct engagement with these individuals, to further illuminate its meaning and impact from their perspective.

Taken together, this evaluation offers valuable and timely insights into the realities of LTS and the potential of HOPE(S) to disrupt and reduce its use. While limitations remain, the study contributes critical evidence and identifies clear directions for further research, refinement of tools, and sustained investment in rights-based, relational approaches that place the needs and voices of children and young people, autistic individuals and those with a learning disability and their families, at the centre.

7.8. Key recommendations for policy, practice and research

Policy and Practice Recommendations

7.8.1. Standardise definitions and language across systems

Undertake a national review of terminology related to long-term segregation (LTS) to ensure consistency in definition, application, and reporting. This should include clarification of distinctions between LTS, seclusion, and related practices, and ensure universal adoption of a shared language across all services and settings.

7.8.2. Identify and act on all cases of LTS

Establish mandatory review processes to identify all individuals currently in LTS, including those not formally recognised as such. Immediate implementation of HOPE(S), or a comparable least restrictive, rights-based intervention, should follow. Every person in LTS must have a clear pathway to exit. Where there are significant barriers to ending LTS, the rights and quality of life of individuals in LTS should be prioritised.

7.8.3. Mandate transparent national monitoring and reporting

Build LTS oversight into regulatory and quality assurance frameworks, with robust data collection on prevalence, use of restrictive practices, and quality of life indicators. Reporting must be consistent, transparent, and used to drive accountability.

7.8.4. Embed mandatory training on LTS and rights-based practice

Introduce national mandatory training for all inpatient and community-based staff to raise awareness regarding the harms of LTS, legal definitions, and rights-based alternatives. HOPE(S) training or equivalent should be extended to all staff involved in the care of individuals in or at risk of LTS, regardless of seniority or role.

7.8.5. Equip leadership to challenge closed cultures

Senior leaders and commissioners must be trained to identify, challenge and dismantle closed cultures. This includes creating psychologically safe spaces for staff to speak up, embedding HOPE(S) or similar models in service strategy, and prioritising trauma-informed leadership.

7.8.6. Shift to proactive prevention

Develop early identification tools and predictive models to flag individuals at risk of LTS. HOPE(S) should be adapted to operate upstream, intervening before segregation occurs.

7.8.7. Centre families in care planning and service design

Establish formal mechanisms for inclusive communication and decision-making with families. This includes considering family members in key consultations and involve them in the identification process of those in LTS (or at risk of LTS) to support their care planning and pathway to exit/discharge or transition fit for purpose in the community.

Expand existing HOPE(S) work with families, ensuring they are recognised as partners in care and supported to navigate systems. The HOPE(S) team have undertaken extensive work with families which led to the amendment of the HOPE(S) clinical guide (HOPE(S) model, 2023) which has been incorporated in the 2-day HOPE(S) clinical team training. It is crucial, however, that this work continues. Current work could be strengthened by expanding the training material, reflective practices and/or through practice leadership.

Enhance flexibility of family support services (e.g. evening/weekend access to Respond therapy).

7.8.8. Safeguard physical health in LTS

Introduce a national requirement for monthly physical health checks for all individuals in LTS, with clear lines of accountability and follow-up embedded in service protocols.

7.8.9. Expand and invest in HOPE(S) practitioners

Increase recruitment and training of HOPE(S) practitioners (or practitioners with a similar role), including the establishment of a national support network to provide mentoring, supervision and guidance for complex cases. This is essential if the model is to scale.

7.8.10. Broaden HOPE(S) scope to include education and community settings, as well as individuals with mental health conditions

Update HOPE(S) training content to include individuals' perspectives and case studies beyond inpatient care, particularly from schools, CAMHS, and residential care.

Implement HOPE(S) model for people with mental health conditions in LTS.

7.8.11. Reframe the language of 'risk'

Review terminology such as "positive risk-taking" and "risk aversion", which may unintentionally pathologise individuals rather than focusing on systemic or environmental failures. Language should reflect a strengths-based, rights-affirming approach.

7.8.12. Clarify HOPE(S) practitioner roles and accountability

Develop clearer role descriptions and boundaries for HOPE(S) practitioners. Where flexibility is required, set expectations explicitly at the start of each engagement to promote shared understanding and team cohesion.

7.8.13. Enhance engagement with clinical teams

Update practitioner training to include strategies for building trust with clinical teams, recognising the teams/staff's existing knowledge and systemic constraints. Engagement should start from a place of shared learning, not critique.

Research Recommendations

7.8.14. Evaluate HOPE(S) across wider settings

Commission further research to assess the effectiveness and scalability of HOPE(S) in community services, education, residential care, and forensic settings.

7.8.15. Deepen understanding of lived experience

Support longitudinal and qualitative research focused on the lived experience of LTS, from both individuals and families. Investigate systemic drivers and psychological impacts and identify factors that influence pathways into and out of LTS.

7.8.16. Improve and validate outcome measurement tools

Critically review current quality of life and restrictive practice measurement tools for use in LTS contexts. Co-develop and validate new tools, where necessary, to ensure they reflect the lived realities of autistic people and people with a learning disability in restrictive environments.

Overall recommendation

The findings of this evaluation provide clear and compelling evidence that the HOPE(S) programme delivers significant benefits for individuals in long-term segregation, their families, and the professionals supporting them. HOPE(S) is more than an intervention; it is a catalyst for systemic and cultural change, offering a rights-based, relational model of care that aligns with national priorities and legal obligations.

There is a strong consensus across stakeholders that HOPE(S) should be sustained, expanded, and embedded across health and social care systems. Without HOPE(S), or a comparable, values and rights- driven alternative, there is a serious risk that services will continue to fall short in meeting the needs of autistic people and people with a learning disability, resulting in ongoing harm, institutional trauma, and irreparable damage to individuals and families.

If the HOPE(S) programme is not commissioned nationally, urgent action must be taken to implement an equivalent intervention grounded in the same core principles: human rights, least-restrictive practice, co-production, and whole-system change. Anything less will risk perpetuating a system that fails those it was designed to protect.

Closing remarks

Long-term segregation (LTS) has a profound and often devastating impact, not only on the individuals subjected to it, but also on their families. The evidence from this evaluation makes it clear that LTS is not a therapeutic intervention, but a practice that strips people of their dignity, identity and hope. There is an urgent imperative to prevent the use of LTS or reduce its prevalence (where prevention is not possible), and radically improve health outcomes for children and young people, autistic individuals and those with a learning disability who are at risk of being isolated within the very systems intended to support them.

This means building a shared understanding across all professions of what LTS is, how and why it happens, and what can be done to prevent it. It requires accurate national reporting, robust oversight, and investment in training and reflective practice that supports staff to feel confident in delivering least restrictive, rights-based care, even in the most complex situations. And where LTS cannot immediately be avoided, services must be held to account for ensuring that individuals experience the highest possible quality of life, with access to meaningful activities, personal relationships and physical health care, alongside a clear, person-centred pathway out.

The HOPE(S) programme offers a clear and credible model for how this can be achieved. This evaluation found that individuals who had been told, or had come to believe, they would remain in LTS indefinitely, began to rebuild their sense of self, form meaningful connections, and, in many cases, move out of segregation entirely. Nearly a third of those who exited LTS were discharged directly into the community. These outcomes were achieved not through coercion or control, but through compassionate, skilled, and rights-based practice, led by staff who had been trained, supported, and empowered through HOPE(S).

Crucially, the HOPE(S) programme challenges a deeply embedded culture of fear-based, risk-averse practice, replacing it with a model rooted in human connection, hope, and ethical care. It supports staff to rediscover their professional values and equips them to deliver relational care, even in high-risk, high-stakes settings. The result is not only improved outcomes for individuals in LTS, but also a more confident, resilient, and values-driven workforce.

At the heart of this evaluation are people who have lived through LTS and their families. Their insights are not a supplement to the evidence; they are the evidence. Their experiences reveal the urgent need for systemic transformation: not transformation of the individual, but transformation around the individual. The burden of change must not rest on children and young people, autistic individuals, those with a learning disability or their families. It must rest on the systems and services that have too often failed them.

Commissioning HOPE(S) or an equivalent rights-based model of care is not optional. It is a matter of justice, ethics, and human rights. It is urgent for the children and young people who will otherwise enter a revolving door of mental health detention, poor physical and mental health, and a system which will strip them of any skills/independence to enjoy a meaningful life close to their loved ones. It is crucial for their families whose life is on hold and suffer in silence while their loved ones are in LTS. It is also a matter of evidence: this programme is not only effective, but transformative. What we do next will determine whether we repeat the failures of the past, or finally create a system capable of supporting, not segregating, the people it serves.

My journey into long-term segregation and difficulty in exiting

"Ultimately, I went into long-term segregation because staff weren't sure how to support me. I was sensory seeking in ways that were dangerous, and my communication was hard for staff to understand. If I had had someone with the expertise of a HOPE(S) practitioner, I doubt I would've gone into enforced isolation in the first place. I might not have even been in hospital.

Long-term segregation (LTS) deliberately frustrated my neurobiological need for connection and cruelly interfered with my understanding of where I was in space and time. I found it profoundly disorientating and the social and sensory deprivation meant I was easily overwhelmed by interaction and/or activity. The longer the toxic isolation went on, the more I grew distressed, and staff withdrew further. No one knew what to do and it felt like everyone had given up. I uncharacteristically, yet predictably, developed action-orientated ways of coping e.g., lashing out.

HOPE(S) practitioners are relentlessly positive and their input would have begun the process of filling the great hole in my soul created by isolation. Practitioners are not afraid to build relationships with people, their preferences, histories, families, and life events, enabling the provision of an experience sensitive approach. Had I had a HOPE(S) practitioner I believe that I wouldn't have endured so much LTS and I would've been discharged sooner."

Alexis Quinn[17]

Image by Alexis Quinn, used with permission.

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[17] Alexis is an autistic campaigner and activist, public speaker, author of Unbroken, and manager at Restraint Reduction Network.

Share your thoughts!

If you have any thoughts or actions that you have taken because of this report, please do let us know by scanning this QR code

Alternatively, click the following link:

HOPE(S) Evaluation Impact Survey

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Research team

Study Principal Investigator (PI): Dr Alina Haines-Delmont

Dr Haines-Delmont is an Associate Professor/Reader in Mental Health & Coercion within the School of Nursing and Public Health at Manchester Metropolitan University. She has a track record of funding awarded by the EU, DHSC, ESRC, NIHR, and NHS trusts, and has successfully delivered research projects in a wide range of settings, including acute and mental health wards, forensic hospitals, prisons and police custody, and the community. Her current research revolves around the prevention and reduction of coercion and restrictive interventions for people with mental health difficulties or learning disabilities and autistic people, focusing on implementation, 'service user' involvement and co-design methodologies, health and racial inequalities.

Study Post-doctoral Research Associate: Dr Kathryn Fradley

Dr Kathryn Fradley is a post-doctoral research associate in Mental Health within the School of Nursing and Public Health and a member of the Mental Health Research Team at Manchester Metropolitan University. Alongside a wealth of volunteer and industry experience (including in care-homes and hospitals), Kathryn's current publications focus on understanding: mental health for individuals with neurodevelopmental conditions; the impact of the COVID-19 pandemic on mental health on young people and parents; and the mental health burden of the pandemic on healthcare professionals (with a focus on moral injury). Kathryn is a mixed-methods researcher; equipped at employing the best methodology for the question at hand. Her current research interests involve improving confidence and competency of healthcare professionals in supporting individuals with neurodevelopmental conditions.

Study Research Assistant: Miss Dineesha Georgeena Rajan

Dineesha Georgeena Rajan is a Research Assistant in Mental Health within the School of Nursing and Public Health and a member of the Mental Health Research Team at Manchester Metropolitan University (MMU). She holds a background in Forensic Psychology, with her master's dissertation, currently under publication, exploring international students' perspectives on the Forensic Psychology curriculum in the UK. Dineesha has contributed to multiple projects supporting neurodivergent individuals and older adults. Her research interests focus on neurodivergent populations, children and young people's (CYP) mental health and the prevention of youth offending. With experience in both quantitative and qualitative research, Dineesha is passionate about improving access to mental health services and enhancing the quality of life for neurodivergent populations, and CYP.

Appendices

Qualitative analysis

A sample of transcripts were coded by multiple researchers involved in the project (JL, AHD, and KG). All the transcripts were coded by KF. Prior to analysing the data KF first engaged in reflective practices to identify potential biases upon analysis. KF was aware of the findings in an unpublished interim report (Haines-Delmont et al., 2024) where the data collected during round one was analysed; and therefore, there were some pre-expectations of the findings. Beyond this, KF prior to analysing the data in this evaluation was unfamiliar with the literature and knowledge around LTS (and seclusion) and the HOPE(S) programme, nor had they had any lived experience or loved one (family or friends) currently or previously in LTS. KF also conducted interviews during the analysis and as such, care was taken during the interviews not to lead the interviewee by using open-ended questions. Yet, questions were included during the interviews conducted by KF to allow elaboration or clarity on emergent ideas drawn from the analysis. Again, this was supervised and overseen by AHD. The reason for the overlap was due to the time constraints in completing this report.

Prior to conducting thematic analysis, the data was separated into types of participants or 'groups' because there were key differences in the narratives and experiences across those with lived experience, family members, and professionals. This proved useful to reach data saturation for each group and for conducting sense checking. For each group, KF first familiarised themselves with the data by reading all the transcripts too. In line with best practice, KF made initial private notes as to their thoughts and feelings about the data. Secondly, KF re-read the transcripts and began coding the data. Once coded, KF reviewed the quotes for each code to ensure that the quotes indeed accurately reflected the initial code. Thirdly, KF developed sub-themes by bringing together initial codes which overlapped conceptually or had close relationships. Sub-themes were then reviewed and then used to inform the overarching theme (henceforth referred to simply as a 'theme'). Once themes were developed for each group, KF reviewed all the initial codes across the groups and developed themes (including sub-themes) for the whole sample to achieve the objectives of this report. See Supplementary Table 1 for an example of the steps taken to analyse the data. Please note that this is an example and is not a true reflection of the analysis of presented in this report. See Supplementary Tables 2 – 5 for the audit trail for the findings presented in this report.

In addition to sense checking, peer debriefing was implemented during and following the analysis of the qualitative data to ensure rigour and trustworthiness of the findings presented in this report. Peer debriefing was performed using a moderation technique. During the initial coding stage, KF and AHD read and generated initial thoughts and codes for three randomly selected interviews (all staff members). There was consensus in the analysis between KF and AHD ensuring rigour during the initial stages of analysis by KF. Further peer debriefing was conducted when reviewing the themes. Beyond changes to some language and structure of the themes, there was an agreement. Additionally, member-checking was performed for the emerging findings with individuals with lived experience, family members and professionals who attended the National HOPE(S) conference in May 2024.

Table 1. An example of the analysis conducted in this evaluation from quotes to developing themes.

Quote	Code	Sub-theme	Theme
"...seeing it done is more important than hearing then how it's done"	Practice leadership was useful for staff	Practice leadership led to better practice as well as a culture change amongst many staff	Although there are challenges, HOPE(S) especially the practitioners, were able to improve the quality of the individual's care and encourage positive organisational culture change overtime
"...every time I’m working with any of the patients now I’m always thinking what would I be thinking if I was in their shoes right now…"	HOPE(S) led to a positive change in practice		
"I see that those have been kind of absorbed, those principles, despite the resistance."	Resistant staff absorbed the model overtime	Yet, it takes time to see change	
"It’s really changing that thinking which doesn’t happen overnight."	Takes time for culture to change		

**Note: Although the information provided in this table is drawn from the data and the analysis, this table is to provide an example of the steps taken for the analysis only.*

Audit trails

Table 2. Audit trail for theme 1.

Code	Sub-theme	Theme
lower quality of life in LTS (n = 15)	Neglected basic human-rights and quality of life	LTS has a devastating impact on families and patients as well as a negative impact on staff
Symptoms or behaviour is worse (n = 6)		
Loved one experienced abuse (n = 6)		
Lack of or denied suitable therapy and, or education (n = 3)		
Reporting on safeguarding incidents (n = 7)		
Loved one feels hopeless (n = 7)	Hopelessness, fear and trauma	
Patient has institutional trauma from LTS and, or seclusion (n = 9)		
Family member experiences trauma (n = 11)		
LTS has a negative impact on family members (n = 8)		
HOPE(S) helps when staff felt 'stuck' and hopeless (n = 16)		
Staff felt concerns for their own safety		
Staff experience trauma		
Staff's fears and anxiety leading to LTS and, or seclusion		
Dehumanisation (n = 8)	Dehumanisation	
Viewed a punishment (n = 7)		
Family members fighting for better care (n = 8)	Fighting the system	
Family members do not feel heard by professionals (n = 10)		
Family members are mistrustful of the system (n = 9)		
Family members feel let down by services (n = 9)		
Family members feel powerless (n = 7)		
Communication breakdown between families and staff (n = 7)		
Clash between families and organisation or staff (n = 6)		
Family members have been threatened by professionals and providers (n = 4)		
Loved one if mistrustful (n = 3)		
Mum guilt (n = 3)		
Families feel isolated (n = 5)	Isolation	
Providers stopping family contact (n = 2)		
Families feel marginalised by society (n = 7)		

Table 3. Audit trail for theme 2.

Code	Sub-theme	Theme
HOPE(S) helps when staff felt 'stuck' and hopeless (n = 16)	Becoming 'unstuck'	HOPE(S) leads to better quality of care and postive culture change
Postive reaction or reflection to the HOPE(S) training (n = 24)		
Practice leadership was useful for staff (n = 17)		
Staff felt that practitioner were understanding and supportive (n = 14)		
Staff learnt from practitioners wealth of experience (n = 6)		
Found the BCC to be useful in practice (n = 24)		
Helps to maintain or grow the essence of HOPES (n = 7)		
HOPE(S) led to a change in culture or mindset about care (n = 34)	Change in general practice	
HOPE(S) led to a postive change in practice (n = 22)		
HOPE(S) reduced risk adversion (n = 13)		
Importance of using the right language (n = 13)		
Takes time for a culture to change (n = 14)		
Resistant staff absorbed of the model overtime (n = 7)		
Practitioner was able to mediate and pushback against systemic barriers (n = 16)	Pushing back against systemic barriers	
Helpful to have someone overseeing the quality of the care (n= 18)		
Helpful that the practitioner was viewed as 'external' but still NHS (n = 26)		
Practitioner as an avocate for the person in LTS (n = 16)		

Table 4. Audit trail for theme 3

Code	Sub-theme	Theme
Practitioner build a trusting relationship with loved one (n = 15)	Building trust and hope through meaningful connections	HOPE(S) can improve the quality of life of individuals in LTS as well as family members and staff
Improved staff relationship with and outlook of the patient (n = 15)		
Families seem happier with the care received (n = 10)		
HOPE(S) gave loved one hope (n = 3)		
HOPE(S) pracitioner has a good rapport with the family members (n = 11)		
Improved quality of life (n = 34)	Enjoying a meaningful life	
HOPE(S) improved the amount of time patient was not in LTS or seclusion (n = 28)		
Families seem happier with the care received (n = 10)		
HOPE(S) has a postive impact on families' quality of life (n = 6)		
RESPOND is helpful for families (n = 8)	Validated experience through trauma-informed Respond service	
RESPOND empowering families to navigate the system (n = 4)		
Professionals will listen to HOPE(S) but not us (n = 3)		
Family groups is useful in reducing isolation (n = 3)	Isolation reduced through HOPE(S) peer-support family forum	
HOPE(S) improved staff's confidence and perceived competence (n = 19)	Staff's confidence and morale improved	
HOPE(S) improved staff morale and reduced burnout (n = 19)		

Table 5. Audit trail for theme 4

Code	Sub-theme	Theme
Lack of shared language and clear terms across sectors (n = 23)	There is a lack of shared understanding and clarity as to what LTS is	There were challenges to the successful implementation of HOPE(S)
Inaccurate or omissions in reporting data (n = 7)		
More people in LTS than what is reported (n = 3)		
The interpersonal skills of the practitioner is important (n = 15)	Fighting against closed cultures	
HOPE(S) practitioner building relationships with team (n = 7)		
Closed culture resisting the model (n = 16)		
Defensiveness and, or denail (n = 13)		
Staff concerns of safety - risk aversion (n = 18)		
Some professionals felt attacked (n = 4		
HOPES was not deemed mandatory (n = 4)		
The role of the practitioner is unclear (n = 12)		
Team and practitioner disagreement leading to conflict (n = 12)		
The role of the practitioner is unclear (n = 12)		
Staff concerns of safety - risk aversion (n = 18)		
Need for upper management support or buy-in for implementation (n = 30)		
Practitioner lack control or decision making power (n = 7)		
Difficulties in sustainability without HOPE(S) practitioner (n = 13)	Working in isolation	
Rewarding or postive feelings as a practitioner (n = 6)		
Huge workload with many different roles (n = 7)		
Practitioner lack control or decision making power (n = 7)		
Practitioner feeling demoralised by closed cultures (n = 4)		
Practitioner feels exploited (n = 5)		
Emotional impact on the practitioner's role (n = 6)		
Difficulties associate with working in isolation (n = 6)		
More practitioners or similar (n = 12)		
Two or more practitioners working on the case or same provider (n = 4)		
Practitioner working as a team (n = 1)		
There is a need for a strategic overview or plan for HOPE(S) practitioners (n = 5)		
Difficulties in in getting all staff to do the training (n = 12)	Training uptake	
There is need for everyone to do the training (n = 6)		
HOPE(S) training should be mandatory and accessible to all (n = 16)		
Staff turnover means not everyone has done the training (n = 2)		

Table 6. Audit trail for theme 5

Code	Sub-theme	Theme
HOPE(S) should be proactive not reactive (n = 20)	Proactive rather than reactive (prevention)	HOPE(S) should continue and expand beyond its orginal purpose
Could be applied to post LTS and even post-discharge (n = 3)		
Professionals will listen to HOPE(S) but not us (n = 3)	Better communication between families and staff is needed	
Practitioners have good rapport with families (n = 11)		
Communication breakdown between families and staff (n = 7)		
Respond wants family avocacy amongst HOPE(S) (n = 1)		
HOPE(S) could help staff and families communicate better (n = 3)		
Desire to keep HOPES and improve awareness (n = 33)	Accessible to all individuals in LTS	
Desires the continuation of a practitioner or something similar (n = 14)		
HOPE(S) should be applied to other services, like the community (n = 15)		
Attempts have been made to focus on the community services (n = 4)		
Attempts have been made to apply HOPE(S) to outside LDA services (n = 8)		
HOPE(S) should be accessible beyond the LDA population (n = 10)		
HOPE(S) should be expanded to cover Ireland and Scotland (n = 8)		

Contact

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