Less than the sum of the parts

Lived experience of ATUs and mental health in-patient settings in the SELTCP region

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August 2020

three Cs

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About Three Cs

Three Cs stands for control and choice in the community. We are a social care and social inclusion charity supporting people with learning disabilities, autism and/or mental health challenges in South East and North East London. User involvement and co-production with people we support and families is at the heart of our approach and we have been the co-production partner of the South East London Transforming Care Partnership since 2017.

South East London Clinical Commissioning Group Learning Disabilities and Autism Programme

Response to Three Cs' Report 'Less than the sum of the parts'

Three Cs was commissioned to support co-production and stakeholder engagement for the South East London Transforming Care Partnership. One of the support requirements includes obtaining views on inpatient units for people with learning disabilities and/or autism. *Less than the sum of the parts* brings together the findings from interviews conducted by Three Cs and provides some recommendations for the care and support of south east London residents with a learning disability and/or autism. The South East London Learning Disabilities and Autism Programme (SEL LDAP) which has evolved from the Transforming Care Partnership is appreciative of the work done by Three C's and Forum members to produce this report.

Since the commencement of this research over two years ago significant strides have been made in the treatment and care of people with learning disabilities and autism. Learning Disability and Autism is prioritised in the NHS Long Term Plan with a continued focus on reducing reliance on inpatient units and targets set for ensuring Annual Health Checks (AHCs) are undertaken. Also, in response to Winterbourne View and more recently Whorlton Hall in 2019 there is an essential focus on the quality of inpatient services with the implementation of Host Commissioner Guidance and 6 and 8-weekly checks on inpatient services. The SEL Learning Disability and Autism Programme is working to ensure that Local Care Partnerships between health, local authorities and providers are well positioned to ensure personalised accommodation and support is available for its residents, of all ages, on discharge from inpatient hospital settings.

SEL LDAP has benefited from having developed a solid foundation and infrastructure to effectively monitor inpatients with the use of an Inpatient Tracker and continues to develop the use of Dynamic Support Registers (DSR) to support admission prevention and effective use of the CETR (Care Education Treatment Review) process.

The Inpatient Tracker used in south east London captures discharge planning, 6-8 weekly checks and CETRS and information on seclusion and long-term segregation and what has been done to eliminate these.

A key priority for the SEL LDA programme is for the repatriation and discharge back to London for current inpatients and we are developing the provider market in South East London to support this. While the majority of our inpatients are in London and we are currently able to admit most children and young people routinely to south London units, we continue to actively monitor and work with NHS England and Improvement (NHSEI), the Care Quality Commission (CQC) and local boroughs to ensure patient safety and clinical effectiveness. Several specialist and/or secure units for people with mental illness, learning disability and autism are provided out of London by various providers, and as stated above, the South East London LDA programme will continue to work with all agencies to implement quality initiatives and guidance for all inpatients particularly those out of London.

The findings and recommendations made in this report reflect the views of interviewees with lived experience, forum members, families, and carers in south East London and will help inform the overall development and commissioning activities.

21/08/2020

Foreword

"Every organisation and professional with a responsibility in commissioning, quality assurance as well as the care and management of individuals, needs to make a concerted effort to implement, prioritise and champion services for children and young people with autism and learning disability."
(Case Review Care of MG, Marsh & Man 2016)

The co-authors of this report wish to acknowledge the commitment SELTCP has made to transforming care beyond the national Transforming Care programme which ended in March 2019 and, in particular, its continuation of the Transforming Care Forum and the commissioning of this research.

This report belongs to Three Cs and has been written in good faith based on accounts provided by those with lived experience, as well as information which is available in the public domain. In addition, members of the SELTCP Transforming Care Forum have kindly given feedback on the research itself and on how to get the best out of contributions from lived experience towards system change.

Early in the research, it became clear that a number of witnesses had experienced ATU and in-patient providers, as well as parts of the wider health and social care system, to be punitive and retaliatory to those who complain or speak out. As a result, and as an additional measure to maintain confidentiality and anonymity, the authors have avoided the inclusion of identifiable case studies in favour of testimony dispersed under common themes supported by testimony or evidence which is already in the public domain.

The important thing for most witnesses in this research was not to point the finger at individuals, Local Authorities or Clinical Commissioning Groups but to make sure that decision-makers across SELTCP genuinely 'prioritise and champion' personalised services for children and young people with autism and/or learning disabilities with 'challenging behaviour' and/or mental illness. The hope is that the stories of 'lived experience' of ATUs and in-patient mental health services will help commissioners to start to put things right in a more radical and innovative way.

There was appreciation for some excellent individual professionals and practitioners and, where clinical and professional expertise was effective, it was prized by patients and their families alike. Unfortunately, this was the exception, not the rule. Far more frequently witnesses experienced clinicians, professionals and healthcare staff in the ATU and in-patient system as uncaring and incompetent at best, punitive and abusive of people's human and civil rights at worst. The fault is not just with individuals and it will not be fixed by the usual continuous improvement interventions like more training or safer methods of restraint, or even more effective inspection by the CQC.

During the lengthy periods ATUs 'spend' seeking to diagnose or exclude specific mental illness, the psychosocial aspects of existence that keep children and adults healthy and mentally well – opportunities to exercise, participate meaningfully, eat well, get enough sleep, spend time with loved ones – are non-existent or in short supply. Since psychosocial deprivation is known to be amongst the primary triggers for 'challenging behaviour' amongst children and adults with autism and/or learning disabilities, this is a deeply disturbing paradox.

The clinical and moral incoherence of the ATU as a model and method of treatment creates the conditions for fundamental breaches of human rights. This is aided and abetted by the faulty Mental Health Act legislation that supports it and the fractured but powerful system hierarchy that keeps it all in place.

The report title – *Less than the sum of the parts* – was chosen to indicate that there is a whole system deficit in services to children and adults with learning disabilities and/or autism who may have mental illness and/or 'challenging behaviour'. As currently constituted, and judged by its outcomes, the system is both poor human value and poor value for money. The wider system of education, health and social care which, according to statute, should serve this group of disabled children and adults as equal citizens throughout their lifetime, lets them

down at every turn and at the worst times possible: when their parents are at the end of coping, when undergoing transitions, when excluded from school; when their physical or mental health changes, when they are in hospital, waiting for discharge or discharged, and when their placements break down and they are in crisis, for the first time or again.

The system of funding invites cost shunting and guarantees crisis-generating delays. The funding is in the wrong parts of the system, continues to fit people to places instead of places to people, is not personalised and wrapped around the child or adult at risk from childhood to old age as it should be. When this group of children and adults most needs health, social care and education to be holistic and collaborative, it is fragmented, compartmentalised and overshadowed by unreconciled conflict between health and social services staff, between medical and social models of care and support.

Only a full closure programme will 'fix' the ATU system problem and stop the human rights abuses which are endemic to it. SELTCP can make this possible in its area of responsibility by leading the way on early identification of children/young people at risk, pre-emptive personalised 'support for living' solutions led by CCGs and LAs in partnership with families, and a full range of local/regional crisis response solutions co-produced with patients and their families. Latterly, most witnesses in this research would say that crisis support is absolutely essential, but not instead of early intervention and prevention, not under Mental Health Act section, and with the exception of Atlas House, not in ATUs.

Finally, despite all the knowledge generated about lived experience and co-production and its value to the system, and the people in it, there remains a counterproductive hierarchy of expertise amongst the professions in which patient and family engagement, despite the rhetoric, is at the bottom. In light of the endemic risk of abuse and neglect in ATUs, PICUs and other mental health in-patient settings – and SELTCP's clear commitment to harnessing co-production and lived experience –

we hope that commissioners across all six boroughs urgently find co-produced ways to make the ethically dubious 'place of safety' and 'nowhere else to go' arguments a thing of the past.

Co-authors
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Executive Summary

This research into lived experience of Assessment and Treatment Units and other in-patients settings was commissioned by South East London Transforming Care Partnership. It involved a total of 11 people with lived experience, including three adults with autism and/or learning disabilities and eight family members. Its methodology, findings, conclusions and recommendations are set out in the full report which follows. The Executive Summary summarises key findings with a summary conclusion and recommendations.

System culture and human rights

Most ATUs do not understand autism-related anxiety, sensory sensitivities, or auditory processing difficulties or support or understand highly personalised communication, which:

- Precludes the development of relationships conducive to patient care
- Generates distress and frustration and causes 'challenging behaviour'
- Prevents genuine patient or user involvement in decision-making, including CTRs and CETRs
- Calls in doubt whether clinicians can distinguish between symptoms of mental illness and behaviour that challenges in an accurate or timely way

The exception to this was Atlas House where staff were competent, developed good relationships with the person and their family and involved both in decision-making.

Most ATUs were characterised by a medical model of service that:

- does not understand its patients or how to meet their mental or physical healthcare needs
- deprives them of the psychosocial elements of life which keep children and adults well (relationships, sleep, meaningful activity, exercise) and the absence of which triggers 'challenging behaviour'
- rarely offers timely or sustainable intervention or treatment

The exception to this was Atlas House which was a highly personalised and ordinary living environment in which the person's psychosocial needs were largely met. There were also important instances of admission where medication was an effective intervention.

Most ATUs were experienced as closed cultures which create the conditions for human rights breaches, including:

- Detention with open-ended assessment and no effective treatment experienced as punishment akin to imprisonment without charge, and seclusion and segregation a form of solitary confinement
- Restrictive practice normalised and physical and chemical restraint used extensively, sometimes causing injury or threatening life
- Lack of respect for dignity of the patient, for their possessions and their privacy, setting the scene for inhuman and degrading treatment
- Neglect of personal care and patient hygiene, which is a notable subversion of well-established healthcare standards and norms
- Concerns about basic healthcare and fear that patients might be harmed or die of manageable and treatable conditions e.g. starvation, infection, constipation, epilepsy

The exception to this was Atlas House with an open culture, low use of restrictive practices, competent and supportive staff and no concerns expressed about breaches of human rights, degrading treatment or neglect.

Battle of the experts

Most family witnesses said:

- They wanted, needed and respected competent clinical and professional expertise and some felt successful clinical intervention had been a matter of life and death
- The experience of hospital was more successful when respect was reciprocated by professionals who listened and respected family expertise

- Hospital was least successful when professionals 'knew best', misunderstood their patients, dismissed the expertise of families and excluded them from decision-making
- They have been excluded at some point from critical decisions
- They have been blamed and treated as a problem.
- (Some said) they have been punished or threatened in order to silence them

The clinical and professional hospital hierarchy sometimes extended to exclusion of the expertise of other professionals e.g. SALT.

Crisis: transitions and funding battles

In terms of behaviour that challenges, normal transitions and life changes constitute 'setting events' or 'triggers in waiting' because they involve pain, anxiety, stress and/or distress which are usually more difficult to understand, communicate or deal with if you have autism and/or learning disabilities.

The reason children, young people and adults ended up in ATUs and in-patient settings (including for long periods of time) included:

- No anticipation, planning or professional support for life transitions ending in crisis (e.g. starting and leaving school, reaching puberty and adolescence, and becoming an adult); life events triggering crisis (e.g. bereavement, sibling leaving home); worsening of conditions, changes in health or medication; sudden and unmanaged transitions generated by providers and schools (school exclusion, placement breakdown)
- Families left to cope with transitions, health crises or escalations in behaviours that challenge without effective intervention or support
- There was nowhere else to go as no suitable crisis response in the community, making PICUs and ATUs a first resort

Funding impasse and funding battles were an important theme, including:

- Funding framework not fit for purpose
- Families having to fight for funding
- Cost shunting between health and social services
- Funding decisions delaying referrals for school or placements, and delaying discharge
- Absence of key decision-makers in CTRs and CETRs
- Turnover or absence of social workers
- Blanket policies (not funding 52 week school places, not funding out of area) presenting obstacles to personalised solutions
- Commissioning which is reactive (crisis-driven) rather than pro-active (life-driven) defeats crisis prevention

Rare good experiences of funding decisions involved diligent personnel from all sectors (teachers, social workers, doctors, commissioners), speedy funding decisions by LAs and CCGs and high co-operation over joint funding (including 50/50 funding splits).

Witnesses and Transforming Care Forum members were vocal about crisis responses that could work, including:

- A support register of children and young people at risk of crisis enabling pro-active prevention and early intervention
- Crash pads in the community
- Pre-planned bespoke crisis responses to support families or individuals in their own homes
- Good awareness about individuals for healthcare professionals and police exercising warrants under MHA sections 135 and 136 to prevent unnecessary admission to hospital
- Preventive use of CTRs in the community

Last resort in-patient admission should be to places that protect rights and buck the trend on ATU/PICU culture, environment and approach, like Atlas House or adapted versions of Brookside Clinic, Essex.

All witnesses evidenced that, in one way or another, good ordinary lives in the right school and/or accommodation with the right support to live safely and happily was possible upon discharge. This included:

- A life that was ordinary or as near ordinary as possible doing the same things as other children/ citizens e.g. fun, learning, social life, work
- Appropriate environment in a mix of residential schools, residential homes and community support
- Highly personalised, well-informed and competent daily support, not always highly specialised
- The appropriate use of Deprivation of Liberty Safeguards
- The use of Deputyship by parents as a route to advocacy and safeguarding
- An understanding and practice in autism, as well as strategies to manage behaviours that challenge
- Good, pro-active support from MDT, health professionals and social workers

Navigating the system

Patients and families had extreme difficulty navigating a highly technical system governed by complex legislation and unseen rules and procedures, resulting in:

- Lack of knowledge about processes to protect the rights of their loved ones
- Experience of statutory systems i.e. education, health and social care, as adversarial
- System professionals – consciously or otherwise – excluding, overriding or disempowering families

Poor communication leads to inaction and frustration including:

- Lack of communication with parents, between organisations, and between professionals, is implicated in unnecessary or prolonged admission
- Where lines of responsibility and accountability are not clear, patients, parents or family advocates cannot have an informed and empowered role in crisis prevention
- When the decisions, actions and inactions of professionals lead to dangerous situations and adverse experiences for child and adult patients and their families, they cause trauma
- Litigation

Information, guidance and signposting needs attention in all six boroughs, including:

- Learning from the good practice that already exists in three boroughs[1]
- Full review of information and signposting for this cohort
- More relevant and helpful content, and links, which are easily found without the need to be 'in the know'

Summary conclusion and recommendations

The authors conclude that the clinical and moral incoherence of the ATU as a model and method of assessment and treatment actively creates the conditions for fundamental breaches of human rights. Whilst ATUs spend inordinate amounts of time seeking to diagnose or exclude specific mental illness, their primary modus operandi (detention, segregation, seclusion, restraint) deprive patients of the psychosocial aspects of existence (sleeping well, eating well, meaningful activity, exercising, time with friends and family) that are known to keep children and adults healthy and mentally well. As well as affecting mental and physical health, psychosocial deprivation is known to be amongst the primary triggers for 'challenging behaviour' leading to the inescapable conclusion that most ATUs cause or intensify the mental health conditions and behaviours they are intended to assess and treat.

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1. Lewisham, Southwark, Bromley

At their absolute worst, ATUs are the antithesis of a 'place of safety' with untenably high incidence of distress, injury and loss of life caused by a combination of detention, seclusion, physical and chemical restraint, abuse and neglect of basic healthcare, latterly including death from otherwise manageable conditions like epilepsy and constipation. The proliferation of abuse scandals and preventable deaths implicating ATUs since the Winterbourne View scandal in 2011, mean that their very mention as a place of potential referral can fill families with dread. As one family witness told professionals "He is not going to […]! People die there".

Children and adults as often as not end up in ATUs and in-patient services as a result of unmanaged transitions and crises, including protracted funding battles. Insufficient anticipation of and support for ordinary life and service transitions together with inadequate or non-existent early intervention and prevention services lead directly to the doors of ATUs and PICUs, simply because there is 'nowhere else to go'.

Whilst the majority of direct witnesses in this research cohort favoured ordinary, community-based living solutions to prevent admission or re-admission to ATUs and inpatient services e.g. homes not hospitals, there was also positive experience of residential homes and residential schools. The authors would therefore underline their conclusion that places need to be shaped and fitted to people, not people to places and one size or one model of support does not fit all. Sustainable living solutions need to be both diverse and highly personalised to each individual, involving the child or adult and their families as much as possible in the design and adaptation of environment and support.

Whilst the authors conclude that only a full closure programme will 'fix' the ATU system problem and stop the human rights abuses which are endemic to it, we acknowledge that SELTCP, and its successor South East London Learning Disability and Autism (SEL LDA) programme are working within the constraints of an NHS long term plan with final performance targets as far away as 2024. Our proposals therefore focus on how SELTCP/SEL LDA might respond in the interim to the propensity in ATUs for human and civil rights breaches and include recommendations about:

- Accelerating resettlement
- Narrowing the criteria for detention
- Getting ahead of the curve on the Mental Health Act and new duties on public bodies
- Treating families as human rights defenders: making restraint, seclusion, and segregation notifiable to families on every occasion
- Ending referrals to ATUs beyond the SELTCP/SEL LDA region
- Adopting a vanguard approach to defending human rights, specifically triangulating standard performance and incident data about ATUs (NHS, CQC) with proxy criteria for assessing the risk of institutional abuse and information from networks of trusted informants
- Measures to accelerate 'life span' and cross system innovations to manage transitions, prevent crises and promote community-based solutions
- Measures to make a reality of 'homes not hospitals' and increase the choice of competent community-based solutions
- Measures to support patients and families to know their rights and navigate the system and its processes
- Afterword on co-production: how to get the best out of contributions from lived experience towards system change

Last but not least, we recommend that SELTCP/SEL LDA partners do not refer children or adults to any service with a current inadequate rating and seek urgent discharge of in-patients from services with historic and persistent inadequate ratings.

Chapter 1
Introduction

Background to the research

South East London Transforming Care Partnership (SELTCP) commissioned research into lived experience of Assessment and Treatment Units (ATUs) and in-patient services as part of a contract with Three Cs to provide support for the co-production element of its Transforming Care programme.

The research or inquiry question formulated by the co-authors was "What is the lived experience of Assessment and Treatment Units and in-patient units for adults and children with learning disabilities and/or autism with 'challenging behaviour'[2] and/or mental illness commissioned by the National Health Service, Clinical Commissioning Groups and Local Authorities in the SELTCP region".

Methodology and approach

The methodology employed was ethnographic and based on grounded theory, involving in-depth interviews with seven people, augmented by relevant public testimonies, focus groups and feedback on *Building the Right Support* from the Transforming Care Forum (See Appendix 1 Building the Right Support). Researchers chose semi-structured as opposed to structured or unstructured in-depth interviews on the grounds that this would provide a guide to discussion with enough freedom and flexibility for new or different themes or perspectives to emerge (see Appendix 2 Interview Guide and Consent Form).

As the research question fundamentally deals with the perceptions of unique individuals the approach to analysis was necessarily inductive and interpretive, rather than positivist (Robson 2011). However, the analysis of data generated by interviews was led by an examination of emergent themes rather than pre-determined domains or codes. With the aim of both widening interpretation and protecting against 'groupthink', this initial examination was carried out separately by three co-authors. The resulting themes were synthesised into manageable domains which were used as codes (see Appendix 3 Primary Source

Coding and Evidence tables) to examine all direct witness testimony and primary source material as follows:

- System culture and human rights
- Battle of the experts
- Crisis
- A good ordinary life
- Funding battles
- Transitions
- Communication, information and guidance

The themes from interviews were cross-referenced with material from public testimonies and focus groups. Transitions and funding battles were so frequently the trigger or cause of crises that they have been discussed within the same chapter (**Chapter 5 Crisis**).

Triangulation of evidence was widened by reference to diverse secondary sources, including official documents relevant to transforming care in the public domain, the published views of those with lived experience as patients or relatives, and relevant media and press coverage.

A cumulative record called 'Building the Right Support' – what good looks like and what bad looks like – was compiled during SEL Transforming Care Forum meetings between 2017 and 2019. As this represents views of those with lived experience of ATU and in-patient services, this is regarded as a primary source and referred to as such in the analysis and findings.

The subjects of the research

The principal subjects of the research were expected to be family members who could speak on behalf of children and young people from their lived experience, together with adult in-patients or former in-patients of Assessment and Treatment Units or in-patient services. We approached 59 ATUs with requests to offer interviews to current patients, accompanied by fully explanatory information packs, including Easy Read material. There was no

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2. The term *challenging behaviour* is widely used in the health and social care system but is contentious because it has come to imply that the cause of socially unacceptable behaviour is in the child or adult, rather than in adverse psychosocial and environmental circumstances. The authors use inverted commas to denote non-acceptance of this term and interchange 'challenging behaviour' with behaviour that challenges services and behaviours of concern as terms more acceptable to those with lived experience.

take-up or response from any of these institutions. We circulated the request and information pack more widely on our own networks, our partner networks and via the SELTCP Forum. In the event, seven people responded and took part in in-depth interviews. Two further focus groups or feedback exercises – one face-to-face group on schools/transitions and online feedback looking at the findings, conclusions and recommendations – widened the total number of direct informants to 11. The majority of these – 8 out of 11 – were members of families with lived experience.

Anonymity

At the outset, researchers promised confidentiality to all of those who participated in interviews and focus groups. It is a finding of the research that those with lived experience, experience 'the system' (including the wider health and care system) as punitive and retaliatory to those who complain or speak out. This has made it even more imperative that views expressed in interviews and focus groups are anonymous and non-attributable. The authors have taken extra care to ensure that none of the quotes from interview transcripts or focus groups are attributable to identifiable individuals. This has required the dispersal of comments under themes and the avoidance of case studies or full stories. All subjects, including those whose testimony is in the public domain, are referred to as witnesses, patients, parents, family members or people with lived experience.

Glossary, abbreviations and definitions

SELTCP – South East London Transforming Care Partnership

SEL LDA – South East London Learning Disability and Autism programme

ATU – Assessment and Treatment Unit

PICU – Psychiatric Intensive Care Unit

Learning Disabilities – a learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life (Mencap)

Autism – a lifelong disability which affects how people communicate and interact with the world (National Autistic Society)

Mental illness – many different conditions which fall into the categories neurosis or psychosis

Mental health – a positive state of mind and body, feeling safe and able to cope, with a sense of connection with people, communities and the wider environment (NHS)

Behaviour that challenges ('challenging behaviour', behaviours of concern) – behaviour of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the person or others around them (NICE)

Psychosocial interventions – therapies or actions used to help a person reintegrate into society in a healthful way when there has been some disconnect with society

Restrictive interventions – when someone receiving care is restrained or put in prolonged seclusion or segregation

Restraint – use or threatened use of force to secure the doing of an act that a person resists, or which restricts a person's liberty, whether or not they are resisting

Force – the force used in restraint might be physical (for example holding the person), mechanical (for example by the use of restraining belts) or chemical (by the use of sedating medication)

Seclusion or segregation – where staff prevent a person from leaving a designated room or rooms. Seclusion may be viewed as the management of immediate violence, whereas segregation is the management of a longer-term threat of violence

Chapter 2
Literature Review

Introduction

The Literature Review of secondary sources has been largely confined to public sector and independent reports, media and publications by those with lived experience, and limited news articles or statements relevant to the research question. The review identifies relevant commentary and evidence in the public domain which pre-existed, led to, informed, evaluated and, in places, indicted the implementation of the Transforming Care policy and programme at a national and local level. The point of this was to set the scene and context for testimonies from lived experience.

What the literature review tells us in a nutshell

Some of the key policy and campaigning documents from the decade prior to Winterbourne View demonstrate that long before that scandal, the issues were known about. Transformational ideas were informing policy and strategy at a national level long before Transforming Care, and families and campaigning organisations were drawing the attention of government, sector leaders and professionals to indifference, health inequalities, neglect, abuse and avoidable deaths in the health and social care system.

Whilst the original Transforming Care policy and voluntary concordat were conceived in good faith, the performance of 'the system' against targets for getting people out of inappropriate placements in ATUs and hospital settings by 2014 was miserable; the subsequent Transforming Care Programme (the advent of Transforming Care Partnerships, NHS Building the Right Support, the national model and financial framework) which was intended to correct this situation has also fallen well short of its 2015-2019 targets, both nationally and locally.

Meanwhile, the scandals have continued unabated – from the avoidable deaths in Southern Health NHS Trust to LeDer reports of death in hospitals from treatable conditions like constipation, CQC revelations about the widespread misuse of seclusion and restraint, the panorama expose of criminal abuse at Whorlton Hall, and the findings of the Joint Committee on Human Rights. The imperative to reform a failing system has deepened even as system performance against reform targets has weakened, and the target and timescale for reform itself, being 2024 in the NHS Long term plan, has also been weakened when most it needs to be strengthened.

For those who are living adverse experience of ATUs and in-patient settings, whether as patients or their families, the situation is terrifying and traumatising. For those with lived experience who have done and are doing their utmost to use their experience to change and challenge the system, it is deeply frustrating and sometimes enraging. Importantly, this is the context which forms the backdrop to this research.

The advent of Transforming Care – a national perspective

Transforming Care came about following the scandal at Winterbourne View in 2011. Led by Norman Lamb MP, the government and the NHS pledged to commit to a programme for change to "transform health and care services and improve the quality of the care offered to children, young people and adults with learning disabilities or autism who have mental health conditions or behaviour that challenges".

The aim of the programme was to ensure better care outcomes for these people and to reduce the number of those receiving inappropriate care and treatment in Assessment and Treatment Units and other secure in-patient settings.

Two key documents which shaped Transforming Care at this time are Flynn's *Winterbourne View, Serious Case Review* (2012) and the Department of Health's final report *Transforming Care: a national response to the Winterbourne View scandal* (2012).

In the Serious Case Review, Flynn reported on abuse at Winterbourne View private hospital, a 24-bed private hospital for adults with learning disabilities and autism run by Castlebeck Ltd. The review was carried out following disclosure of the abuse of adults with learning disabilities and autism in the BBC Panorama programme 'Undercover care: the abuse exposed'. Terms of reference for the review included: the effectiveness of the multi-agency response to safeguarding referrals; the volume and characteristics of the safeguarding referrals; the responses to whistle blowing made; the role of the Care Quality Commission as a regulator; the role of commissioning organisations in initiating patient admissions to Winterbourne View hospitals; and the policy, procedures and operational practices of Castlebeck Ltd.

Sections of the report described the hospital and its personnel; the chronology of events; the experiences and perspectives of patients and their families; the agencies involved. The review showed the abuse resulted from serious failings in management procedures. Recommendations include a call for greater investment in community-based care in order to reduce the need for in-patient admissions at assessment, treatment and rehabilitation units such as Winterbourne View Hospital. The report also called for notifications of concern, including safeguarding alerts, hospital admissions and police attendances, to be better co-ordinated and shared amongst safeguarding organisations to allow earlier identification of potential problems and earlier action to be taken.

In its final report, *Transforming Care: A national response to Winterbourne View Hospital* (2012) the Department of Health stated clear, timetabled actions for health and local authority commissioners working together to transform care and support for people with learning disabilities or autism who also have mental health conditions or behaviours that challenged service. This shared objective was to see the health and care system get to grips with past failings by listening to this very vulnerable group of people and their families, meeting their needs, and working together to review and decommission inappropriate ATU and hospital places; move people to more appropriate accommodation and support nearer their homes; commission the range of services and support which enabled adults and children to lead fulfilling and safe lives in their communities.

The concordat which accompanied this report set out its commitment to work together, with individuals and families, and with the groups which represented them. It stated that delivery of real change, improved quality of care would have ensured better outcomes. The report was ambitious in that it stated that together it would set a strategic direction and measuring progress. To do this it required real system leadership across all sectors, including elected councillors as well as across health and care to reduce inequalities.

The first targets for reviewing and moving people out of inappropriate in-patient services which were set to be achieved by June 2014 under the Transforming Care agenda were failed miserably. As a consequence the Transforming Care Programme was initiated by the NHS and plans set out in Building the Right Support (2015) accompanied by a national service model for commissioners of health and social care services which stated that good practice should:

> *"[…] focus on ensuring the best outcomes for people by working in partnership with individuals and families/carers and through adopting person-centred approaches – vital to delivering independence and control for people and ensuring that the person's wishes and aspirations for their own life are at the centre of their care and support arrangements."*

In alignment with previous government policies Valuing People and Valuing People Now, the principles underlying the policy, model and programme were cited as rights, independence, choice and inclusion.

Building the right support (2015) was "A national plan to develop community services and close inpatient

facilities for people with learning disabilities and/or autism who display behaviour that challenges, including those with a mental health condition". It gave commissioners a clear framework to develop more community services for people with learning disabilities and/or autism who display behaviour that challenges including those with a mental health condition. It was also looking at the closure of some inpatient facilities. It was accompanied by a new financial framework which included asking local TCPs to use the total sum of money they spend as a whole system on people with a learning disability and/or autism to deliver care in a different way that achieved better results.

This plan was developed by NHS England, the Local Government Association (LGA) and the Association of Directors of Adult Social Services (ADASS) – with active input from people who use services and their families. This should have enabled people to live more independent lives in the community, with the right support and closer to home.

Forty eight transforming care partnerships (TCPs) – which included the first six (Fast-Track) sites – developed three-year plans to re-shape services, to meet local needs. The aim was to reduce in-patient beds by up to 50% but when community services are developed.

By the end of the three year period, none of the 48 partnerships had achieved its targets and SELTCP was (one of) the worst performers.

Transforming Care – a South East London perspective

At a local level the Transforming Care Programme sought to deliver three programme outcomes:

1. Reduced reliance on inpatient services (closing hospital services and strengthening support in the community)
2. Improved quality of life for people in inpatient and community settings
3. Improved quality of care people in inpatient and community settings

The South East London Transforming Care Partnership consists of the Care Commissioning Groups (CCGs) and councils of Bexley, Bromley, Greenwich, Lambeth, Lewisham and Southwark, together with NHS England (specialised commissioning).

For South East London the adult inpatient target set under Building the Right Support was 58 patients by end of March 2019 with the final performance 84 adult inpatients.

The NHSE operational target for 2019/20 set for SELTCP is 64 adult inpatients by end of March 2020 and the position at the time of writing is 74 [3] (data 10/02/2020)."

Before Transforming Care

There follows an appraisal of key documents relating to transforming care in the decade before Winterbourne view.

Valuing People – A New Strategy for Learning Disability for the 21st Century (Government White Paper 2001)

The white paper, *Valuing People: A New Strategy for Learning Disability for the 21st Century*, was intended to underpin the government's "new vision" for people with learning disabilities by confirming four "key principles" of rights, independence, choice and inclusion.

Key elements were:

- An end to the last long-stay hospitals
- A five-year programme to modernise local council day services
- A new national learning disability information centre and helpline in conjunction with charity Mencap
- A national forum for people with learning disabilities
- A learning disability task force
- Specialist local services for people with severe and challenging behaviour and integrated facilities for children with severe disabilities and complex needs
- An extension of eligibility to "directs payments", a scheme which allowed service users to choose and purchase their own care

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Treat me right! (Mencap 2004)

This report looked at how and why people with learning disabilities in England and Northern Ireland have poorer health than the rest of the population. The report sought to engage with everyone involved in improving the health and the healthcare experiences of people with a learning disability. It summarised what is known about their health needs and looked at what is actually happening when people seek health service support. It also aimed to build support for the changes that are needed, by proposing recommendations that would make a real difference.

The report aimed to make the health of people with a learning disability visible to public health practitioners when they assessed the whole population's health. Through real stories, it confirmed sobering national and international research findings about the health inequalities experienced by people with a learning disability and said that urgent action was needed by all those with power and responsibility in the system to improve the health of people with a learning disability.

Our Health, Our Care, Our Say: a new direction for community services (Department of Health and Social Care 2006)

This White Paper stated the Government's proposals to reform and expand community health and social care services in order to meet local needs, especially in poorer deprived communities. Four key objectives are highlighted in the White Paper: better health prevention services with earlier intervention; increased patient choice; tackling inequalities and improving access to community services; and increased support for people with long-term needs to live independently.

Specific measures included: expansion of local care settings outside hospitals; increased joint commissioning between Primary Care Trusts (PCT's) and local authorities to improve service integration; the introduction of practice based commissioning, where General Practitioners (GPs) are given more responsibility for local health budgets; increased provision for new primary care providers to compete for PCT contracts; and the introduction of a new NHS 'Life Check' which promoted healthier lifestyles with a pilot scheme spearheaded by PCTs by 2007-08.

Death by indifference (Mencap 2007)

In March 2007, Mencap published "Death by indifference, which reported the deaths of six people with a learning disability – deaths that the six families involved and Mencap believed were the result of failings in the National Health Service (NHS). The report stated that there is institutionalised discrimination within the NHS which is why people with a learning disability get worse healthcare than non-disabled people. The report detailed the stories of six people who died unnecessarily. Mencap wanted healthcare professionals to realise the seriousness and fatal consequences of the lack of understanding. Mencap believed that by doing this it would ensure that tragedies can never happen again.

Services for People with Learning Disabilities and Challenging Behaviour or mental health needs: Report of a project group (Mansell 2007)

Professor Jim Mansell published this report as a good practice guidance for commissioners purchasing services. The original report was published in 1993 and later revised and superseded by the 2007 version. The recommendations focused on services for people with learning disabilities and whose behaviour presented significant challenges.

Mansell recommended that:

- Educational and training facilities as well as day services for people with learning disabilities should be provided locally

- Direct payments and individual budgets should be considered and made widely available

- Local and health authorities should work with other agencies and organisations to identify current expenditure on learning disabilities and to pool budgets

Department of Health Valuing People Now: a new three-year strategy for people with learning disabilities (January 2009)

This three year strategy reaffirmed the commitment to the principles of equality, dignity, rights and inclusion set out in *Valuing People: A New Strategy for Learning Disability for the 21st Century*, published by the Department of Health in 2001. New funds promised were:

- A learning disability development fund of up to £100m from 2011 to 2013. This was to be spent on modernising day centres, helping people move from long-stay hospitals to more appropriate accommodation in the community, developing specialist local services for adults with severe, challenging behaviour as well as integrated facilities for children with severe disabilities and complex needs

- An implementation support fund, worth £6m from 2011 to 2013, to fund new advocacy services as well as the learning disability information centre and helpline

- Extra funds were also promised for self-advocacy organisations

For the first time, national objectives were established for quality and performance monitoring of learning disabilities services. These objectives aimed to provide clear direction for local agencies. They were backed up by new targets and performance indicators. A new qualification route for care workers was established, through a learning disability awards framework.

Although many organisations and individuals continued to adopt and work to the principles espoused by Valuing People and Valuing People Now, national policy commitment effectively ended with the election of a new government in 2010.

Six Lives: the provision of public services to people with learning disabilities (Local Government Ombudsman ordered by The House of Commons March 2009)

The Health Service Ombudsman and the Local Government Ombudsman investigated complaints made by Mencap on behalf of the families of Mark Cannon, Warren Cox, Edward Hughes, Emma Kemp, Martin Ryan and Tom Wakefield, who died whilst in NHS or local authority care between 2003 and 2005.

The report revealed significant and distressing failures in service across health and social care. One person died as a consequence of public service failure. It is likely the death of another individual could have been avoided, had the care and treatment provided not fallen so far below the relevant standards. People with learning disabilities experienced prolonged suffering and poor care, and some of these failures were for disability related reasons. Some public bodies failed to live up to human rights principles, especially those of dignity and equality.

Many organisations responded inadequately to the complaints made against them which left family members feeling drained and demoralised. The Ombudsmen recommend that NHS bodies and councils urgently confront whether they have the correct systems and culture in place to protect individuals with learning disabilities from discrimination, in line with existing laws and guidance.

The Care Quality Commission, Monitor and the Equality and Human Rights Commission, should satisfy themselves that the approach taken in their regulatory frameworks and performance monitoring regimes provided effective assurance that health and social care organisations are meeting their statutory and regulatory requirements in this area. The Department of Health should have promoted and supported the implementation of the recommendations and published a progress report within 18 months. This paper was laid before Parliament in response to a legislative requirement.

During and after Transforming Care

The Bubb Report (2014)

Following the failure to achieve Transforming Care targets by June 2014, Sir Stephen Bubb was commissioned to form and Chair a Transforming Care and Commissioning Steering Group which published *Winterbourne View – Time for Change* (2014).

Based on further research and consultation, the report recommended radical changes to the way the nation treats people with learning disabilities. The Bubb report, as it came to be known, proposed two key reforms, broadly welcomed by the Government and NHSE. The priorities were:

1. The closure of inappropriate institutions and the ramping up of community provision

2. That Government legislate for a Charter of Rights for people with learning disabilities and their families

By the end of the Transforming Care programme in 2019, neither of these priorities had been achieved.

The Mazar's Report (2015)

Following the death of Connor Sparrowhawk in July 2013 in a unit run by Southern Health NHS Foundation Trust. NHS England commissioned an independent review of deaths of people with a Learning Disability or Mental Health problems in contact with Southern Health NHS Foundation Trust April 2011 to March 2015. Subsequently referred to as the Mazar's Report, it specifically looked at all the deaths of people with a learning disability or mental health issues that had occurred at the Trust and reviewed all the investigations done in regards to those deaths. A summary of the key findings were:

- That the trust lacked leadership with a lack of time and attention to detail in reporting and investigating deaths

- That investigations took too long to complete and were poor in terms of quality

- That family were not involved in the investigations after a death plus there were

opportunities for the Trust to learn and improve but these were missed

- The findings in the report are of serious concern

The report makes a number of recommendations for change which have been accepted by Southern Health NHS Trust, Clinical Commissioning Groups and NHS England. The Trust was issued warnings by the Care Quality Commission (CQC) and NHS Improvement.

The continued failure of the Trust to hold the incumbent CEO accountable for these failings, including the death of Connor Sparrowhawk, was the subject of intense media scrutiny and challenge by families and campaigners, notably Sara Ryan, mother of Connor Sparrowhawk, and the campaign Justice for LB (Laughing Boy).

At a local and individual level, families were fighting their corner in a system which was still not addressing the issues, as the *Report and Recommendations from the Case Review into the Care of MG* (Marsh and Man 2016) demonstrated.

This is a case review into the care of MG, a 15½ year old boy with severe autism from the SELTCP region. The report detailed a number of recommendations with actions and leads with specified timeframes. NHS England Specialised Commissioning and NHS England London Region who were responsible for commissioning the inpatient care for MG noted the significant areas for improvement that this case review highlighted and apologised to MG and his parents.

The report stressed that the learning from this case should be implemented and acted upon so that what happened to MG and his family, did not happen to any other people in the future. Following interviews for this case review, all professionals interviewed noted that MG's case was not an isolated case. The case review revealed problems in a number of the areas around MG's care which led to 30 recommendations grouped into four key areas:

1. Planning and commissioning
2. Local Services
3. Flow of patients through the system
4. Governance

The report noted that some of the recommendations were simple and could be immediately implemented by the relevant organisations. Others were extremely challenging and required high level support and commitment in order to effect change that would decrease the chance that other children will follow the same journey as MG at a time of great need.

Department of Health
Local Support for people with a learning disability – The National Audit Office – March 2017

This report examined how the NHS in England and local authorities sought to improve the lives of the 129,000 people aged 18 to 64 who used local authority learning disability support services (Part One). It also assessed the setting up of the Transforming Care programme (the programme) which aimed to move some of the 2,500 people with a learning disability and/or autism out of mental health hospitals (Part Two); and progress of the programme (Part Three).

The NAO correctly predicted that the Transforming Care programme would not deliver the 35% to 50% reduction in bed numbers by 2019, citing the causes as TCPs not putting in place community-based accommodation and support, or a workforce with the right skills, as well as lack of proven and timely ways to enable the funding to follow the patient. It said that:

> *"One of the key mechanisms designed to manage the flow of patients into mental health hospitals is not working effectively, and money is not yet being released from mental health hospitals quickly enough to help pay for extra community support."*

The authors note that the Funding Transfer Agreement which was intended to enable money to follow patients and release funding for new infrastructure has worked very poorly and is being reviewed with a view to replacement in 2020.

Rose, S (2017) Breaking the ATU impasse following Winterbourne 2017

Rose, S (2017) asked why the Transforming Care programme had been a difficult and a disappointing process. He stated that some of the barriers to the TCP working were "private hospitals deliberately frustrating the process to avoid income loss, inept commissioning, risk averse local authorities, tedious and unnecessary procurement procedures, mistrust of competent providers taking the lead and falling to give families more control" However, Rose also confirmed that there were certain "ingredients" that would help the programme to be successful: trauma based approaches to care, ongoing support for families as well as the disabled person, circles of support, trusting experienced providers to get on with the job, light touch commissioning or the use of Individual Service Funds or Personal Health Budgets, ongoing investment in training and skilling up the workforce, paying above the living wage, carefully planned bespoke packages of support and giving families more control."

Ryan, S (2017), *Justice for Laughing Boy*

On July 4th 2013, Ryan's son, Connor Sparrowhawk (known as Laughing Boy or LB) was found dead in a specialist Assessment and Treatment Unit run by Southern Health NHS Trust. Connor, who had autism and epilepsy, had a seizure in the bath with no member of staff on hand to stop him from drowning. In *Justice for Laughing Boy: Connor Sparrowhawk – A Death by Indifference* (2017), Sara Ryan writes frankly and lovingly about her son's early life and preventable death and charts the burgeoning #JusticeforLB campaign. She shines a light on professional indifference to the lives of children and young people with autism and learning disabilities, and the deficit of leadership across the healthcare system. Sara Ryan coined the phrase 'lack of an imagined future' which is, arguably, at the heart of the way the system fails those with autism and learning disabilities.

Good intentions, good enough? A review of the experiences and outcomes of children and young people in residential special schools and colleges
Dame Christine Lenehan and Mark Geraghty, November 2017

The review was commissioned in the context of the Children and Families Act 2014, which sought to give more control to families and improve outcomes for children and young people with special educational needs and disabilities (SEND), through improved identification and assessment and by improvements in joint working across agencies to meet those needs.

Lenehan reported examples of good practice in alignment with the intentions of the Act:

> *"We've been encouraged to see examples of services doing this throughout the review. Whether for a traumatised child supported to overcome their experiences, an autistic child struggling with anxiety but transformed by positive behaviour support, or a child with profound and multiple learning difficulties providing valuable skills to their community while on work experience, we know that the right support can be life-changing for these children and young people."*

However, Lenehan observed that this good practice was far from widespread and too many children and young people were having bad experiences in mainstream schools. Families had to fight to get the support they felt their child needed and too many schools and colleges were not ambitious enough about the potential that children and young people with SEND can realise and the things that they can achieve. Lenehan concluded that:

> *"Many of the children and young people currently in residential special schools and colleges could be educated in their local communities if better support was available. To achieve this, local authorities (LAs) should in future work more closely with parents, clinical commissioning groups (CCGs) and all providers to develop a range of flexible, local solutions for these children and young people."*

Broach, S. (2018) RightfulLives – all the court judgments upholding the human rights of autistic and / or learning disabled people.

Broach recognised, the stories and experiences of people with learning disabilities and/or autism that has suffered any kind of abuse during their lives, "the legal framework of the Human Rights Act seems to barely touch the lives of people with learning disabilities." He confirmed that these experiences "involve unlawful deprivations of liberty", especially in both articles 5 and/or 8 of The Council of Europe (1950) that states that "Everyone has the right to liberty and security of the person.", "everyone who is arrested shall be informed promptly, in a language which he understands, of the reasons of his arrest and any charge against him […]Everyone who is deprived by arrest or detention shall be entitled to take proceedings by which the lawfulness of his detention shall be decided speedily by a court and his release ordered if the detention is not lawful." (European Convention of Human Rights, Art. 5) It is also essential to mention that Article 3: "prohibition of torture", "no one shall be subjected to torture or to inhuman or degrading treatment or punishment." (European Convention of Human Rights, Art. 3)

Transforming Care – The Challenges and Solutions VODG 2018

This report from VODG (Voluntary Organisations Disability Group) focuses on key steps to help people move out of long-stay inpatient care. Outlined are the challenges and solutions to moving people with learning disabilities, autism and/or mental health conditions out of long-stay hospitals and into facilities closer to home. This followed on from NHS England's policy ambition to enable people to move from inpatient settings into the community, with the right support. A summary of the proposed solutions were as follows:

- **Discharge plan delays – Provider Capacity**
  Having agreed discharge dates before a provider is identified to move people from hospital with a support proposal designed, fully costed and agreed in advance would reduce delays. Identifying providers at the earliest opportunity with a commitment to work towards bespoke support is critical to success. TCP's to have an overview of

providers who are available to create intensive support as alternative to hospital provision.

- **Lack of clarity about expectations and accountability – A one provider approach**
Having one provider co-ordinating all stakeholders early on in the process and managing priorities resulted in greater progress made. An approach that is "best fit" with one provider is preferred when developing both housing and a support packages. This is an intensive approach which needed a clear understanding of outcomes and realistic costs. VODG knew of providers that commissioners had no awareness of and who could respond in an individualised way to those needs. A pan-London provider infrastructure that is responsive to support delivery at scale would be beneficial.

- **Negative attitudes and aspirations – Understanding people's needs**
A London demonstrator has resulted in identifying needs, wants and aspirations and how this can be aligned with what others are seeking. Having a more detailed demand analysis would assist planning and priorities of future work and finding providers early on. This should also extend into knowing about those people who live alone that may require additional support. There are good practice examples of people who do not share the same TCP but may benefit from shared housing and/support which assist discharge times and financial sustainability. The development of a strategic overview of the numbers and needs will build provider capacity with increased face to face meetings to discuss needs. A pro-active approach to case management, assessment and support planning with specific providers leading can be beneficial as can stakeholders working across TCP's to jointly plan.

- **Confusion about costs – Early conversations**
Earlier dialogue is needed about the level of support and costs. By involving NHS England, commissioners and input from specialist services and support planners. Having an early start on assessment ahead of funding discussions assists with a shared knowledge and expectations of the support costs along with best approaches.

- **Lack of support to families – Involve and invest**
There is a growing awareness of the need to include support to families as part of the community support offer. Providers can help to build approaches to working with families to better understand and deliver support to families as part of their overall offer.

The Learning Disabilities Mortality Review –
Annual Report 2018
Reports, Published: 21 May 2019 Author: HQIP

This is the third annual report of the English Learning Disabilities Mortality Review (LeDeR) programme. It presented information about the deaths of people with learning disabilities aged four years and over notified to the programme from 1 July 2016 – 31 December 2018.

The methodology of the LeDeR review process included families of those with learning disabilities and recommended that all families should have the opportunity to be involved in the review of their relative's death from the outset. Over three-quarters (81%) of families were invited and contributed to the review of their relative's death in 2018.

In the period under review, 4,302 deaths were notified to the programme. In 2018, this was approximately 86% of the estimated number of deaths of people with learning disabilities in England each year.

Key findings included:

- The proportion of people with learning disabilities dying in hospital is higher (62%) than in the general population (46%)

- Almost a half (48%) of deaths reviewed in 2018 received care that the reviewer felt met or exceeded good practice, slightly more than the 44% in the 2017 report

- The proportion of deaths notified from people from Black, Asian and Minority Ethnic (BAME) groups was lower (10%), than that from the population in England as a whole (14%). However, children and young people from BAME groups were overrepresented in deaths of people with learning disabilities

Brown, M, James E and Hatton, c (2019),
Is Care Transformed? A review of Transforming Care in England, Lancaster: Centre for Disability Research (ceDR)

This report looked at Transforming Care and Building the Right Support and gives an overview of what has worked and what has not worked. It takes information from Transforming Care Implementation Plans, Freedom of Information requests, Assuring Transformation data about the numbers of people in in-patient hospitals and information from evaluations commissioned by NHS England. The government set a target to reduce by over a third the number of people with learning disabilities people in hospitals, by March 2019. The reports said that this target has not been met. The government and NHS England have said that the number of people in in-patient hospitals has gone down by almost 20%. The reports stated that this is wrong and the number of people in in-patient hospitals has actually gone down by 14%.

The report stated that many local health and social care partnerships asked for money from the £85 million allocated by the government but many did not receive it. Families have reported an improvement since 2017, when CTR's and CETR's have been introduced however this is in context to the report stating that the NHS and Government have not done enough to support people with learning disabilities in under Transforming Care. The report highlighted that both Transforming Care and Building the Right Support are not mentioned in the NHS Long Term Plan 2019 and the commitment to reducing unnecessary admissions is disappointingly low.

Lelliot, P. Ivanova, D (2019) *Review of restraint, prolonged seclusion and segregation for people with a mental health problem, a learning disability or autism*, Interim Report. CQC

This interim report by the CQC on the use of long-term segregation on mental health wards for children and young people and wards for people with a learning disability and/or autism. It looked at the information returned by 89 registered providers of these services.

The key data from those providers said that:

- 62 people were in segregation
- 16 people had been in segregation for a year or more
- On average, people were placed in a hospital that was 87km away from their home address
- 39 people were visited in segregation by the CQC for this interim report. They found that 31 people had autism
- People communicated their distress and needs in a way that is labelled challenging
- There is a pattern of very unsettled childhoods, chaotic support typified by people being moved in and out of residential settings
- Staff lacked training/skills to work with people with complex needs and/or challenging needs. Many were unqualified staff
- In the case of 26 people, staff had stopped attempting to re-integrate people back in to the main ward usually because of concerns around violence and aggression
- 13 people had experienced delayed discharge from hospital as there was no suitable package of care available in a community setting

The CQC concluded that the 'current system of care', which incorporated national bodies, providers and commissioners, had failed people whose care pathway had ended with them being segregated in a hospital. The system is not fit for purpose. A follow up report is pending in March 2020.

Who Are They? Where Are They? Children Locked Up Children's Commissioner for England May 2019

This report stated that at any given time almost fifteen hundred children in England are 'locked up' in secure children's homes, secure training centre, young offenders institutions, mental health wards and other residential placements, either for their own safety or the safety of others. These are some of the most vulnerable children in the country who, for a variety of reasons, have not been helped to live freely in their own homes or communities. The report looked to identify who these children are and where they lived, the costs of keeping them locked up, and to understand more about whether these places are truly meeting their needs.

BBC Panorama 2019: Undercover Hospital Abuse Scandal http://tinyurl.com/y3gloo4d

Secret footage from inside Whorlton Hall, a hospital for vulnerable adults showed patients mocked, taunted, intimidated and illegally restrained by abusive staff. Reporter Olivia Davies filmed staff deliberately provoking and physically restraining patients with autism and learning difficulties. This investigation came eight years after Panorama exposed the scandal of abuse at Winterbourne View. The government promised to reform care for the most vulnerable. Many now feel that they have broken that promise.

Ledger S, Shufflebotham L (2019):
Staying local: stories of how it worked
Community Living 33(1) 26-27

An article by Ledger and Shufflebotham (Community Living 33 (1) 2019) about making local support happen features three success stories about people with learning disabilities who found themselves in crisis and were able to remain in their local area instead of being referred to out-of-area provision "cut off from others and increasingly vulnerable to abuse". The stories revealed that the key to success was crossing multiple service boundaries, operating flexibly (sometimes beyond remit), in order to develop holding or interim solutions. This, combined with support from skilled, committed staff working closely and sensitively with people with learning disabilities and their families meant that, even in intensely difficult, life-changing situations and crises, long term local solutions could be found.

Newcombe J, (2019):
Banging the rights-based drum
Community Living 32(4) 14-15

In an article from the co-founder of the Rightful Lives exhibition, *Banging the rights-based drum* (Community Living 2019 32(4) 14-15), mum, advocate and campaigner Julie Newcombe, cites the Reach Standards (Paradigm) and the Real Tenancy test (NDTi) as the right standards when it comes to bespoke care, and questions the legitimacy of cost-driven decisions and pseudo

Supported Living, which is just Residential Care re-badged. Newcombe pledges to continue to campaign to ensure that the human rights of her autistic son – and all other children and adults with autism and learning disabilities – are to the forefront of the minds of public bodies and decision-makers.

Joint Committee on Human Rights: The detention of young people with learning disabilities and/or autism (October 2019)

The House of Commons and House of Lords' Joint Committee on Human Rights (JCHR) held two sessions in 2019 to hear evidence from witnesses with lived experience and expert organisations, including the Challenging Behaviour Foundation, on the detention of young people with learning disabilities and/or autism.

Their resulting proposals for change include the establishment of a Number 10 unit, with cabinet level leadership, to urgently drive forward reform to minimise the number of those with learning disabilities and/or autism who are detained and to safeguard their human rights; a legal duty on Local Authorities and Clinical Commissioning Groups to ensure the availability of sufficient community-based services; a legal duty on Local Authorities and Clinical Commissioning Groups to pool budgets for care services for people with learning disabilities and/ or autism; stronger legal entitlements to support for individuals; Care and Treatment Reviews and Care, Education and Treatment Reviews to be put on a statutory footing.

As well as concluding that "Our country is prosperous and values human rights. We cannot turn away from the reality of the lives of these young people and their families. It's time to act", Chair of the JCHR, Harriet Harman stated unequivocally that:

> "Families of those with learning disabilities and/or autism must be recognised as human rights defenders, and other than in exceptional circumstances, be fully involved in all relevant discussions and decisions."

Chapter 3
System Culture and Human Rights

Risks to, and breaches of, human and civil rights of the children and adults covered by this research, was a highly prevalent theme in the interviews and focus groups. In evaluating the testimony of witnesses to patient experience, the researchers have taken into account the requirements of the Human Rights Act 1998 and the European Convention on Human rights (ECHR) the Mental Capacity Act 2005, Mental Health Act 1983 (as amended 2007), the Mental Health Act Code of Practice (2015), the Care Act 2014 and other guidelines relevant to upholding the civil and human rights of people with learning disabilities, autism, mental illness and/or behaviour that challenges services.

Compulsory detention and reasonable adjustments

As a witness pointed out to the Joint Committee on Human Rights, the Mental Health Code of Practice states clearly that compulsory detention is rarely helpful for people with autism. She told the Committee:

> "It's just the wrong environment, so people get completely, completely, out of sorts in there."

People with autism and/or learning disabilities have a human right not to be discriminated against on the grounds of their disability and the right to reasonable adjustments to access goods and services under the Single Equality Act. When one witness asked for her son's rights as a disabled person to be respected, they were overtly denied:

> "There is no accountability in the system whatsoever. At one of the PICUs, I asked the manager if she would make reasonable adjustments for […] because he has autism, and she said, "I am not going to". I said, "It is a legal requirement", and she said, "I can't. I am not going to.""

Communication as a reasonable adjustment

A number of family witnesses said, in one way or another, that their loved ones' frustration at not being able to make themselves understood in an ATU or hospital setting actually created problems. This included increased anxiety and/or negative, depressive thoughts and/or induced feelings of fear and anger, with inevitable 'fight or flight' responses which were then badged as violence or aggression, justifying (sometimes retaliatory) restraint.

There was a theme of failure by most institutions to understand autism-related anxiety, sensory sensitivities, or auditory processing difficulties or to support highly personalised communication needed by the child or adult patient to cope in an alien environment:

> "The ATUs speech and language therapy report, highlighting […] auditory processing difficulties and the need to use visual support, was not implemented by staff. This increased […] confusion and anxiety, and consequently this impacted on his behaviour."

> "And I mean social stories are such a classic thing for autism […] They don't do those in hospitals, don't be silly."

This chasm in communication is a fundamental flaw in the health system and, in this part of the health system, leads to a situation in which children and adults cannot form trusting relationships with those who care for them, cannot ask for help, express their needs or describe their feelings. From the outset, they do not have the same access to goods and services as other patients and, as a result, their physical and mental healthcare is inadequate and, sometimes, catastrophic.

Autism and communication – just a training issue?

It was clear from the testimonies that just providing basic training to staff as a 'fix' will not fill the deficit. Autism awareness or generic knowledge about communication methods and aids used by

people with autism and/or learning disabilities is necessary, but is not sufficient on its own to provide an adequate patient experience. This is because expressive communication is ultimately unique and can differ so profoundly from child to child, and adult to adult that a highly individualised and informed view is needed:

"He can speak but it's very much on his terms and in his world. If you don't understand his world, you've got no chance. It's very, very – What's the word? Idiosyncratic, it really is."

"No, he doesn't need to sign. He can talk very well, he's got a very good vocabulary, but it's specific to him and he talks. He does a lot of his conversations through stories. He makes up these stories and you can see, actually, that the stories sometimes represent his hopes, his fears, his anxieties, but he puts it in story form. So a lot of it is quite repetitive as well."

As well as being personal and developmental, influenced by families and schools as well as Speech and Language professionals and others, communication capabilities are dynamic and can defy the diagnoses and predictions of health professionals. The family in one instance had been told that their son would probably not be able to talk so they were delighted when, alongside visual supports, he developed his speech much more than anticipated:

"When anxious […] will smash plates, TVs, cut electrical cords on his gadgets plus his sleep often deteriorates. He uses PECs to help communicate his needs, he does have limited speech […] Visual supports are important tools for […] to understand the world."

In another instance, it was the parent's discovery of a language meaningful to their son which made it possible for him to express a range of feelings, including fear which can be a trigger to his 'challenging behaviour':

"The major breakthrough was me finding a way of getting him to understand and

communicate his feelings. We did that with Thomas the Tank Engine […] So instead of saying, "I'm feeling frightened", he'll say, "I'm Percy in the signal." And when he says, "I'm Percy in the signal", he means he's frightened. He gets that. That's so meaningful to him."

As anxiety and depressed mood is also common to psychosis – and shouting and lashing out sometimes associated with hallucinations and delusional behaviour – it is difficult to see how, without reasonable adjustments, clinicians can ever distinguish correctly between symptoms of mental illness and behaviour that challenges in a hospital environment. When you add to the mix stress and distress which are effects of detention itself, the likelihood of accurate or timely assessment is reduced still further.

Personalised communication – a pre-requisite to involvement in decision-making

Genuine involvement in Care and Treatment Reviews (CTR) and other decision-making meetings is also impossible if the forms of communication being used are not highly personalised. One witness claimed that during the CTR process "communication tools were not really according to the needs of the people supported in the hospital", that records were often not updated, that Support Plans and risk assessments were usually in plain English but not in Easy Read, that no pictures were used, and there were no tools to help people communicate their emotions and how they were feeling.

In one instance, professionals ignored a parent's advice that their son had no tolerance of meetings involving lots of people in confined spaces and, with it, her warning that he would become aggressive if put in this position:

"One meeting, he'd had enough. He asked to leave. They said, "No, you can't leave." So he hit the support worker that had said no. What else did they think was going to happen?" […]

Had professionals understood the patient's autism-related needs in the first place, or respected the parent as an expert on their son and listened to advice, the meeting would not have happened in this way and a setting event for aggression avoided. Had they respected the patient's view during the meeting and acceded to a polite request to leave, his need to end a meeting which was intolerable to him would have been met in an acceptable way and behaviour that challenges might, again, have been avoided.

What happened as a result illustrates the barbarity of using restraint to manage behaviour that challenges, and its propensity for retaliatory violence from staff:

> "[The] support worker then got hold of his arm, and he'd only been there a really short space – Only been there a few weeks. Wrenched it up behind his back and snapped that bone."

Wrong environment, wrong treatment

When a child, young person or adult with learning disabilities and/or autism ends up in an acute mental health hospital, there is always some immediate need which is not being met or a crisis which needs to be managed. It is absolutely critical, therefore, that what happens next is the right treatment in the right environment. The only clear example of the right treatment in the right environment in this research – which cited more than 16 different admissions – is a case of the exception proving the rule:

> "[…] was admitted to an ATU following a 'Blue Light' CTR. He was there under DoLS with both family and hospital trying to avoid him being sectioned. It was important to them that he was admitted to hospital, Atlas House, in a dignified manner. His family stated that staff in hospital were excellent. On the suggestion from the hospital they were able to visit the hospital to ensure that […]'s room was personalised so that he had familiar toys and items around him for when he arrived to the hospital. […] was calm in his transition to hospital. The family feel that

the staff, consulted and involved them as equal partners."

The predominant experience could not be further removed from this exception. The paradox of the so-called assessment and treatment being itself injurious, going nowhere or worsening the conditions of adults and children is a thread in both public testimony and this research:

> "She will have been there for two years next Thursday, and the majority of that time has been spent secluded, locked in a cell, with no treatment and no therapy."

> "You have just locked up a child, effectively, even though he is in a man's body. You have locked him up in an environment with a lot of distressed people and, sadly, with staff who do not really understand how to care for him."

The number of mentions of institutions (schools, ATUs, PICUs, residential and community settings) who excluded, terminated placements, could not manage behaviour, did not know what to do, referred on without treatment those in their care, numbered >24 with one family member experiencing this as many as five times in three years.

Latterly, one witness sums up the futility of a medical model of service which does not understand its patients and which offers no sustainable intervention or treatment:

> "He was in two PICUs altogether, one ATU and two locked rehab units. He was shipped from one to the other because they did not know what to do with him, so they passed him on to somebody else."

The root causes of this appear to be reactive (crisis-driven) rather than pro-active (life-driven) commissioning, and inflexible commissioning. This culminates in a tendency to try to 'fit' children and adults into beds, places, and voids at the last minute instead of imagining, designing and funding a unique and sustainable ordinary life well in advance.

"[He] refused to attend the adult respite services or day services and so therefore didn't fit the services available and had no support from social services. An individual budget was denied, stating that it could only be used to access activities outside the home, which [he] was refusing to attend."

This combines with a lack of appropriate supports and interventions at inevitable life transitions (e.g. adolescence, from child to adult), changes in physical and mental health, or crises generated by unpredictable life events (e.g. bereavement, carer or family ill health).

Breaches of Human Rights

The only legitimate use of deprivation of liberty, seclusion, physical and chemical restraint is in the cause of protecting people from harming themselves and/or others or reducing distress. These interventions are not in and of themselves therapies, or health interventions with any therapeutic value, and used inappropriately can cause acute harm and distress:

"My son was kept in seclusion for up to nine hours at a time. The rule was that he could not leave until he was quiet. With his anxiety and sensory presentation, there was no way this was possible. He started to bang his head against the wall and would bite the wood in the door frame out of desperation."

At one end of the spectrum, the wrong assessment methods and treatment in the wrong environment generates unacceptably high incidence of restraint and restrictive practice and harms people in the cause of protecting them, and at the other end of the spectrum it has high potential to culminate in criminal abuse, as in the highly publicised cases of Whorlton Hall and Winterbourne View, or neglect leading to preventable deaths, like the manslaughter of Connor Sparrowhawk by Southern Health NHS Trust and many others (Mazars 2015, LeDer reports). ATUs are not simply susceptible to exceptional or anomalous events carried out by a few errant,

incompetent or criminal individuals, although they are that too. This is a misapplied medical model of assessment and treatment and human rights abuses are, therefore, endemic to it.

The Mental Health Act – punishment and imprisonment

All UK citizens have the right to liberty and freedom and the State can only imprison a person with very good reason e.g. if convicted of a crime which attracts a custodial tariff or if appropriately detained under the Mental Health Act. Depriving people of their liberty under the Mental Health Act when their diagnosis is not a mental illness is potentially a breach of Article 5, the right to liberty, Article 6 the right to a fair hearing, and Article 7, no punishment without law.

Unfortunately, the right to liberty under Article 5 is a qualified right through which the UK Mental Health Act as currently drafted drives a 'coach and horses'. This is because diagnoses of autism and learning disabilities are included in the definition mental disorder, which means that people who have autism or a learning disability can be lawfully detained even when they do not have a treatable mental health condition:

"There was no appropriate treatment and care. He received containment, seclusion, restraint and overmedication."

The fact that this state of affairs is potentially lawful does not alter the fact that such a system of detention is both clinically and morally incoherent, which has profoundly distressing consequences for the patients who are subject to it:

"He was so anxious and distressed that he froze for long periods of time (sometimes for half an hour or more) unable to speak or move."

Detention with open-ended assessment and no effective treatment is experienced as punishment akin to imprisonment, with seclusion and segregation the equivalent of solitary confinement:

"[T]he majority of that time [two years] has been spent secluded, locked in a cell."

"What can you do with a child through a little square hole in the door?"

"He spent most of his time in his room and sometimes in seclusion. He rarely went outside, he rarely had any exercise and he rarely had any meaningful activity or access to education."

"He did not understand why he was in hospital. He didn't feel ill. He thought he was in prison. He didn't understand why the doors were locked, why he couldn't go home."

"They said 'It was like a prison sentence to me'."

Unlike a prison sentence, the potential for serial sectioning under the Mental Health Act means that detention is open-ended, with patients subject to inordinately long admissions and reportedly worse off in terms of their rights to liberty:

"I spoke to a guy in one unit somewhere a long time ago, and he was there when he was 18 and now he is nearly 40 or 50 but he is still under criminal justice."

"[…] said it was like prison life; you are sent to prison. That is what some people think. Some people say that you go in and don't come out."

This likeness to being imprisoned without charge, sentence or tariff prevalent in this research is borne out by NHS Digital statistics for Learning Disabilities Services (September 2019) which reports the average length of stay to be 5.4 years in in-patient units largely intended to assess and treat within six months.

Even a good experience of hospital challenges the idea that so-called secure settings like ATUs really are secure. In a good ATU, witnesses report that it was the behaviour of another patient which put their son at risk resulting in him having a high volume of staff presence for his security and/or being unfairly secluded, thence isolated, for his own protection.

The environment

Living conditions in some ATUs rival those of the worst prisons with inadequate space, no dignity, no respect for personal possessions, and no semblance of a meaningful life.

"The only place was the room and the area was dull. It was old fashioned, dark and everything."

"The building had the ward in the basement. The shutters were always shut. [T]here was no natural light and the air stale."

"[B]edrooms were not large enough or well enough equipped to provide an individual living space."

"[…] realised that the physical environment would pose considerable risk and danger."

Many people with autism and complex needs experience sensory over-sensitivity and hospital settings have unpredictable sensory stimuli in terms of light and noise which may cause anxiety and distress, not least the sound of distress from other patients. Many also become distressed in confined spaces and need larger than average living spaces to be and feel safe, not smaller spaces and cells:

"She has massive sensory issues. She cannot cope with that environment. I am neurotypical and I could not cope with that situation, so [she] was unable to survive in that environment without resorting to fight or flight."

In its inspection of St Andrew's Healthcare in 2019, the CQC found most seclusion rooms did not have basic furnishings like beds, pillows, blankets or mattresses, and "records referred to patients as sitting or lying on the floor while in those rooms" (BBC News 2019: Mental Health Hospital in Northampton 6th June 2019 deemed unsafe).

Restrictive interventions may also lead to high volumes of staff in small spaces, and extremes of invasion of privacy and personal space at one end of the spectrum

or deprivation of human contact and interaction at the other. At worst, this combination of poor environment, segregation and seclusion was experienced by some witnesses to be a form of torture.

Restrictive interventions

The NHS reports that 3530 restrictive interventions were used for patients with Learning Disabilities in July 2019, 1000 of which were against children (NHS Digital September 2019). According to the CQC (Lelliott 2019), this includes:

Restraint Use or threatened use of force to secure the doing of an act that a person resists, or which restricts a person's liberty, whether or not they are resisting.

Force The force used in restraint might be physical (for example holding the person), mechanical (for example by the use of restraining belts) or chemical (by the use of sedating medication).

Seclusion or segregation are where staff prevent a person from leaving a designated room or rooms. Seclusion may be viewed as the management of immediate violence, whereas segregation is the management of a longer-term threat of violence.

This high prevalence of restrictive interventions is reflected in this research and discussed below under the headings segregation and seclusion, physical restraint, and chemical restraint.

Segregation and seclusion

The impact of unsuitable and distressing living conditions is made worse by the high incidence and frequency of seclusion and segregation. Six witnesses in this research had witnessed segregation or seclusion of their loved ones, with one in a public testimony saying that it went on for two years.

In its report *Segregation in mental health wards for children & young people in wards for people with a learning disability or autism* (May 2019) the CQC reported that 62 people were in segregation with

16 people in segregation for a year or more, that wards lacked suitable environments for people with autism; for 26 people, staff had stopped attempting to re-integrate them back on the main ward with staff believing that for 25 people the quality of life was better in segregation.

Of this situation, Dr Paul Lelliott, then Deputy Chief Inspector of Hospitals at the Care Quality Commission, said:

> *"Their world is narrowed to a highly restricted existence in a single room, or small suite of rooms. For many, their interactions with other people are characterised by distress and sometimes by the use of force by staff who consider this necessary to protect the person or others from harm. They have little or no say over decisions about their lives or their future. Many are also a long way from home – which can make it difficult for families to maintain contact." (CQC Interim Report…May 2019)*

One witness's experience of taking her son out of the unit under Section 17 leave demonstrates the extent to which seclusion is a default way of operating rather than a necessary safety measure or, in any way, a meaningful intervention:

> *"I was able to visit and take him out under Section 17 leave. In the morning in the hospital, he would be restrained or in seclusion. In the afternoon, I would take him out into the community by myself. We would go to Costa, to a farm, on a train ride, doing all the things that he loved, and we never had a single problem in all that time, because he was doing things that interested him and kept him fulfilled."*

When she took him back to the hospital, her son would often be secluded again, with short-staffing one of the reasons given. Another witness, who fought successfully to overturn her son's compulsory detention, said that within 24 hours of leaving the ATU – in which her son had been secluded on and off for two years, his leave outside the institution severely curtailed – he was out and about in the community

safely, making a nonsense of the restrictive practices to which he had been needlessly subjected.

The purposive isolation of patients through detention a long way from home – an average of 87km in the CQC findings (Lelliott 2019) and more than 100 miles away from home in the case of two witnesses – together with seclusion and segregation, is mirrored by ways of operating e.g. unreachable and absent social workers, which also effectively lock out or isolate families from their loved one and the service:

"They also don't give you a mobile phone number anymore so you can't phone them. I don't think I even had an email for one of them so there's no contact. You can't contact them."

"It was in the middle of nowhere, where there was no Wi-Fi ... No mobile phone signal, and it had actually gone into administration."

Physical Restraint

Three witnesses' sons had been subject to substantial physical injuries caused by physical restraint, including prone restraint:

"His arm was broken in three places. He has had black eyes, wrist burns and bruises all over his body. Carpet burns have taken the skin off his face and chin."

"The hospital called to say they were taking my son for an x-ray for a lump on his chest. It turned out to be a broken clavicle bone and the injury had actually occurred several weeks earlier."

"I can see how hyper-alert he is to the staff who have used restraint on him."

"That was his first experience of the private sector, and that's where they broke his arm."

"He had his arm broken in a restraint, the right humerus bone. His arm was wrenched up behind his back until the bone snapped."

Physical injury as a result of restraint is not an isolated or exceptional experience and professional guidelines are routinely ignored.

Another witness was led to believe by staff that her son's broken arm resulted directly from him punching a member of staff when in fact it was caused by the violent restraint which followed.

In only one of the incidents of physical injury experienced by witnesses was action taken against the perpetrator. Physical restraint and consequent physical injury seem to be system norms commanding high levels of management tolerance and cultural acceptability. Even when staff are operating in good faith and without conscious or criminal intent to abuse, their routine and permitted non-therapeutic responses are experienced as (and are) fundamentally abusive of the patients in their care. It would therefore be a mistake, on the basis of Winterbourne View and, more recently, Whorlton Hall, to conclude that this is simply a type of service open to malpractice by abusive individuals and those with criminal intent. The system and its preferred and permitted methods create the conditions for abuse.

All behaviour happens for a reason, and so-called challenging behaviour is no different. Responding to self-harm and hitting out under stress caused by detention and restrictive practices with yet more detention and restrictive practices highlights the absurdity of the in-patient assessment and treatment model, which can be devastating and traumatising in its effect. One witness presented evidence of her son being diagnosed with post-traumatic stress disorder as a direct result of his in-patient 'treatment', the mental health care in this case actually causing a mental illness.

Chemical Restraint

Whilst there were two examples of the judicious and successful use of medication as a treatment, and appropriate use of medication is critically important, there were more examples of the use of medication as a chemical cosh to manage behaviours that challenge:

> "He was kept on medication because the staff couldn't manage his behaviour."

> "He was in a comatose state, unable to stand or sit up straight, or string a sentence together, for four days."

> "There is an overreliance on medication that people frequently do not need."

One witness strongly expressed the view that restraint, and chemical restraint in particular, is used in ATUs because it is easier and means patients will not be a problem to staff:

> "I would say it is easier. It is easier to restrain. It is easier to seclude. It is easier to medicate. We also need to remember that one of the big solutions in these places is to pump people full of drugs so that they are completely sedated and will not be a problem to the staff. It is service driven, not person driven."

As well as being a clear breach of Article 5, the right to liberty, the misapplication of chemical restraint can also be a threat to life under Article 2:

> "We think his life was put at risk by medication changes that were really dangerous. I went to visit him one day and he could hardly stand up. He was so overmedicated it took him 40 minutes to tell me what he had had for lunch."

Three witnesses referred to incidents of the use of antipsychotic medication to control behaviour that challenges in the absence of a diagnosis of psychosis. The National Institute of Clinical Excellence (NICE) recognises that antipsychotics are the most frequently used medication for people with a learning disability and behaviour that challenges, often in the absence of a diagnosis of a mental health problem. Accordingly, in its quality statement NICE seeks to limit the administration of antipsychotics to people with learning disabilities with behaviour that challenges:

> "People with learning disabilities and behaviour that challenges only receive anti-psychotic medication as part of treatment that includes psychosocial interventions." (NICE Quality Statement 11: Use of Medication)

Psychosocial risk factors in in-patient settings

NICE makes it clear that psychosocial interventions should be the first-line interventions to address any identified triggers for behaviour that challenges. Whilst NICE describe psychosocial intervention as therapies or actions used to help a person reintegrate into society in a healthful way, it is also well-recognised that negative psychosocial factors – particularly inappropriate environment, isolation and absence of family and friends, lack of meaningful and outdoors activities, loss of sleep, no physical exercise – can cause or increase the risk of behaviour that challenges.

During the lengthy periods ATUs 'spend' seeking to diagnose or exclude specific mental illness, the things that keep children and adults mentally and physically well – opportunities to exercise, eat well, get enough sleep, spend time with loved ones – are in short supply in many of them:

> "[He] had this walk where he walked round the outside of the sitting area, down the corridor where the bedrooms were, up, back round, and he'd go and do that circuit a few times, just for something to do."

"I don't remember too many activities being done in hospital."

"To say to him, "You cannot go out", is the ultimate punishment, and of course it resulted in him panicking and fighting."

One witness described her son has having no meaningful activities at all apart from a small number of speech and language therapy and occupational sessions which he enjoyed and was able to participate in because they were one-to-one. There was very little timetabled for him each week. What was timetabled was vague (e.g. sensory activities with nurse) or psychotherapy group work which he found impossible to participate in.

He rarely went outside. He was allowed on very few outside ground visits with his family (e.g. to the hospital café or for a picnic in the grounds) and on one or two local area visits (e.g. to the local park) with his parents. He did very little exercise and his health deteriorated.

The advice of *Young Minds* to young people with autism about looking after their mental health, is to seek advice about common co-morbid or other specific conditions and to look after their general mental health in much the same way as other young people:

"We recommend regular exercise, eating well, getting enough sleep and talking things through with people you know and trust." (www.youngminds.org.uk 2019)

The absence of key elements of ordinary life and things which keep children and adults mentally well creates stress and distress, leading inevitably to setting events and triggers for behaviour which challenges.

Punishment and reward; punitive culture

Proponents of positive behaviour support have long discredited old style 'punishment and reward' techniques as ineffective and counter-productive responses to children and adults with learning disabilities and/or autism. Unfortunately, restraint is threatened or used as a punishment in ATUs and freedom is offered as a reward.

In one instance, in breach of Article 4 no slavery or forced labour, one patient was forced to clean wards in order to earn the right to visit home:

"My son had to earn home leave by cleaning wards."

Staff in charge in another instance shifted blame to the patient for a broken arm sustained during what was retaliatory 'restraint'.

"So I went to see the nurse in charge. I said, "Why, what has he said? It's hurting. What are you going to do?" And he said, "Oh, well, it's his own fault. He hit the support worker so hard he's damaged his arm." They didn't tell me, the support workers, that he'd been restrained in any way or what the support worker had done."

Threat of punishment from those with power in the system extended to parents and advocates, not just patients. One witness's account of a bullying psychiatrist made it clear that this threat is practical and real and that parents have a lot to lose if they challenge the status quo:

"You're just scared, because this guy, he was a bully, this psychiatrist. He took my husband aside and said, "If you carry on questioning me, I'm going to send your son to a medium-secure unit a long way away."

Neglect and malpractice in clinical settings

Article 2, the right to life, protects every individual's life by law and the State is required to investigate suspicious deaths and deaths in custody. Although no-one in our research cohort had directly experienced death in service of a loved one, many of them knew families whose loved ones had died in a hospital setting or had heard and seen reports of avoidable and suspicious deaths in the newspapers or in official reports, including the Mazar's report [2015] and, more recently, the Learning Disability Mortality Review (LeDeR) Programme (2019).

Parents being frightened that their loved ones might die was not uncommon:

> "I was allowed to go in afterwards, sit and listen to their decision, which was actually to recommend a move to [.....]. I spoke through clenched teeth with tears pouring down my face: "He's not going to [.....]. People die there", so we managed to avoid it, luckily, and he was shipped off somewhere else, where they just broke his arm."

Being pushed to conclude that physical injury is 'least worst' in comparison to death chimes with feedback from parents at a closed legal seminar in London 2018 at which some parents said they preferred physical restraint to chemical restraint because they thought their children had a better chance of surviving the intervention.

In her book *Justice for Laughing Boy* (Ryan 2018) Sara Ryan says of the independent report into her son's death (Verita 2014):

> "The report, together with the failings identified by the CQC inspection, painted a picture of an NHS unit bereft of leadership, the most basic of healthcare provision and an almost wanton carelessness around the lives, and deaths, of patients."

Failings in basic healthcare and carelessness were a significant feature of the research:

> "He was given nuts, even though he has a nut allergy, and then he had his EpiPen administered unnecessarily. Considering he has had heart surgery, that was a pretty dangerous thing to do."

> "[…] "Yes, and then they didn't take him to A & E for 24 hours." […] "Twenty-four hours in pain and agony, and I was [visiting that day]" […] "I went to see him and his arm was all swollen up."

Latterly, had Mum not visited and intervened, medical negligence could have had a catastrophic outcome:

> "He was very unwell, and there was a question mark about whether he'd had some kind of infection in the break site that had spread through his body. So he was in intensive care for several nights but he got help so... Just, "No, he's not got a temperature", and then he ends up intensive care."

Tragically, twelve deaths where constipation was the recorded cause of death have been reported to the LeDeR programme to date (LeDer 2019) even though constipation is preventable and amenable to treatment. As it is a known side effect of anti-psychotic medication, routine monitoring should make this a 'never event' in a clinical mental health setting, adding to the impression that such places cannot get even get the basics of healthcare right for this group of patients, let alone meet their unique needs.

Lack of deviation from hospital mealtime routines meant that patients who were ill or restrained or could not get out of bed for some reason often missed meals. One family worried that their son was being starved:

> "[He] hated the food, he missed two meals a day and they didn't get him any replacement for the meals he missed because he was still in bed."

Degrading and inhuman treatment

Article 3 of the Human Rights Act says that none of us should be treated in an inhuman or degrading way, no matter what the situation. The lack of respect for the dignity of the patient and their possessions sets the scene for inhuman and degrading treatment in breach of this right. One witness said that they regularly found their son dressed in other patients' clothes and another that her son went in with a carefully packed suitcase and came out with stuff crammed into bin bags:

"He went into the Psychiatric Intensive Care Unit (PICU) in Southampton with a suitcase of clothes, seven days' worth of clothes and a small carrier bag. He came out with two sacks of crap, to coin a phrase, half of which wasn't his. His toothbrush was stuffed in his trainers."

In clear breach of General Data Protection Regulations and the right to privacy enshrined in Article 8 (ECHR/HRA) this same witness said that another patient's private papers were sent home with her son's personal possessions.

Another witness presented evidence to the Joint Committee on Human Rights (Conditions in Learning disability in-patient units) of the lack of dignity and privacy entailed specifically in secluding a child in a small cell:

"In that room [she] has no privacy. They watch [her] showering and going to the toilet."

The extent to which personal care of patients was neglected by staff in ATUs is both a breach of the right to dignity and a further sign of fundamental incompetence in the most basic aspects of care:

"He had no hot water for three weeks."

"He did not get help with his self-care, so he was often smelly and dirty."

"Because he needs help with personal care and they weren't doing it."

"Whenever I visited, he smelt awful. He was not washed or shaved and his nails were ridiculously long. He often wore someone else's clothes, and they were always dirty."

"I know, nobody helped him. Came out with this big beard, hair up here, smelly. The toothbrush and toothpaste that he went in with came out dry."

Given the priority for infection prevention and control in the NHS, and standards of personal care in CQC regulated services, neglect of patient hygiene is a notable subversion of well-established healthcare standards and norms.

Some of the situations to which distressed children and their parents are subject is palpably degrading and inhumane:

"I was left with my son distressed, in a cage in the back of a van, and I fed him sweets through the bars of the cage to try to calm him down."

"When I visited [my daughter] I knelt down at a hatch in the door six inches square and talked to my daughter through that hatch, the hatch they feed her through. That is the hardest thing I have ever had to do and there is no need for it."

"[…] is living and being treated in shocking and inhumane conditions."

Chapter 4
The Battle of the Experts

Clinicians and professionals know best

All family witnesses wanted, needed and respected clinical and professional expertise and intervention at times of crisis and in a number of instances getting expert intervention was felt to be a matter of life and death:

> "I can remember the relief of when he was in hospital to be honest because they knew what to do. And he'd stopped drinking water and that was such a relief because you just don't know what to do."

When respect was reciprocated by professionals who, in turn, listened and took account of family expertise, the experience of hospital was both easier and more successful:

> "The hospital staff communicated in an appropriate way and they listened to [our] recommendations. The hospital had time for us and we had time for them, so that made everything easier."

One forensic psychiatrist clearly understood the dichotomy of a young adult being assessed as needing secure accommodation whilst his Mum was happily and successfully taking this allegedly dangerous person out of hospital into the community, reportedly saying:

> "[If] he needs to go to a secure hospital it has got to be close to you because you are making all the difference here."

The least successful interventions and outcomes were characterised by professionals 'knowing best', misunderstanding the needs communicated by their patients, dismissing the expertise of families and excluding them from decision-making.

In the Case Review of the Care of MG in 2016, Marsh and Man accepted that professionals did not always know best and that understanding and accounting for the views of parents would have led to better outcomes:

> "When parents disagree or disregard options suggested by professionals (e.g. for CAMHS involvement, school choices) the professionals in health and education should aim to understand the parents perceptions and reasons for disagreeing. With better understanding of the parents views and concerns different decisions may have been made that could have resulted in a very different outcome e.g. earlier involvement of CAMHS or earlier placement at MG's current school in Sussex rather [than] a School that couldn't meet his needs." (2016)

Health professionals, including psychiatrists and psychologists, need to be competent in their area of expertise, but also have knowledge and skills about people with autism and/or learning disabilities. They need to be able to engage with and understand the needs being communicated by the person or patient and/or can work in partnership and harness effectively the expertise and knowledge of families about their loved ones.

Parents blamed, ignored and excluded

Family witnesses gave accounts which demonstrated the extreme lengths to which they have gone to understand, communicate and advocate for the needs of their loved ones. They continued to care for and support them at home in the most adverse of circumstances, went to superhuman lengths to prevent crisis and admission to hospitals and ATUs and, once admitted, fought to get their loved ones back home and into appropriate and sustainable school placements or living ordinary lives with the right support. Yet, with few exceptions, families have experienced disrespect, blame and been treated as if they are part of the problem, not the solution.

In the battle of the experts within some ATU and in-patient settings, it appears that those without specific expertise or knowledge about the needs of people with learning disabilities and/or autism dominate – and in so doing make things much worse for the patient. In one instance, failure to respect and

implement expert advice about a patient's autism-related communication needs led directly to stress and anxiety which caused, rather than treated or reduced behaviours of concern.

> *"The ATUs speech and language therapy report, highlighting auditory processing difficulties and the need to use visual support, was not implemented by staff. This increased [...]'s confusion and anxiety, and consequently this impacted on his behaviour."*

Where hospital staff ignore the expert advice of their professional colleagues, families feel they have little or no chance of being heard. Families in our research cohort have experienced professional meetings which exclude them from critical decisions about the future care and support of their loved ones:

> *"I can remember going to one meeting when 20 professionals had had their professionals' pre-meeting, like they do, and made all the decisions without me even being there."*

> *"You are scared. Nobody has a GCSE in the Mental Health Act. You suddenly have to do a whole load of learning and you are excluded at every opportunity."*

> *"Where has my parent voice been? I am the expert on my daughter. Two months ago, I had to fight to be included in what they called a professionals' meeting. I am the professional about my daughter."*

In the worst ATUs, empowered and vocal families who spoke out about poor care or mistreatment of their loved ones were punished by revoking visits, cancelling home leave and, in one instance, threatening to send their loved one to a unit hundreds of miles away. There is also evidence that experts by experience involved in CTRs worry that they may suffer a detriment to their own funding and support if they 'speak out' about what they have witnessed.

Two witnesses referred to the misapplication of the Mental Capacity Act (MCA) by social workers and professionals as a way of excluding them from decision-making and influence once their child or relative had attained 18 years old. In one instance, it was clear that a formal assessment which concluded a relative had capacity to make specific and potentially illegal decisions led to him being at unnecessary risk of imprisonment for offending behaviour. According to the witness, the social worker held that his right to make unwise decisions under MCA Principle precluded giving him advice, information and guidance about the consequences of his decisions, which is an abdication of MCA Principle 2.

Families' instincts to care about and protect their loved ones does not stop at 18 years and a practice of social workers misapplying the MCA to excuse inaction or exclude rather than include families in decision-making is very poor practice which leads to risk of detention, whether in prison or in ATUs or hospitals.

Chapter 5
Crisis

Nowhere else to go

The reason for children and adults being in hospital at all was almost always because a crisis point had been reached at which schools, parents and/or support providers could no longer meet their needs safely:

> "[Residential Care Unit] said they could not manage his behaviour. They were not prepared to accept that the behaviours he was displaying were as a result of his autism."

> "It was a very frustrating time for the family as he wasn't getting the required support [...] they felt very let down by social services in terms of the lack of support."

This is in line with the CQC's interim findings on detention and restrictive practice in hospitals:

> We heard stories of where the person's non-hospital, residential community placement had broken down because of a sudden or escalating challenging situation which caused staff working with the person or the family to conclude that they could no longer meet the person's needs. The person had ended up in hospital because there was nowhere else for them to go. (Lelliott and Ivanova 2019)

Far from meeting their needs safely and resolving a crisis, 7 out of 9 in-patient settings experienced by our research cohort failed to assess and treat successfully or actively endangered the physical and mental health of the children and adults in their care. Yet under Building the Right Support and the National Service Model (NHS 2015), commissioners are required to develop clear care pathways and appropriate community services, as the CQC made clear in the same report:

> "The strategic intention is to support people with a learning disability and/or autism to live alongside others in their local community – in the same way as any other citizen."

Five years on, and without clear care pathways and appropriate crisis support for this group of children and adults, this is nowhere near a reality.

Those clear care pathways and appropriate community services, many believe, will not be commissioned for children and adults at risk until and unless these illegitimate holding units with doubtful diagnostic or therapeutic value are no longer a lawful option.

Transitions

Unplanned transition defeats crisis prevention

Normal life transitions were prevalent causes of crisis leading to hospital admission and included starting and leaving school, reaching puberty and adolescence, and becoming an adult. Other changes included changes in physical and mental health e.g. tonic clonic seizures, organic psychosis, suspected ADHD, and the life events of close family members e.g. death, illness, going off to University. In terms of behaviour that challenges, all of these normal transitions and changes constitute 'setting events' or 'triggers in waiting', not least because they involve pain, anxiety, stress and distress which are usually more difficult to understand, communicate or deal with if you have autism and/or learning disabilities.

As one of the witnesses pointed out, no-one across the education, health and social care system holds the ring or is responsible for the continuing assessment, care, support and treatment of children with learning disabilities and/or autism as they move through childhood, adolescence, and into and through adulthood. As a result normal transitions and life events are not anticipated and planned for and children and young people 'crash' into them with no contingency or support. The same is true of referrals between the parts of the system and known transitions (e.g. child to adult services, change of school, change of placement, hospital resettlement).

There is no doubt that this situation stands in the way of prevention, as was accepted in the Case Review of the Care of MG:

> *"Lines of responsibility and accountability were not clear to the parents and at times even to the professionals. When MG was at risk of a crisis this may have contributed to the failure to prevent the crisis and his admission to the PICU, with appropriate local interventions and support."* (Marsh & Man 2016)

Unfortunately, the innovation intended to remedy the lack of joined up planning for the future – Education, Health and Care Plans (EHCP) – remains for the most part aspirational and a number of families felt they had to fight for EHCPs as they had for its predecessor, a Statement of Special Educational Needs. Where EHCPs are in place, they are largely education-led and SEN schools report difficulty in getting health and care professionals around the table. If they are not 'whole life' oriented or holistic in nature, they will inevitably perpetuate what Ryan calls 'the lack of an imagined future.' (2017)

This gap in joint working, accountability, continuity and contingency planning means that the child, adult and their families are not properly engaged, involved or supported through recognised 'vulnerable spots', transitions or setting events for crises and behaviour that challenges.

System-centred versus person-centred practice

This lack of accountability and continuity is made worse by one size fits all practices, system-centred solutions and blanket policies which defeat personalised referrals and transitions. Working out which school placement is the right one requires a collaborative approach by informed and interested parties with the child or young person firmly at the centre of considerations:

> *"They have a brokerage system and that is not very good for someone like [my son] because you can't speak to the broker. So there's this disparate thing where there's the school, you, the broker, the social worker and you can't all talk to each other. That's ridiculous when you've someone like [my son]."*

Changing the social worker just as the young person moves from child to adult services, an acknowledged moment of critical change, is system-centred not person-centred. This unnecessary loss of familiarity and expertise is further exacerbated by the high turnover of social workers in adult services.

> *"Then you go into Adult Services so at a critical time when you need all that knowledge and stuff from the past, it's all gone. And we had a social worker about every five minutes. I mean, we've had six."*

This situation increases families' frustration at having to tell their stories over and over again and adds to a sense of abandonment at the time of greatest need.

Funding Battles
The human cost of cost shunting and rationing

Policies and system processes which lead to cost shunting, funding delays and rationing of treatment seriously get in the way of early intervention and crisis prevention. One family reported this as extremely frustrating:

> "There was significant delay in agreeing the funding for support as there were ongoing discussions around who should pay for […]'s service. […] health and social care were in prolonged discussion about the financial matters with a final agreement that health and social care would contribute 50% each from their allocated budgets…"

One witness said that a policy of pupils who are getting SALT intervention at school not being allowed SALT intervention at home deprived the family of expert input at a critical time.

Whilst the various parts of the health and social care system are protecting their budgets and their workforce from over-demand, the resulting toll on families is untenable. In this instance, a husband gave up paid work so that he and his wife could support their son. At a time of physical and mental health crisis, when they were worried that he would not survive, they worked in shifts over 24 hours seven days a week in order to keep him safe. The service equivalent to this is 12 hours on shift, 12 hours off shift seven days and seven waking nights a week carried out by an unpaid team of two, which no CQC registered hospital or care service would be allowed to countenance. In the same instance, the young person was not allowed to have psychology and psychiatry input simultaneously, causing a delay of three months in psychiatric treatment when the psychology input did not work.

One parent described her local commissioner as 'rubbing his hands with glee' at the decision to refer her son to a secure unit because that would come out of the health budget rather than [his] social care budget:

> "Of course, the […] commissioner, he was rubbing his hands with glee because that's 'So specialist commissioning can take over funding now, he's going to secure'."

Chapter 6
Good Ordinary Lives

Building the Right Support and the National Service Model (NHS 2015) are intended to support people with a learning disability and/or autism to live alongside others in their local community in the same way as any other citizen. Without exception, witnesses evidenced that once the obstacles of detention, discharge, and funding for a suitable place were overcome, ordinary life in the right accommodation with the right support to live safely and happily was possible.

During a period of serial sectioning under the Mental Health Act which included regular seclusion and restraint, one parent's experience of enjoying Section 17 leave with her son without incident highlights the paradox of detention versus ordinary life:

"I would take him out by myself, this dangerous person, and this is what you have to remember in all of this. Take him out by myself, and we'd go for a coffee, we'd go to the cinema, we'd go to the horticulture centre or garden centres."

It is an indictment of the system that, post-detention, the biggest prize of a good ordinary life in the community is freedom from a futile period of detention and restrictive interventions. One witness summed this up succinctly:

"Now that […] is being appropriately supported in the community by adequately trained staff using the right approach, he is no longer restrained, no longer secluded, no longer over-medicated. He is no longer prescribed antipsychotic medication at all."

Successful resettlement from ATUs and in-patient settings is invariably characterised by just doing very ordinary things, which are the same kind of thing that any citizen can do:

"I used to be in a bad place. I used to have injections. But now it's much better. I do lots of nice things here. There are lots of nice people here. And my favourite is football man."

Many sensory or other challenges (noise, crowds and unacceptable behaviour) can be met in a non-restrictive way in the ordinary course of support from well-trained care staff and capable families. The utter joy of this prospect for one parent was palpable:

"What we're going to do soon is me taking him out. We'll go with his carers. We're going to Winter Wonderland. We'll be out for the whole day, we'll go on all the rides, it will be crowded, but we'll make sure he gets help to deal with that. He'll love it, he'll have all the food, all the hot chocolate, he'll be fine on the train, he'll be fine coming back. It will just be anything that anybody can do. He can do it now."

The resettlement solutions – effected, interim or anticipated – in the research cohort were all very different from each other. Whilst the adults or children concerned needed targeted and skilled support which was well-informed and competent, it was a mix of residential and community support, and not always or necessarily highly specialised; the application of Deprivation of Liberty Safeguards was used to keep people safe.

During resettlement, two families had had good experiences of residential accommodation and in the online feedback, one witness was very concerned that a commitment to good ordinary lives in the community did not exclude residential accommodation as being the right thing for some. She said:

"I am very concerned that we have a variety of provision to suit a variety of needs and not just one."

The common theme for success, regardless of type of provision, was personalisation and one-size fits all approaches were neither appropriate nor effective. As one witness observed, professionals need to keep developing and adapting their skills to the people they are supporting. Another witness said that her son needed person-centred and proactive care and an understanding and practice in autism, as well as strategies to manage behaviours that challenge:

"It is also essential to receive Positive Behaviour Support, a highly structured and predictable day, to have meaningful, purposeful and motivating activities."

Whilst not everyone in the research group agreed that Positive Behaviour Support was the right approach, the need for a structured and focused approach to behaviours, behaviours of concern or 'challenging behaviour' was mentioned by five witnesses.

Whatever type of accommodation or service it is, witnesses gave high importance to it being as ordinary or near ordinary as possible:

"It's a residential home but it's split into flats. […] has the top floor flat in the roof. In the penthouse, we call it. He's got his own bathroom, bedroom, kitchen and living room, and it's lovely."

"[…] is now living in a big house where the kitchen is the centre of the house. He has a lot of space and a big garden with a security door that prevents him from running away."

Latterly, the family are very happy with this place and their son has not gone through a crisis since he lived there which they think could be because it reminds him of his family house.

A successful placement for another witness was still restricted but very much nearer to ordinary living and highly personalised. The proper use of Deprivation of Liberty Safeguards keeps him safe. He receives medication (mood stabiliser) in a community rather than hospital setting. One-to-one support for activities outside the home is part of the success, but low income threatens how much and what he can do, including putting sensory sessions out of reach.

Another witness also made it clear just how important learning, working and making connections was for her son:

"[…] went to Orchard Hill College, which is a special needs college. Yes, he went there. Did building skills for independence course. So he made a lot of connections there in terms of community activities that he can now do, because two mornings a week he does voluntary work. One on […] allotments and the other at […] Community Farm, which he just loves."

Since both universal and bespoke activities like sensory sessions meet psychosocial needs, which is a key factor in reducing behaviour that challenges, there should be a push for social prescribing at commissioner level. Health funding should be made available by CCGs to fund a whole range of meaningful activities for children and adults at risk of in-patient admission, or being resettled.

In one way or another, family witnesses said that homes in the community with the right support, not hospitals, were the right models of support. Whether this was supported living or residential, the overwhelming message was that this needs to be competent, highly personalised and the environment designed or adapted in partnership with the person and/or their family or advocate. Two witnesses advocated high levels of control and involvement of family through deputyship.

Safely home

Places a long way from home are highly inappropriate as well as unsafe and there was support from witnesses for resettling or placing adults and children in their home boroughs wherever possible. However, there was also a natural fear of one-size fits all solutions and blanket bans. In one instance, a parent felt that decision-makers in her borough used the policy of bringing people back into borough as an excuse to refuse referral to an ideal residential school for her son.

In another example, the LA did not have a suitable placement within borough, tried to force a young man into an unsuitable void, but eventually funded

a (close) out of borough placement. The suitability of the placement in this case was more important than the location. The challenge for Local Authorities is not to bring people back in borough, but to bring people back into suitable placements in borough, and until that is possible, the suitability of the placement is the most important thing.

In *Banging the rights-based drum* (Community Living 2019 32), mum, advocate and campaigner Julie Newcombe questions the legitimacy of cost-driven decisions and warns against pseudo Supported Living, which is just Residential Care re-badged. Newcombe is on the same page as the CQC when she recommends the Reach Standards (Paradigm) and the Real Tenancy test (NDTi) as true measures of support for living an ordinary life.

Crisis response

In its record Building the Right Support, the Forum discussed the idea of developing a register of children and young people with autism and/or learning disabilities at risk of crises at known transitions and using it as a passport to early intervention and prevention – an idea which is gathering momentum under the title 'support register' in other quarters e.g. Bringing Us Together and CQC Better Systems Summit 2019.

They also discussed merits of a crash pad style service to give people a respite area to avoid a hospital admission which requires collaborative commissioning. One of example of this was the 'Durham model', an alternative to Police and A&E and a place which a young person knows about in advance and where both the family and the person can be supported. The idea of a crisis pad which people can got to or a crisis team which can come to them was also mooted in the research:

"They need to be doing the assessment. They need to be doing the sensory assessment. They need to have all these skills. You've got to have people who can be trained to go and help in a crisis, even if it's just a crisis team, and you've got to have a crisis pad where people

can go so they can be taken away from the situation. Give the staff, if they've got them, or the family a chance to recover. Put the training in place, stabilise the person – A much better word, and then they can go home again."

Although it was acknowledged not to have particular expertise in relation to autism, the Brookside Child and Adolescent Inpatient Service in Essex which had been visited by two Forum members in 2017, was cited as a model which might be adapted for use in the SELTCP region. Brookside are operating a new model of service for 12-18 year olds, an age bracket where there is a high propensity for in-patient admissions. The model combines an in-patient unit with extensive community (home) based support managed under the same multi-disciplinary team.

It is used in crisis situations and in some cases to prevent a crisis arising and average duration of admissions are less than a month. Treatment in the unit bucks the trend on restrictive practice giving each patient their own key fob to their room, freedom of movement and extra support and encouragement from staff (rather than seclusion) when in crisis:

Calming room

A 'calming room' has been specifically designed to enable staff to support the management of young people when in crisis, without impacting on the wider ward community. This will also avoid any potential seclusion of patients. The calming room is designed in such a way that once in use the door cannot be locked, so the CYP has the option of leaving the room whenever they wish. While in the room they would always be supervised by staff and hence receive an enhanced level of support, attention, reassurance and encouragement www.nelft.nhs.uk/services-wards-brookside/

Whilst this service is specifically focussed on mental health, the same model could work for other groups of adults, children and young people including those with autism and/or learning disabilities with 'behaviours that challenge'.

Good community teams, good awareness

There was a discussion at one of the Focus Groups about the importance of first diagnosis and getting the diagnosis right. There is a risk that a person with a learning disability or autism is being diagnosed with a mental health problem actually caused by the so-called treatment e.g. trauma from being in an ATU. One witness felt it was important to strengthen wider community services, including the police, in order to prevent people being admitted to hospital:

> *"Awareness throughout the community in the medical profession and in the police as well. We are talking about compulsory training […] I would bet that you would probably be in a crash pad in a crisis for a matter of weeks, rather than being on ATU for a matter of years. I think that is the solution. It's good community teams, good awareness."*

Good awareness about individuals at risk is particularly necessary for healthcare professionals and police exercising warrants under MHA sections 135 and 136 to remove people from private or public spaces to a place of safety in order to make further assessment. Advance personalised directives, agreements and contingency plans would give these agencies more options and prevent unnecessary admission to hospital.

Chapter 7
Navigating the System: communication, information and guidance

Understanding statutory processes and navigating the system

Families' experience of statutory systems i.e. education, health and social care, was notably adversarial with frequent reference to conflict and the use of terms like fighting and battling. Far from feeling supported and helped to understand and navigate highly technical statutory processes (e.g. Care Act assessments, EHC plans/SEN statements, Care and Treatment Reviews, Mental Capacity Act and Best Interests decisions, Mental Health Act sections and Mental Health Tribunals, Deputyship) families are left to fend for themselves.

Lack of knowledge about such processes and about the rights of their loved ones makes it easier for system professionals – consciously or otherwise – to exclude, override or disempower families. One family member felt that the Mental Capacity Act and the concept of independence at 18 years was misused during transition to stop her family from discouraging high risk behaviours, whilst the laissez-faire approach of a social worker and a support provider nearly landed her brother in prison.

Two witnesses felt strongly that applying for Deputyship, whether relating to Property and Financial Affairs and/or Personal Welfare, was key to regaining a measure of control and protecting the rights of their loved ones. Both said that it would have been helpful much earlier in their journeys if they had had information and support to make such applications.

The effect of this adversarial environment on families whose children and young people are in crisis undermines trust and the potential for partnership working, as the Case Review of MG accepts:

> "The current processes and procedures relating to obtaining a Statement of Special Educational Need (now known as Education, Health and Care Plans) result in a poor experience for parents seeking a statement for their child. The system feels adversarial to the parents and is not conducive to effective partnership working." (NHS Report and

Recommendations from the Case Review into the Care of MG – Marsh and Man 2016)

Advice and signposting to suitable education, treatment or support options was also very poor amongst the research cohort, with four family members claiming that they were left on their own to source suitable schools or support options for their loved ones:

> "[T]here was no assistance to find suitable housing for [our] son."

When families' efforts to find the right placements eventually led to successful outcomes (in one case after 12 months of searching) the scale of their fight to get there was apparent:

> "This makes it seem reasonably simple but in reality it was months of battle, escalations, lack of response, conflicting information and a social worker that was all but absent."

> "So I phoned them and nagged them every day for weeks."

Nowhere to go and no-one to advise

The lack of responsiveness from services during crisis – whether before, during or post admission to hospital – was the cause of a great deal of stress to both patients and families:

> "That seemed to be one of the lowest points where we simply didn't know what to do."

> "So, we managed to get an appointment, and that took a little bit of time, but it was quite worrying that there was nowhere to go. You know, what do you do when you've had this rise of behaviour that becomes more and more difficult?"

One parent said that as soon as her son was in crisis she had to become effectively a key worker. Crisis led in another instance to both parents providing round the clock care and support seven days a weeks – a

staffing level which, in a registered service, would be regarded as untenable and treated as a breach of both CQC regulation and EU working time directives.

Communication with parents, and between organisations and professionals

Whilst seen as vital, Care and Treatment Reviews carried out in ATUs and hospital settings came in for some criticism, usually on the grounds that the patient or their families were excluded, that key decision-makers did not turn up, or, in the case of an independent advocate with lived experience, fear that speaking out would impact their own funded support. However, when carried out to prevent admission and attended by all relevant members of a multi-disciplinary team (typically psychologist, psychiatrist/MH nurse, SALT, social worker) together with patient, family, independent advocates and current provider, they can be highly functional and ensure co-operation and responsiveness between patients, parents, professionals and providers.

The support and advocacy of individual professionals and practitioners within the system was highly prized. In one case, a parent was satisfied that the doctor at the ATU did want to discharge her son and played their part in trying to make it happen at three months but it was the Local Authority who failed to attend meetings which caused the delay and he was eventually discharged at six months:

> "Dr was very keen to discharge him in the January, and [LA] just didn't do anything. That's the problem we had. […] He called a big meeting in December, and nobody from [LA] ever turned up. No one from [LA] ever went there. We went there every week. I was there most of the time, and my daughter was there a lot of the time, and no one from [LA] even saw him."

As mentioned elsewhere, feedback about the wider systems and the availability and accessibility of both professionals and providers to parents was identified as an issue:

> "They also don't give you a mobile phone number anymore so you can't phone them. I don't think I even had an email for one of them so there's no contact. You can't contact them."

> "It was in the middle of nowhere, where there was no Wi-Fi ... No mobile phone signal, and it had actually gone into administration."

Lack of communication with parents, between organisations, and between professionals, is also implicated in unnecessary or prolonged admission, as admitted by NHSE in MG's case:

> "Communication with the parents by the different organisations involved has been uncoordinated and at times poor. […] Communication between different professionals and organisations involved in MG's care between the summer 2015 and March 2016 was inadequate and probably contributed to the prolonged stay in the PICU." (Case Review into the Care of MG – Marsh and Man 2016)

If the lines of responsibility and accountability are not clear to professionals, there is little hope of patients/parents/family advocates having an informed and empowered role in crisis prevention:

> "Lines of responsibility and accountability were not clear to the parents and at times even to the professionals. When MG was at risk of a crisis this may have contributed to the failure to prevent the crisis and his admission to the PICU, with appropriate local interventions and support." (Case Review into the Care of MG – Marsh and Man 2016)

Inaction, frustration and litigation

These gaps in the system and the lack of a transparent, coherent and accountable professional response to patients are common nationally. Across the SELTCP sub-region, they have been known

about for some time, generating frustration amongst some witnesses:

"There are a lot of gaps, and there are actually very similar gaps, and similar gaps in the same authorities. So, obviously, they're not being filled and addressed."

Two witnesses had involved lawyers in their cases, and were contemplating or had initiated legal action against the relevant CCG or LA. A third witness, in hindsight, would have considered involving a lawyer, albeit acknowledging that lawyers also can fail to listen or be too aggressive:

"You've tried everything and you think, "I don't know what to do." And I think, looking back, the moment I'd gone in, I would have gone to a lawyer. You know, the second week and said, "This is what's happened and this is what we need to do."

When the actions and inactions of professionals lead to dangerous situations and adverse experiences for patients and their families, they cause trauma, which is defined by the NHSE Family Trauma Research project as:

"Trauma is how a person feels when he/she or someone they love is in a situation that could, or does, cause physical or emotional harm. As a result, the person feels helpless or overwhelmed and the world no longer feels like a safe place. They may find it harder to trust people, feel permanently on edge or anxious. It may be more difficult for them to concentrate or sleep, and they may have less patience on a daily basis."

Transforming 'transforming care' will entail system professionals in repairing past and current damage to relationships with patients and families, including understanding the origins and consequences of trauma, and the part that health and social care professionals might play in mitigating or preventing it.

Information and Signposting

A number of interviewees and members of the Transforming Care Forum recommended as very useful a series of Survival Guides created by families under the Bringing Us Together umbrella. These guides cover Care and Treatment Reviews, Crisis Prevention, and Special Educational Needs and Disability Education. Whilst the Bringing Us Together website has a specific link to each council's Local Offer, none of the six Council websites we searched had a link to this information which is vital for families not in the know.

A member of the Transforming Care Forum proposed that a good practice example of information and signposting by a Local Authority was an education and transition guide, which had been co-produced by the London Borough of Bexley and Bexley Voice. This document was easily accessed through the Bexley Voice website but a simple search on the Council website did not lead directly to the discovery of this document, suggesting that, as a parent or carer you would currently need to be 'in the know' to access this useful tool.

Our research assistant carried out simple searches on Council websites in all six SELTCP boroughs against a selection of key words and concepts used commonly in the system: learning disabilities, autism, transitions, challenging behaviour, learning disabilities and autism, learning disabilities and mental health, learning disabilities and challenging behaviour, autism and challenging behaviour, autism and mental health (Appendix 4 Relevant Word Searches).

Variations across boroughs notwithstanding, none of the top five results are helpful to carers and family members with children and adults with learning disabilities and/or autism who have mental health problems and/or behaviour that challenges, much less those in crisis or already detained in ATUs/PICUs. On this first search it suggested that, even if helpful information does exist, it is buried and difficult to discover.

A second search was conducted on words thought to be more commonly known and used beyond the system, and thence more likely to be used by parents or others searching on council websites, notably difficult behaviour, behaviour of concern, school exclusion. This search was more successful for half of the websites with Bromley, Lewisham and Southwark having relevant information in two or more categories, including guidance for managing challenging behaviour, links to the Challenging Behaviour Foundation (Southwark), guidance for parents of children with autism and information about counselling for children with SEN and their parents (Lewisham). Learning from the good practice that already exists in these boroughs, a full review of information and signposting for this cohort of children, young people, and adults and their parents and families across the SELTCP region would result in more relevant and helpful content, and links, which are easily found by local citizens without the need to be 'in the know'.

Chapter 8 Conclusions

With few exceptions, ATUs are not fit for purpose and actively harm those they are intended to treat. Only one children's ward (Bethlem Hospital) and one of eight ATU, PICU or in-patient services (Atlas House) was described by witnesses as fully competent at assessment, treatment and resettlement of children and adults with learning disabilities and/or autism. The rest were mixed (in one case) or experienced as fundamentally incompetent and routinely breached the human and civil rights of patients with learning disabilities and/or autism (six cases).

If what happens in ATUs is not effective and does not make sense as an assessment or a treatment, then it is self-evidently an inhumane and unethical way in which to treat children, young people and adults at risk. Under the Human Rights Act 1998, it is unlawful for a Public Authority to act in a way which is incompatible with any of the rights protected under the European Convention on Human Rights.

Human Rights breaches

As well unlawful (or lawful but unethical) application of the Mental Health Act and a failure to make reasonable adjustments for a disability under the Single Equality Act/DDA, the human rights principally breached or at risk of breach in ATUs and other secure in-patient settings according to our findings were:

Article 2 – the right to life
Article 3 – no torture, inhuman or degrading treatment
Article 5 – the right to liberty
Article 6 – the right to a fair hearing
Article 7 – no punishment without law
Article 8 – the right to a private and family life

Other rights potentially compromised by punishment and reward practices prevalent in some parts of the system are:

Article 4 – no [slavery or] forced labour
Article 10 – freedom of expression
Article 11 – the right to protest

Pre-requisite quality measures which safeguard human rights

NICE guidance describes good practice for commissioners, specifically that they should ensure that services set service-level and individual outcomes and that service providers show evidence of achieving these outcomes. NICE recommends that this evidence includes satisfaction and quality-of-life ratings:

- outcomes measured by personalised and validated tools
- reduced behaviour that challenges
- less use of restrictive interventions
- participation in education by children and young people
- contact time with specialist professionals
- quality checks by user-led organisations

It is clear from the research that if these outcomes are being set by commissioners, they are not currently being met by all providers and a full re-evaluation of the commissioning approach in respect of contract compliance is necessary.

Wrong treatment in the wrong environment

Some of the most expensive and allegedly specialist parts of the system – ATUs, PICUs and other detention-based in-patient hospitals – are fundamentally the wrong treatment in the wrong environment. With few exceptions, they have been incompetent at both physical and mental healthcare, do not understand autism, learning disabilities or 'challenging behaviour', cannot distinguish between the causes and effects of detention, and often fail to assess or treat mental illness.

Absence of reasonable adjustments

The consequences of health inequalities for children and adults with learning disabilities and/or autism are frequently catastrophic and have been documented in compelling testimony of avoidable deaths, abuse,

physical injury and trauma for decades e.g. Death by Indifference (Mencap 2007), Treat me Right (Mencap 2004), the Mazar's Report (2015), LeDer reports (up to 2019), BBC Panorama films of Winterbourne View (2011) and Whorlton Hall (2019), Justice for Laughing Boy (Ryan 2018).

Unfortunately, witnesses to patient experience of in-patient services commissioned by SELTCP in this research tell a very similar story. Most institutions have continued to neglect the most basic and necessary reasonable adjustment for the disabled patients in their care, having neither the skills to understand nor the wherewithal to support their highly individualised communication needs, their unique experience of autism and/or learning disabilities, or even how to recognise behaviour that challenges, much less how to manage, prevent or reduce it. Latterly, there is high propensity for behaviour caused by the distress of the detention itself to be labelled violent and aggressive, falsely legitimising the use of segregation, seclusion, physical and chemical restraint.

Meeting the communication challenge

Since communication is the basic currency of all human services, and trusting relationships and patient involvement cannot be developed without it, this communication deficit in medical or quasi-medical mental health services like ATUs, means that patients' symptoms cannot be assessed effectively or speedily unless the patient's feelings, expressions and behaviour are fully understood. This communication deficit causes long and tortuous delays in achieving effective treatment at best, and as often as not ends in the wrong treatment, no treatment or being shunted off to another equally inept part of the same system.

The communication challenge in services will not simply be addressed by autism awareness or communication skills training for staff. This is because fully personalised communication is a pre-requisite to involvement in decision-making, including Care and Treatment Reviews, and must be informed

by those who know the child or adult best, notably families, together with relevant professionals. Latterly, this should not be confined to Speech and Language Therapists, though for some individuals this may be critical. Meeting the challenge means recognising 'challenging behaviour' as communication and being informed by assessments and guidelines from psychologists and behaviour support specialists, and/or behaviour support plans designed by schools and other providers where appropriate.

Imprisonment, torture and punishment

Adults and children were detained for an average of two years in our cohort, over 5.4 years across the whole system. In the worst units, assessment and treatment is experienced as imprisonment, without cause or charge, and its interventions a form of torture. It is a toxic mix of wrong model, punitive culture, professional ignorance and indifference to the human rights of children and adults with autism and/or learning disabilities, which is responsible for inordinately long periods of detention, and a frightening, futile and unnecessary cycle of challenge and restraint reported in such high volume by the NHS, by CQC, and confirmed by the witnesses in this research.

Far from just practiced by the criminal few, as in the case of Winterbourne View or Whorlton Hall, unethical detention, segregation, seclusion and restraint is practiced by the many and is a cultural norm for this sector. The environment causes psychological and emotional trauma and distress, is physically injurious, causes mental illness such as post-traumatic stress disorder, and is life-threatening. Latterly, risk to life also comes from sub-standard basic healthcare and neglect.

A clinically and morally incoherent system

Paradoxes and contradictions are so prevalent in the experiences of witnesses that it points a finger at ATUs as clinically and morally incoherent: detention to a dangerous 'place of safety', assessment and treatment which neither assesses nor treats and

sometimes constitutes a threat to life and limb, interventions that injure and traumatise and make patients ill, basic healthcare standards suspended and neglect normalised, vulnerable patients treated as perpetrators and their parents as enemies.

Working in such a system where one can see that the treatment is not working or is actually making the patient worse is highly stressful for staff; experiencing this day after day and being part of a regime which causes pain and distress rather than reducing it, is itself distressing and potentially traumatising. If there is high incidence of staff turnover and correspondingly high agency usage in this sector, it is not surprising. If, in the worst institutions, staff who stay are numb to suffering or brutalised, thence brutal, it is also unsurprising.

Silencing the critics

Where there is most to hide, there appears to be active suppression of complaints and the greatest resistance to involvement of families, experts by experience and other third parties.

Concerns about worsening the treatment and circumstances of their loved ones almost certainly inhibits families from complaining. Families who had complained were prevented from visiting and, in one instance, threatened that their loved one would be moved to a unit far away. There is some evidence that experts by experience with learning disabilities and/or autism worry that their own care and support might be prejudiced if they speak out or are critical of key stakeholders.

This fear of reprisals is true to the extent that the authors of this report have found it necessary to go beyond the normal requirements of confidentiality and anonymity in order to avoid identifying contributors. For example, we have avoided the use of case studies in favour of dispersed testimony organised under themes.

Wrong treatment model worsens health and well-being

A toxic combination of closed culture, wrong treatment model, a deficit of professional expertise and/or incompetence – as well as an abdication of safeguarding and disregard for the human and civil rights of this cohort of patients – is responsible for a futile and unnecessary cycle of challenge and restraint, both physical and chemical. The situation frequently causes or intensifies the mental health conditions or behaviours of concern that it is intended to assess and treat.

No amount of monitoring, surveillance or extra vigilance will change this situation, as the CQC Deputy Chief Inspector of Hospitals implied in a media statement responding to the Whorlton Hall expose:

> *"This illustrates how difficult it is to get under the skin of this type of 'closed culture' where people are placed for long periods of time in care settings far away from their communities, weakening their support networks and making it more difficult for their families to visit them and to spot problems. When you add staff who are deliberately concealing abusive behaviour, it has the potential to create a toxic environment."* (Lelliott 2019)

Medical Model versus the Social Model of care and treatment

Across the system, including ATUs, the most successful services in terms of good treatment and outcomes are those that consult, involve and include patients and families, in decisions and in the design and delivery of the support. A hierarchical 'medical model' approach inherent in most ATUs relegates social and relational expertise to the status of 'lay' or inexpert and, therefore, dismisses the insight and knowledge of patients, families, experts by experience and non-medical professionals.

As a result, critical elements are frequently missing from the assessment and treatment of patients, and guarantee its failure. These include:

- A personalised appreciation of the needs of children and adults with complex autism and/or learning disabilities
- Personalised communication and engagement with the patient by health staff
- Understanding what patients' behaviour is communicating
- Accounting for and addressing the psychosocial and biological causes of behaviours of concern
- Recognition of the part played by trauma and the unconscious in behaviours of concern

The only discernible medical treatment in any of the in-patient experiences described by witnesses was medication which, in the example of a good ATU, was key to recovery in relation to a co-existing mental health problem. However, medication was used more frequently as a form of restraint or mood-stabiliser, and often to deal with distress caused by the lack of appropriate treatment and/or mistreatment. Forcible injection of antipsychotics when no psychosis was diagnosed was prevalent.

Meaningful activities and community participation

In the wider mental health system, there is recognition that social isolation causes or exacerbates mental illness and distress. Many ATUs themselves are both isolated and isolating, reducing the opportunity for visits to and from family and friends and increasing loneliness through seclusion and physical and chemical restraint.

Witnesses said that in the right placements in community settings, regardless of whether the type of setting was residential or more independent in nature, the right level and kind of personalised activities keep people well and help reduce behaviours of concern. In stark contrast, in most ATUs there was both a paucity of opportunities for meaningful activity and community participation, and simple things like fresh air and exercise were in short supply. Understaffing is a frequent barrier to these very ordinary measures for physical and mental well-being, as is being situated at too great a distance from local communities.

The right treatment model

By total contrast, most successful placements on discharge were characterised by heavy doses of ordinary life in ordinary homes and the freedoms and activities available to all citizens. It is no coincidence that the only ATU which came in for significant praise was Atlas House, where the environment is ordinary accommodation and highly personalised, the approach integrates clinical and psychosocial interventions, and restrictive practices are reportedly kept to a minimum. Critically, the person was at the centre of decision-making, and families were listened to and treated as equal partners.

This suggests that the right model of assessment and treatment should be much more aligned to a social model of support than its medical model counterparts:

- Designed to feel like homes rather than hospital
- Highly personalised environment, communication and support
- Competent staff who worked in equal partnership with the family
- Able to assess, treat and resettle the person in six months or less

Homes not hospitals

Despite poor experience of specific community providers in two instances, witnesses said that homes in the community with the right support, not hospitals, were the right models of support. Whether this was supported living or residential, or bespoke individual solutions, the overwhelming message was that this needs to be competent, highly personalised and the environment designed or adapted in partnership with the person and/or their family or advocate. Two witnesses advocated high levels of control and involvement of family through deputyship to mitigate the risks associated with all providers.

Nearer home

Placements a long way from home are highly inappropriate as well as unsafe and there was support for resettling or placing people in their home boroughs. However, the right placement for the person in a near or neighbouring borough is more important than a blanket policy of bringing people back into borough. One-size fits all policies should not get in the way of highly personalised and effective solutions.

Similarly, one size fits all services are totally inappropriate, as are voids-led or costs-led referrals. The right placement for the person should include:

- a safe, personalised and appropriately designed home environment
- staff competent in supporting people with autism and learning disabilities
- a structured approach to behaviours of concern e.g. Positive Behaviour Support

Crisis

No-one across the education, health and social care system holds the ring or is responsible for the continuing assessment, care, support and treatment of children and adults with learning disabilities and/ or autism. As a result referrals between the parts of the system and known transitions (e.g. adolescence, child to adult services, change of school or service, hospital resettlement) remain very poorly anticipated, planned for and managed.

Successful placement: before a crisis, not afterwards

This gap in accountability and provision means that the child, adult and their families, schools or support providers are not properly engaged, involved or supported through recognised 'vulnerable spots' or setting events for crises and behaviour that challenges. Unfortunately one of the holistic innovations intended to remedy the lack of joined up planning for the future – Education, Health and Care Plans (EHCP) – remains

for the most part aspirational as schools struggle to get health and care partners around the table. In any case, these plans should be more whole life oriented and contain features of 'an imagined future' based on strengths and learning potential.

Reactive funding and funding battles

Rather than funding being pro-active and following the person at the centre, as it ought to do for personalised services to children and adults with complex needs, families are often left to chase down and challenge funding decisions; funding squabbles between health and social services and lengthy decision-making processes are believed to cause delay and obstruct early intervention and resettlement, or worsen the crises they are intended to prevent.

Personalised Health Budgets have not yet been piloted/rolled out for this cohort of children and adults. Delay in adopting innovations like this which are intended to help, means that support and funding remains fragmented rather than wrapped around the child or adult, and decision-making continues to be piecemeal and reactive rather than planned. In turn this means that families are left to cope with health crises, exclusions, failed or delayed placements without the necessary physical and mental reserves, resources or skills to meet the changed needs of their loved ones.

The whole system solutions for addressing the issue of the funding being in the wrong part of the system, including Funding Transfer Agreements, are simply not working:

> "One of the key mechanisms designed to manage the flow of patients into mental health hospitals is not working effectively, and money is not yet being released from mental health hospitals quickly enough to help pay for extra community support […] Unless the funding is released for local services this will be an unfunded pressure on local authorities and clinical commissioning groups."
> (National Audit Office 2017)

Whilst it may be difficult for CCGs to 'break out' of NHS and Local Government rules and constraints around funding, the volume of backfill of mental health hospitals suggests that CCGs in SELTCP are destined to continue for many years to pick up the bill for inappropriate care and treatment in the most expensive part of the system. Whether through early adoption and adaptation of Personalised Health Budgets for this cohort of children, young people and adults or a more radical approach (Appendix 7 Personalised Health Economics) the CCGs should fund personalised pre-emptive solutions for keeping children, young people and adults out of hospital.

Whatever the solution, securing flexible and pro-active long term funding is critical to early intervention and prevention and, together with the proposal for a 'support register' to identify children and young people at risk of crisis and admission, will be pivotal to transformational change in the system.

Parent blame and the battle of the experts

All family witnesses gave accounts which demonstrated the extreme lengths to which they go to understand, communicate and advocate for the needs of their loved ones. Yet, with few exceptions, families have experienced disrespect, blame and been treated as if they are part of the problem, not the solution.

The least successful interventions and outcomes were characterised by professionals 'knowing best', misunderstanding the needs communicated by their patients, dismissing the expertise of families and excluding them from decision-making. Health professionals, like psychiatrists and psychologists, need to be competent in their area of expertise, but also have knowledge and skills about people with autism and/or learning disabilities. Health staff need to be able to engage with and understand the needs being communicated by the person or

patient and/or can work in partnership and harness effectively the expertise and knowledge of families about their loved ones.

As previously stated, in the worst ATUs, empowered and vocal families were punished by revoking visits, home leave and, in one instance, threatening to send their loved one to a unit hundreds of miles away. There is also evidence that experts by experience involved in CTRs worry that they may suffer a detriment to their own funding and support if they 'speak out' about what they have witnessed.

Social Services and Social Work

Social Services and social workers play a vital role in the lives of children and adults with learning disabilities and/or autism. When witnesses had good experiences of local authority decision-making or good, professional support from social workers it was usually pivotal to good outcomes in relation to things like transitions, referrals, school placements and resettlement.

Unfortunately, system pressures and staff turnover lead more frequently to slow decision-making or poor decisions, absent or obstructive social workers, and referrals for placements that are voids or funding-led rather than personalised. One Local Authority Commissioner was described as rubbing their hands with glee when a young person was admitted to a secure unit because they no longer had to fund him. Legal action to get Local Authorities to fulfil their statutory duties, or legal action for breach, had been taken in two cases.

Witnesses referred to the misapplication of the Mental Capacity Act by social workers and professionals as a way of excusing inaction in relation to risky behaviour or excluding family from decision-making and influence once their child or relative had attained 18 years old.

Autism awareness and communication skills

Having general autism awareness and some knowledge about the range of communication skills and methods in use is a starting point but will not in and of itself render staff in ATUs and in-patient settings competent. Good theoretical knowledge about how children and adults with autism communicate is not sufficient to understand the communication needs of a specific individual. That understanding must be highly personalised and informed by those who communicate with the person on a daily basis i.e. families and/or support staff, and, if necessary, augmented by relevant professional input e.g. Speech and Language Therapy assessments, functional assessments.

Evidence of highly personalised communication 'in use' during daily interaction, the administration of treatment, and as a medium for the involvement of the patient in Care and Treatment Reviews should be seen as a proxy measure for quality and equality. It indicates reasonable adjustments and a genuine attempt to offer equal access to goods and services for that patient.

Navigating a fragmented system

The effective interventions for adults and children with learning disabilities and/or autism who have 'challenging behaviour' and/or mental health issues are, without exception, multiple and from a range of different agencies operating across completely different systems i.e. health, education, social care and housing, or from within those systems. At the point of crisis, professionals need to co-operate rapidly, coherently and cohesively within and across systems to prevent admission and find temporary and permanent solutions.

Equally importantly, patients and their families need to be able to 'see' and understand how this pathway and its lines of responsibility are intended to work, as well as be fully informed about all the statutory instruments and technical processes involved. In this way, patients and parents can exercise their rights and responsibilities (directly or on behalf of children or adults) in an informed and constructive way, including alerting relevant agencies and professionals to delays and breakdowns in the system from their unique perspective.

Until that happens, the relationship between system professionals and patients, parents or other family advocates will be strained and conflict-ridden at best, at worst adversarial and increasingly litigious. Whether they feel powerful or not, and whether by acts of omission or commission, those who work in the system have power over children, adults and their families, and when their actions and inactions lead to adverse and life-threatening experiences, they cause inestimable distress and trauma.

Chapter 9 Recommendations

1. How SELTCP/Learning disability and Autism programme might respond to the propensity in ATUs for human and civil rights breaches

a) Accelerating resettlement

All UK citizens have the right to liberty and freedom and the State can only imprison a person with very good reason e.g. if convicted of a crime which attracts a custodial tariff or if appropriately detained under the Mental Health Act. Unfortunately, the right to liberty under ECHR Article 5 is a qualified right through which the UK Mental Health Act as currently drafted drives a 'coach and horses' for children and adults with learning disabilities and autism. We therefore welcome the recommendations by the Joint Committee on Human Rights (2019) for reform of the Mental Health Act.

Meanwhile, a system of detention which is both clinically and morally incoherent continues to have traumatic consequences for the patients who are subject to it, the families affected by it and (though it is beyond the scope of this research) the staff who work in it.

It is therefore the recommendation of the report authors and SELTCP Transforming Care Forum that, as a matter of urgency, SELTCP plan to:

- Radically accelerate the resettlement of current child and adult in-patients from ATU and in-patient services currently commissioned to a revised target with a revised timetable which is considerably more ambitious than that set by the NHS

- Identify those institutions which pose the greatest risk of abuse and (i) make no further referrals (ii) resettle existing patients as a priority

- Resettle patients into highly personalised accommodation and support determined by the patient, their family and/or independent advocates in partnership with relevant professionals, providers and commissioners

Resettlement should be funded speedily either directly by Local Authorities, via CHC funding, through pooled budgets and agreements between the relevant CCG and Local Authority, which include or account for the following:

- personalised health budgets which can be spent on measures to meet the specific mental health, well-being and psychosocial needs of the child or adult patient e.g. meaningful activities, social relationships, physical fitness, sensory activities

- assessments of care and treatment which takes full account of the person's autism and/or learning disability, and the need for behaviour support as distinct from any diagnosed mental illness

- agreements from the Local Authority for provision of, or capital funding for, adapted or built accommodation in borough in line with the proper interpretation of Section 117 rights

- automatic frontloaded funding to account for more support needed in making the transition from ATU/hospital, taking account of the effects of institutionalisation, trauma and other effects of the detention

- a passport to unrationed professional input from psychology, behaviour support, occupational therapy, speech and language therapy and any other professional input deemed necessary to support recovery from detention, promote physical and mental health, maintain quality of life, and prevent re-admission to hospital

- any interim arrangements pending fully personalised resettlement 'back home' to be as personalised as possible and agreed with the patient, their families and/or independent advocates i.e. not simply policy or voids-driven

b) Anticipating reform of the Mental Health Act and new duties on public bodies

We welcome the findings of the Joint Committee on Human Rights (JCHR 2019) and draw SELTCP's attention to the following recommendations and implications:

i) Narrowing the criteria for detention

"The criteria for detention under the Mental Health Act must be narrowed to avoid inappropriate detention. Those with learning disabilities and/or autism must only be detained in situations where:
treatment is necessary;
treatment is not available in the community and only available in detention (i.e. the last and only resort);
treatment is of benefit to the individual and does not worsen their condition; and
without the treatment, there is a significant risk of harm to the individual or others."
(JCHR 2019)

The implication is that the practice of referring children, young people and adults to ATUs, PICUs and other Special Hospitals just because there is *nowhere else to go* will cease to be lawful.

We recommend that this drive SELTCP to:

- accelerate measures to support families without delay when their children are in crisis

- explore the 'support register' approach for early identification of children and young people at risk

- invest in holistic, highly personalised Education, Health and Care plans at an earlier age for those at high risk or in need of support (i.e. on the support register)

- work across education, health and social care systems to focus on early intervention and prevention

- invest in local crisis support and management solutions which are not hospital or A&E based

ii) Treating families as human rights defenders; making restraint, seclusion, and segregation notifiable to families on every occasion

As well as treating families as human rights defenders and involving them in all discussions and decisions, the JCHR recommends that "On every occasion that anyone is restrained or kept in conditions amounting to solitary confinement their families must be automatically informed".

We recommend that SELTCP partners make notification to families of each occasion of restraint, seclusion or segregation an obligatory contract requirement for all its suppliers of assessment and treatment, with immediate effect.

iii) Ending referrals to ATUs beyond the SELTCP region

The JCHR also recommends that the law be changed to end placements at long distances from home:

"Young people must not be placed long distances from home as it undermines their right to family life under Article 8 ECHR. Financial support must be made available to ensure that families are able to visit their loved ones."

We recommend that SELTCP partners i) stop referring to any providers outside the SELTCP region, (unless the patient, their family and/or an independent advocate agree that it is the right solution for that child or adult at this time) ii) fund accommodation and travel expenses for regular visits by families.

c) Adopting a vanguard approach to defending human rights

Pending the reform of the law and large-scale decommissioning of the current system as advocated or implied by recommendations of the Joint Committee on Human Rights, SELTCP could and should adopt an innovative vanguard approach to the defence of human rights at a commissioning level. The case for this approach is based on the scale of the abuse, its propensity for going undetected, the gaming of the system and false data, and the silencing of victims and their families and is set out below.

i) The scale of abuse and its propensity for going undetected

In its State of Care report 2019, CQC cited 14 in-patient units (10% of those registered) rated as inadequate and in special measures. Immediately before the abuse scandal was exposed by BBC Panorama in 2019, Whorlton Hall had a good CQC rating, from which we can deduce that 10% inspected as inadequate is likely to be the tip of a much bigger iceberg.

Whilst improved CQC inspection is necessary and can make a vital contribution towards the detection and prevention of abuse, it can also accidentally give a clean bill of health to an offending institution, as in the case of Whorlton Hall. Even improved, inspection is not capable of detecting and eradicating abuse in a fundamentally closed and isolated care system where risk of abuse is endemic to the modus operandi.

ii) Gaming the system and falsifying data

At Whorlton Hall, the propensity of staff to 'game the system'[4] and conceal malpractice and criminal abuse was evidenced in the way illegal restraint was reported by the name of an acceptable method (MAYBO) and in discussions and demonstrations by staff on how to subvert CCTV surveillance which had been recommended for the service by CQC. The NHS relies on reporting against a range of quality and safety measures e.g. restrictive interventions which, from the worst institutions, will be 'gamed' and unreliable, concealing abuse.

iii) Silencing the victims, their families and advocates

As evidenced by our research, this is experienced as a punitive and retaliatory system and fear of recrimination and worsening the situations of patients inhibits formal complaints by patients, their families, and independent advocates. Advocates with 'lived experience' of learning disabilities and/or autism sometimes fear that their own support will be compromised if they speak out or are too critical of arrangements. Somewhat like CQC inspection ratings of inadequate, the formal reporting of complaints must be treated as the tip of a much bigger unreported iceberg.

iv) A triangulated approach

Under circumstances in which witnesses to abuse and neglect are effectively silenced and official sources of assurance on quality and safety are 'gamed', under-reported or otherwise liable to be incomplete or unreliable (CQC inspection; NHS performance statistics), only a radical departure from the current orthodoxy and system norms will achieve a defence of human rights of children, young people and adults with learning disabilities and/or autism in the ATU and in-patient system.

We therefore recommend that SELTCP develops an innovative triangulated approach to evaluating risks of institutional abuse and neglect which includes:

A. Proxy measures for assessing the risk of institutional abuse

B. Data from an intelligence network of trusted informants

C. NHS, CQC and other orthodox quality and safety assurance data

We recommend that partners in SELTCP use this approach (i) to fund and fast track the urgent resettlement of children and adults from implicated institutions (ii) to outlaw any future referrals to such institutions from the SELTCP region. We believe this assessment should be applied to CCG commissioned services and NHS Special Commissioned services. Proposals for (A) and (B) follow below.

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4. Using the rules and procedures meant to protect a *system* to, instead, manipulate the *system* for a desired outcome.

A. Developing intelligence networks of trusted informants

We recommend that SELTCP treats a range of stakeholders – patients, former patients, their families, independent advocates, advocates with 'lived experience' of learning disabilities and/or autism, visiting professionals and involved organisations – as trusted informants who may provide opinions and facts about what they have witnessed without being required to make formal complaints which may further prejudice the situation of patients and their families. We suggest that such an 'intelligence network' is pro-actively developed and supported to feed into an urgent assessment of currently commissioned institutions, as well as ongoing performance evaluation.

B. Suggested proxy measures for assessing risk of institutional abuse

There are a series of characteristics of ATUs and in-patient institutions which, in significant volume, are more likely to create the conditions for institutional abuse and neglect of this group of patients. These are set out in Appendix 5 (Proxy Measure) and are recommended to be used as proxy measures for assessing risk of institutional abuse.

A mixture of data in the public domain, official CQC inspection and NHS performance data, official complaints and whistleblowing combined with information from trusted informants on new intelligence networks should provide adequate sources for gathering this data. Further work in this area may result in the discovery and adoption of other proxy measures which are not currently on the list.

d) End referrals to, and placements in, services rated by the CQC as inadequate

We recommend that SELTCP/SEL LDA partners do not refer children or adults to any service with a current inadequate rating by the CQC, and seek urgent discharge of in-patients from services with historic and persistent inadequate ratings.

2. Measures to accelerate 'life span' and cross system innovations to manage transitions, prevent crises and promote community-based solutions

There are a number of key cross-system measures which, when taken together, have the capacity to improve planning and funding for the life chances and social, economic and educational inclusion of children and young people with autism and/or learning disabilities. They include:

- Care and Treatment Reviews
- Care, Education and Treatment reviews
- Education, health and care plans
- Pooled health and social care budgets
- Personalised health budgets

Simply waiting for these measures to become embedded consistently and impact the lives of children and young people positively will consign a generation to half measures and preventable crises and admissions.

We recommend that CCGs and Local Authorities accelerate the consistent and full adoption of these measures and, in the case of CTRs and CETRs, ensure they comply with relevant policy and codes of practice. We note that personalised health budgets are already in SELTCP's sights for co-production activity and recommend that this proceeds rapidly.

3. Measures to make a reality of 'homes not hospitals' and increase the choice of competent community-based solutions

a) Bespoke and shared housing options

Whilst there is nothing wrong with seeking a good match between the person and existing accommodation and support provision (not least to speed up discharge) resettlement should not be voids-driven or policy-driven. Rather, resettlement should be highly personalised and bespoke in order to maximise successful recovery and attainment of a good ordinary life.

The risk of not grasping the nettle of personalisation at the discharge planning stage is that one-size fits all, financially expedient or otherwise unsuitable

accommodation and support ends in failure. The child, young person or adult is liable to end up back in an ill-suited PICU or ATU just because they have nowhere else to go, and SELTCP partners inadvertently keep backfilling a type of service which, with few exceptions, needs to be decommissioned in its entirety.

For individuals who want to live and share with others, shared housing and support may be an appropriate option for people who have similar or complementary needs. However, for some individuals with autism and/or learning disabilities, it is simply the wrong option and will not work. There is also growing recognition amongst families and those providers experienced in resettling people under the Transforming Care programme that for some individuals "bespoke accommodation where someone can live alone and receive intensive support may be necessary for the period immediately after discharge" (VODG 2019). Our research suggests that a bespoke arrangement with intensive, then appropriately decreasing support, will need to be considered as a permanent rather than a temporary arrangement for those who cannot live with others, with significant implications for capital funding.

b) Replacing mistrust with confidence in competence

Families have an understandable mistrust of providers, caused by a mixture of bad experiences, bad press and misleading information in the system. One of a number of unhelpful narratives which has developed as a result of the failure of Transforming Care, is the idea that 'nowhere to go' is largely the fault of providers of services in the community. This is made worse by the trend for some providers of residential care to seek to re-badge their services as Supported Living without significant change in institutional practices, creating pseudo Supported Living (Newcombe 2019).

Whilst the CQC may be rightly criticised for its failings in inspection, it appears to be genuinely seeking to play its part by preventing providers registering old multi-bed residential units as Supported Living through robust implementation of its policy 'Registering the Right Support' (see Lifeways vs CQC 2019).

In addition to this, the CQC is helpfully recommending that providers comply with the REACH Support for Living standards (Paradigm) and the Real Tenancy Test (NDTi), which when used together are an incisive measure of whether support for living is genuinely support for living a good ordinary life.

Other key features of competent provision according to our research are:
• a safe, personalised and appropriately designed home environment
• staff competent in supporting people with autism and learning disabilities
• a structured approach to behaviours of concern e.g. Positive Behaviour Support

It is worth noting that some SELTCP Local Authority commissioners e.g. Lewisham, are already specifying competences in autism awareness and Positive Behaviour Support in their tender specifications, latterly in well-informed detail, which is an approach which we recommend all SELTCP adopt if they are not doing so already.

Regardless of whether they are private or not-for-profit, providers can only provide what is commissioned and funded. Sustainable person-centred organisations do not acquire properties on the 'off-chance' of being able to fill them and, as VODG observed "Providers do not have support options that people can be immediately discharged to" (VODG 2019). A common practice of setting a discharge date before identifying suitable providers, making the funding available, arranging multi-agency planning (including the patient and their family/advocate), leads inevitably to delays, loss of availability, and loss of faith by patients, families and providers alike. From the providers point of view the process is also thwarted by being asked to make proposals with insufficient time, insufficient information and while funding disputes are unresolved. The solution is not to delay discharge, but to start planning discharge prior to or at the point of admission. Lead agencies need to hold their managers and staff accountable for ensuring that their critical part in a complex process lines up for early and successful discharge and resettlement.

Excerpt from *Transforming Care: the challenge and solutions VODG*

Lack of support to families

Case study

Support to family members who themselves have also often been through significant trauma and/or abuse is often not considered, factored into proposals or costed. Yet the support needed by families is intensive and critical to the ongoing sustainability of the support to the individual. Without responsive ongoing support to families, there is likely to be a knock on impact on the quality of community-based support to the individual.

Involving and investing in families from the beginning is critical to sustaining community support once someone moves from hospital. One provider started working with the family at the point of assessment, involving them in the development of the support proposal and identifying a dedicated family support worker once the proposal was agreed. Weekly meetings took place with the family during the transition stage, using the time to learn more about the person and their wider family while also providing practical and emotional support.

The family were actively involved in recruiting and training the support team and developing the support plan that will be used post discharge. The emphasis has been on building a team around the person which means the family, support staff and professionals are working collaboratively. Whilst this approach can mean a shift in practice for providers, it is required alongside time, commitment and resources to ensure people and their families are well supported.

c) Families are a critical part of the solution, not treated as adversaries or problems

When the traumatic impact of detention on families, as well as their expertise in respect of their loved ones, is acknowledged, respected and accounted for, they play a pivotal role in young people and adults making a success of transition into ordinary life. As the VODG Case Study below demonstrates, significant involvement and investment in family members is key to the sustainability of accommodation and support solutions in the community and should be specified in commissioning proposals/tenders and funded.

d) Getting ahead of the curve on potential new legal duties

The Joint Committee on Human Rights has recommended that:

> *"A review to be carried out by the Number 10 unit of the framework for provision of services for those with learning disabilities and/or autism. At a minimum Government should introduce:*

> • *a legal duty on Local Authorities and Clinical Commissioning Groups to ensure the availability of sufficient community-based services*

> • *a legal duty on Local Authorities and Clinical Commissioning Groups to pool budgets for care services for people with learning disabilities and/or autism."* (JCHR 2019)

It is noted that there are already some instances of 50/50 funding splits but that this is not the same as pooled budgets. Funding decisions are marred by cost shunting, delays, disputes which wreck or undermine the already lengthy process of discharge and resettlement. It is recommended that SELTCP partners should get ahead of the curve on potential new legal duties by agreeing a consistent approach and process for pooling budgets voluntarily and implementing as quickly as possible. This is a precursor to the second 'duty' – ensuring availability of sufficient community-based services – as there

is no such thing as availability without advance agreements on funding for shared or bespoke accommodation and support. As both of these duties are pre-requisite to successful discharge and resettlement, voluntary adoption will contribute to the acceleration of SELTCP performance against NHSE operational targets.

The sufficiency of community-based services should include the provision of a range of crisis responses which prevent resort to Accident and Emergency and hospital admission, but promote the tenability of continuing to live with family or reduce the likelihood of 'placement' breakdown which is a common experience. This should be extensively consulted on to learn from the experience of a range of stakeholders, including patients, families and provider support staff, as well as multi-disciplinary teams (MDTs). This may include:

- multi-agency mobilisation (MDT/provider/emergency services) which brings treatment to the patient, rather than the patient to a hospital

- crisis arrangements configured to give the person and their regular support (family, support staff) mutual respite

- local non-institutional models of assessment and treatment (Atlas House model)

Summary Recommendations 'Homes Not Hospitals':

a) It is recommended that SELTCP partners consider permanent as well temporary bespoke property and support arrangements for those who cannot live with others, and that capital funding options forms part of this consideration.

b) To insure against institutionalisation on resettlement, it is recommended that Local Authorities and CCGs adopt REACH Support for Living standards and the REAL tenancy test in their service specifications and contract monitoring requirements for support for living.

c) SELTCP LAs consider specifying autism awareness and Positive Behaviour Support in all tenders for relevant community-based accommodation services.

d) It is recommended that lead agencies (CCG, NHS, LAs, independent providers) need to hold their managers and staff accountable for ensuring that their critical part in a complex process lines up for early and successful discharge and resettlement. To this end, learning from failed discharge processes is critical to improvement.

e) Significant involvement and investment in family members is key to the sustainability of accommodation and support solutions in the community and should be specified in commissioning proposals/tenders and costed. Families should also be reimbursed out-of-pocket expenses to ensure their full participation.

f) SELTCP partners should get ahead of the curve on potential new legal duties recommended by the JCHR (October 2019) by agreeing a consistent procedure and approach to pooling budgets voluntarily and implementing as quickly as possible. This is a precursor to a second 'duty' – ensuring availability of sufficient community-based services.

g) The sufficiency of community-based services should include a range of crisis responses which prevent resort to Accident and Emergency and hospital.

4. Measures to support patients and families to know their rights and navigate the system and its processes

It is recommended that SELTCP Local Authorities:

a) Link and signpost all six boroughs' websites to Bringing Us Together Family Survival Guides

b) Review existing content and search links and improve discovery by citizens 'not in the know'

c) Learning from good content which already exists in three out of six boroughs, produce relevant new content informed by co-production, including plain English explanations of relevant legislation and well signposted links on how to apply for deputyship.

Afterword:
Co-production and system change

How to get the best out of co-production and the contributions from lived experience towards system change

SELTCP's continuing investment in co-production and commitment to learning from lived experience is both acknowledged and commended.

In terms of change at an individual level, SELTCP partners should take their lead from the recommendations of the Joint Committee on Human Rights and recognise families as human rights defenders and involve them fully in discussions and decisions:

> *"Families of those with learning disabilities and/or autism must be recognised as human rights defenders, and other than in exceptional circumstances, be fully involved in all relevant discussions and decisions." Joint Commission on Human Rights: The detention of young people with learning disabilities and/or autism.*

In terms of influencing change at a system level, current patients are not at liberty to participate, and many former patients are too traumatised or ill as a result of long term effects of detention to relive their experiences in the cause of continuous improvement and some simply do not want to be involved. The potential pool of patients with lived experience of ATUs is therefore limited, which makes the involvement of families, and people with learning disabilities and/or autism with other types of experience (independent advocates, CTR reviewers) crucial. The idea of families as experts by experience and human rights defenders should be adopted more broadly and reflected in their status, their role, and the way in which they are included and valued.

We have compiled a list of dos and don'ts from family members and adults with lived experience who are active in co-production which might help commissioners and programme managers to be more successful at including them (see below).

DO	DON'T
Listen and act	Listen and do nothing
Involve us in an equal and meaningful way	Involve us in a tokenistic way which has no impact
Involve us in processes to which we add clear value and real impact	Over-focus on NHS and CQC data
Use our knowledge and experience to challenge or triangulate your data	Give late notice of meetings or arrange meetings without consulting us
Broaden your evidence base to give 'lived experience' more status and value	Give us insufficient time to respond
Give us full and timely access to information we need to be involved and contribute effectively	Remunerate co-production at rates which do not reflect the value of 'lived experience' to decision-making
Present information in a clear, non-medicalised way, with visual supports or Easy Read if needed	Over-medicalise and ignore social dimensions and 'ordinary life' solutions
Speak in plain English	Use medical or other professional jargon

Members of SELTCP have also given their feedback as follows:

> "The expertise of families and patients' needs to be given a higher priority in terms of planning and designing. Our experience can focus on analysis of experience of services, outcomes, and impact on family/patients. We need to challenge the data focussed approach that the SELTCP seem to have. Patients/ families need to have on ongoing ability to comment and assess – not just a role in initial design of services." **Mary Shrimpton**

> "NHS England recognises the value and importance of co-production, acknowledging that people with lived experience are best placed to advise on what support and services will make a positive difference. It advises that people with lived experience should be included at the earliest stages of service design, development and evaluation. I hope that in future, SELTCP will work with the Forum in this way to achieve much-needed lasting and sustainable change, so that people with learning disabilities and autistic people can live safe and happy lives in homes not hospitals." **Isabelle Garnet**

> "I hope that SELTCP can build on the pockets of good practice that exist within the region to ensure we have high calibre community services for all autistic people and people with learning disabilities so that institutions become a thing of the past and human rights are upheld." **Julie Newcombe**

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Building the Right Support (SEL Transforming Care Forum)

Feedback on activity for reducing reliance on specialist inpatient care

Lived experience of activities (logic model for Building the Right Support)

1. Support to have a good meaningful life		
What good looks like	**Source of experience / model good practice**	**Thought/ idea/ action (who/when)**
Relates to capacity		
Fulfilment of some kind		
Flexible support with same aspirations		
Least restrictive	Brookside Child and Adolescent Inpatient Service in Essex. They are operating a new model of service for 12-18 year olds, an age bracket where there is a high propensity for in-patient admissions. The model combines an in-patient unit with extensive community (home) based support managed under the same multi-disciplinary team. It is used in crisis situations and in some cases to prevent a crisis arising. Whilst this service is focussed on mental health the same model could work for other groups of people. From memory the average in patient admission is 23 days.	It might be worthwhile the SELTCP board inviting / visiting to see whether such a model would benefit SEL. Could CCGs visit this unit? This could influence how they write the spec for Bed Allocation
Age appropriate opportunities valued		
Value the contribution of autism as a quality		
What bad looks like	**Source of experience / evidence poor practice**	**Suggestions for continuous improvement (proposed action when/who)**
Direct payments instead of appropriate support	London Borough of x gives direct payments but there is nothing appropriate to buy in that borough. People go to supported living through direct payments.	It is difficult to get accountability for this, direct payments are low and people get what they pay for. Observation made by RL in March 2019. Suggestions for improvements coming from Alan Hicutt report an Liz brown, as the MOU enable to achieve the six boroughs working together.
One size fits all	Even units of good practice (Brookside Unit) do not necessarily cater for people with Autism.	Even Models like The Brookside Unit don't work well for people coming from outside of the CCG as they lack continuity of care.
Containment in the community without meaningful activity	Cuts in support hours as a result of care assessment reviews can lead people to be stuck at home more with little to do,	Providers urged to support people and families to appeal against assessments where quality of life clearly reduced by cuts in support hours.
Too much same old, same old		
Not just kicked into others routine	Fixed shifts in Supported Living provision (all boroughs) means people's preferred activities have to fit around staff timetables.	Commissioners asked to audit their service specifications and make flexible working a mandatory criterion.

2. Person-centred, planned proactive, coordinated care, including through risk stratification, support navigators, person-centred care plans

What good looks like	Source of experience / model good practice	Proposed action (who/when)
Co-ordinated Care	Brookside Unit - Continuity of Care between hospital and community. The same MDT (OT/psychologist/etc.) in the unit and in the community.	"Terms and Conditions" written up by MDT in the unit to be passed on to the provider(s) in the community who then take on the care.
Personalised	Michael Marsh recommendations about planning and commissioning services for children and young people with learning disabilities, autism and/or mental health problems.	"All Clinical Commissioning Groups (CCGs) and TCPs (Transforming Care Partnerships) were aware of the report but our local SELTCP (South East London Transforming Care Partnership were not aware of it. Three years on, it would be good to see where we are now and if progress has not been made, why not." - Forum minutes on 04/07/2019
Transition guide	A good practice example of transition guide produced by London Borough of Bexley and Bexley voice. https://www.bexleyvoice.org.uk/education-and-transition.html	Bexley Voice are co-producing with Bexley LA a series of guides for parents and carers on various subjects, including SEN support and getting an EHC Plan Needs assessment.

What bad looks like	Source of experience / evidence poor practice	Suggestions for continuous improvement (proposed action when/who)
Not having a discharge Plan	The local offer has no challenging behaviour support and not much information. Every family member needs to be able to know what to do when they need support.	Everyone who has been in an ATU that had a CTR should have a discharge plan - Idea proposed by MS in July 2017
Jobs for those who can work - Experts by experience	At the moment there are experts by experience working closely to CCG but not inside the teams of CCGs.	CCG should have people with LD working in different jobs - Idea proposed by BY in July 2018

3. Choice & control over how care needs are met, including through personal budgets, PHBs, advocacy

What good looks like	Source of experience / model good practice	Proposed action (who/when)
Advice	Creation of a process of where to go for advice when a person with LD and/or autism is in crisis.	Idea proposed by RL in January 2018
Autism Strategy	An autism strategy is necessary covering all ages, not just adults.	Idea proposed by RL in September 2018

What bad looks like	Source of experience / evidence poor practice	Suggestions for continuous improvement (proposed action when/who)
No information online	There is no information regarding challenging behaviour on Bromley's website	Observation made by MS in September 2017- there should be information online for parents and carers to know the options they have.
Over 18 transition risks	The family at risk of being excluded when a person with learning disabilities and/or autism is over 18. Experience shared by MS in January 2019	Liz Brown confirmed that there can be difficulties if the person over 18 doesn't want to share information about the family.

4. Provision of day-to-day care/support, provided by families/paid carers with the right expertise/experience to support people whose behaviour challenges		
What good looks like	**Source of experience / model good practice**	**Proposed action (who/when)**
Engagement	SELTCP Forum as a good model of engagement	RL in September 2018 said that people need to involve the families and that the SELTCP forum is a good model to do this.
Crash Pad	A crash pad style service to give people a respite area to avoid a hospital admission. This requires collaborative commissioning. *Durham model - an alternative to Police and A&E - a place where a young person knows about. Both the family and the person would be supported.	All Forum members in September 2018
Dynamic Risk Register	LB said that there is a joint understanding that having a good risk register will really help to stop people going into hospital. A good example is Doncaster where they have an agreement that everyone shares their information. Sahred by LB in April 2019.	At the moment it is in its early stages and only focused in adults. There are some barriers with sharing information. Looking at the South-East London process will also help with the data and commissioning services. A concern was shared by DH in April 2019 about how to inform the people with learning disabilities and/or autism whether or not they are put in the risk register.
What bad looks like	**Source of experience / evidence poor practice**	**Suggestions for continuous improvement (proposed action when/who)**
Schools	need to look at children holistically	observation made by RL in September 2017
Lack of family involvement	APPG (All Party Parliamentary Group) Looked after children - bad support to families in 2016	Observation made by AM in November 2017
Punishments in schools	Forum member reported bad support when experiencing punishments in his schools regarding challenging support.	Experience shared by BY in January 2019

5. Choice of housing, with all offered settled accommodation		
What good looks like	**Source of experience / model good practice**	**Proposed action (who/when)**
Young People living together	West Wickham model	observation made by RL in May 2017
People living and working together	Community in Essex model	observation made by MCA in May 2017
What bad looks like	**Source of experience / evidence poor practice**	**Suggestions for continuous improvement (proposed action when/who)**
Accommodation not suitable	CH commented that it is difficult to find a suitable option in London as often accommodation offered is small and cramped	A big and spacious accommodation is needed. Commented by CH in September 2018
Not having people in Borough		CH said it is important to have the information about where are the standards for accommodation. Atlas House are getting people out of borough into borough 'Atlas House is a purpose built specialist inpatient service, based in south east London, providing care for up to 12 adults with learning disabilities. The service is divided between four flats, enabling our team to provide care in a single sex environment where necessary. We provide a 24 hour therapeutic/treatment environment. Our service works with people who have a learning disability together with complex challenging behaviour, mental health needs, neuro developmental needs and/or offending behaviours. Atlas House provides specialist treatment that cannot be appropriately met in mainstream services.'
Moved away from community - removes safeguards, excludes family relations.	LB said families are impacted on travelling to see a loved one.	The solution would be to provide new services that are provided locally, finding and developing local property is very expensive so TCP would have to look at SEL and further out to build these models. Suggested in March 2019.

6. Access to mainstream NHS services, with reasonable adjustments made

What good looks like	Source of experience / model good practice	Proposed action (who/when)
Informed services	Doctors making home visits when person refuses to visit the surgery	Training GPs in MH, Autism and ADHD. GP "Champions" who can advise on best practice. GPs knowing what are the right questions to ask with these client groups.
Advice on complaints	Mary Busk piece of work about "Top tips for families and carers - Making feedback, concerns and complaints easier for families and carers of children, young people and adults with a learning disability, autism or both"	According to Busk, M. in 2018: *'Co-production is part of laws such as the Children and Families Act 2014 and Care Act 2014. This means organisations need to support people and families to influence the support and services received, and make sure people can influence the way that services are designed, commissioned and delivered.'* https://www.england.nhs.uk/wp-content/uploads/2018/06/Ask-Listen-Do.pdf
Information about what is available around locally	We need to know if the services out there are working properly - we need to get experiences. Observation made by RL in March 2019.	The Programme Team - creation of a signposting service of what is out there locally. A proactive service rather than a reactive service. Suggestion made by LB and CM in March 2019
What bad looks like	**Source of experience / evidence poor practice**	**Suggestions for continuous improvement (proposed action when/who)**
Pathway for late diagnosis	Forum member mentioned a consideration regarding the lack of a pathway for late diagnoses.	AM in September 2017 proposed to have a pathway for late diagnosis that is linked to social care and late support.
Not knowing what to do when complaining.	Forum member explained an experience about being passed to and from different complaints departments.	Observation made by JN in May 2018

7. Specialist community health/care services, including 24/7 multi-disciplinary teams to prevent/manage crises

What good looks like	Source of experience / model good practice	Proposed action (who/when)
Crisis support from mental health specialists	CIPP @ The Maudsley	This is a national scheme and so people are not referred locally. A local provision of the same nature would be useful
Annual health checks	Three Cs tips for annual health checks	Forum members recommended this presentation in April 2017
Dentist understanding LD	Expert by experience that is a Forum member shared a good experience with the dentist at the Maudsley.	Forum member stated that good communication with the dentist, good with the medication and very understanding of LD
Drop-in centre	SLAM - drop-in centre model, you can go and talk to someone	observation made by AM in July 2018
Case managers	Support Workers have already a lot of responsibilities. A case manager does not replace a social worker - there should not be a lack of continuation of support.	All the services should be taking responsibility, it is a national problem- recommendation made by IG in November 2018
What bad looks like	**Source of experience / evidence poor practice**	**Suggestions for continuous improvement (proposed action when/who)**
Disconnection with CCG	One year on' report stating there is a big disconnection with CCG. Shocking people to get the service.	Observation made by AM in November 2017
Bad experience from a Forum member	Brookside CTR	Experience shared by DH in January 2018
Nor recording if someone has LD	Doctors don't record if someone has a learning disability in Bromley	Observation made by RL in May 2018

8. Support to stay out of trouble, including community forensic support

What good looks like	Source of experience / model good practice	Proposed action (who/when)
Training for families	Challenging Behaviour Support training proposed for Forum members	Proposed by ES in January 2018
Risk registers	The risk register is intended as a support guide, there are no negatives of being on the list. Observation made by LB in March 2019.	There is a worry that young people don't get into the risk register until there is crisis. However, a lot of young people get specialist support in schooling and might be candidates to go on the risk register. Observation made by RL in March 2019.

What bad looks like	Source of experience / evidence poor practice	Suggestions for continuous improvement (proposed action when/who)
Having people in hospital for too long	xxxx xxxxx xxxx [5] – All forum members have been pointing it as an example of bad support. BBC reported people staying in xxxx xxxxx xxxx for over 7 years.	IG proposed in November 2018 to write a letter to take the people out of this hospital - *'there are serious concerns about how the organisation is run and it is a priority to get vulnerable people out of that place where they can be cared for more humanely.'*
Little information about people in forensic services	People in prisons. RL noted that there is no information about people in forensic services in the Root Analysis and confirmed this group needs to be included, not just CCG and Spec. Comms Beds.	LB mentioned that the profile of the TCP needs to be raised and that there is a challenge to get the information out to social care team and health teams. Observation made in January 2019
People staying in prisons	BY noted there is no information about people staying in prison.	LB mentioned that the TCP and SLP are designing a forensic service and a service for those people who have been in prison with additional support being given to the existing teams.

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5 The name of the provider has been redacted to protect forum members from prejudicial treatment.

Interview Guide and Consent Form

three Cs

INFORMATION SHEET FOR RESEARCH PROJECT:
Three Cs have been commissioned by the South East London Transforming Care Partnership (SELTCP) to interview patients with a learning disability and/or autism who have mental health conditions or behaviour that challenges about their experience of mental health hospitals or Assessment and Treatment Units (ATUs)

NAME AND POSITION OF RESEARCHERS:
Alison Love (Three Cs Head of Social Inclusion) plus operational lead for the South East London Transforming Care Partnership (SELTCP) work.
Miren Cerezo (Three Cs Development Worker) assisting the SELTCP work.

OUR RESEARCH QUESTION IS:
To ask patients, ex patients and/or their families on behalf of their relatives (if required) to tell us about their lived experience of mental health hospitals and ATUs, specifically:

a) Their life before admission
b) What led to their admission
c) Their life whilst in hospital / inpatient unit
d) Their life after discharge

THE METHOD:
We are using QUALITATIVE and INTEPRETIVE methods based on 'grounded theory' and semi-structured ethnographic interviews. Interviews are guided but informal and flexible.

We may use prompt questions in easy read/pictures/digital imagery to explain the questions in an accessible way as appropriate to the communication needs of the patients. The whole process will be relaxed and conversational. What the interviewee says will help generate the theory.

There are no right answers because we are not testing a hypothesis or trying to prove a theory. We are collecting opinions and views on a service which may lead to conclusions and recommendations.

Three Cs 82-84 Childers Street, Deptford, London SE8 5FS **Tel:** 020 8269 4340 **Email:** info@threecs.co.uk **Website:** threecs.co.uk

Control and Choice in the Community for People with Learning Disabilities, Autism and/or Mental Health Challenges

INVESTORS IN PEOPLE | Silver   disability confident EMPLOYER   LDE MEMBER   We support STOMP   THE BRITISH ASSESSMENT BUREAU ISO 9001   The Gr8 Support Movement

Three Cs is a company limited by guarantee and registered in England & Wales. Company registration No. 2768427   Registered Charity No. 1047736

three Cs

THE RESULTS are confidential and anonymous and you will not be named or otherwise identifiable in any of the reports or communications which result from the research. Confidentiality will be assured and consent to the use of anonymous quotations only will be sought before the interviews begin.

OPT OUT There is no obligation on you to take part in this research and it is voluntary. You can withdraw at any time without explanation.

Personal data:
All personal data will be handled in accordance with Three Cs Data Protection policy 2015, Confidentiality Policy 2017 and in compliance with the General Data Protection Regulations.

In summary, all personal data will:

1. be processed lawfully, fairly and in a transparent manner;

2. be collected only for specified, explicit and legitimate purposes, and not be further processed in any manner incompatible with those;

3. be adequate, relevant and limited to what is necessary in relation to the purposes for which it is processed;

4. be accurate and, where necessary, kept up-to-date;

5. not be kept as identifiable data for longer than necessary for the purposes concerned; and

6. be processed securely.

The final report will be the property of Three Cs. We will work in partnership with the commissioners (SELTCP) to distribute the report as widely as possible to inform future practice.

three Cs

CONSENT FORM

Purpose of Research Project: To ask patients, ex patients and/or their families on behalf of their relatives (if required) to tell us about their lived experience of mental health hospitals and ATUs.

a) Their life before admission
b) What led to their admission
c) Their life whilst in hospital / inpatient unit
d) Their life after discharge

Name and Position of Researchers: Alison Love (Three Cs Head of Social Inclusion) plus operational lead for the South East London Transforming Care Partnership (SELTCP) work. Miren Cerezo (Three Cs Development Worker) assisting the SELTCP work.

Consents	Please initial
1. I confirm I have read and understand the information sheet for this research project Consentsand have had the opportunity to ask questions about it.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without explanation	
3. I agree to take part in the research	
4. I agree to the interview being audio-recorded	
5. I agree to the use of anonymised quotes in resulting publications if relevant	

Name of participant	Signature	Date
Name of researcher	Signature	Date
Name of researcher	Signature	Date

Three Cs 82-84 Childers Street, Deptford, London SE8 5FS **Tel:** 020 8269 4340 **Email:** info@threecs.co.uk **Website:** threecs.co.uk

Primary Source Coding and Evidence tables (snip samples only)

System Culture and Human Rights

B
"His arm was broken in three places. He has had black eyes, wrist burns and bruises all over his body. Carpet burns have taken the skin off his face and chin";
"The hospital called to say they were taking my son for an X ray for a lump on his chest. It turned out to be a broken clavicle bone and the injury had actually occurred several weeks earlier";
I can see how hyper-alert he is to the staff who have used restraint on him";
"Whenever I visited, he smelt awful. He was not washed or shaved and his nails were ridiculously long. He often wore someone else's clothes, and they were always dirty".
"My son was kept in seclusion for up to nine hours at a time. The rule was that he could not leave until he was quiet. With his anxiety and sensory presentation, there was no way this was possible. He started to bang his head against the wall and would bite the wood in the doorframe out of desperation";
"My son had to earn home leave by cleaning wards"
"[....] is living and being treated in shocking and inhumane conditions.
The Human Rights Act and the Equality Act are there to protect people like [...] and it was immensely important to us to help her and her family in this case".
CTRs, which were the big flagship thing about transforming care, routinely do not get done properly, or if they are the recommendations are not followed up. They just get put in a drawer in cyberspace.
It was just an empty room, really, with a bed in it.

`... | 1 Battle of the Experts | 2 System Culture & Hu Rights | 3 Good Ord Lives | 4 Funding Squab | 5 Crisis | 6 Info Comms Guid | ... ⊕`

Funding battles

B
This makes it seem reasonably simple but in reality was months of battle, escalations, lack of response, conflicting information and a social worker that was all but absent. There was no proactive input from CCGs / social services even whilst Person A was in hospital and in the knowledge that a placement outside of the home environment was the only way forward.
The family described tensions around funding which in their case slowed down the discharge of their son from hospital into the community. Basically who was going to pay - was it social services or health.
The time frame between when social services agreed Person A's budget to when he was discharged was very brief.
He was originally detained under the Mental Health Act as a result of some medication changes and some in appropriate behaviour management which was essentially punitive.
When witnesses and experiences that, he anxieties trigger and she becomes upset. She wants to fly or fight but cannot. That leds to more and
When he was first detained, he was sent to a psychiatric intensive care unit, which is possibly the worst kind of environment for someone with autism to be in, because it is for very unwell people.
[....] needs to be somewhere safe where she does not have access to things, even though they are therapeutic things.
it always feels like it is you against them, everywhere. It is you against the hospital, you against the local authority, you against the commissioners. It is just you, the parent, trying to fight for your child.
Why would care and support for people who do not have a mental health condition be led by psychiatry?
There is an overreliance on medication that people frequently do not need.

`... | 1 Battle of the Experts | 2 System Culture & Hu Rights | 3 Good Ord Lives | 4 Funding Squab | 5 Crisis | 6 Info Comms Guid | 7 Transition | ⊕`

Good ordinary lives

B
he's been so good. But they're very good at the way they do things. I mean, first of all we got three to one staffing a lot of the time, which he needs because that way he can go out.
But I think what's great for him is they've given him a timetable around him. So in the day he chooses what he wants to do. He's structuring his own timetable and one of the biggest things I think was autonomy.
they give him as many choices as you can. You know, because obviously-
he's eating less, less anxiety eating, not drinking water.
They have a very good staffing system. They're very mindful of things like Winterbourne View. They're very mindful of how to- they have very good managers who manage very well and-
They've got six people
I have an email and phone. I phone most days. I speak to them all the time.
They're very open. We're welcome at any time.
It's difficult but you have to ... security gates
We have a very high level of deputyship actually for [....]. We have everything on it, even down to choosing his clothing and where he lives. Just everything. And that was really useful. We did that two years ago in the light of everything like this-
We have supervisions with that and we think it's critical because I think it means that you always have the potential to use those things and say, "I am concerned about where he is."
I personally think so and I think more people should do it and they should make it easier.
what we say is we are [....] when you pick that up.
We're [....] saying what I want and need and so I think, yes, to extend the deputyship and health and welfare is critical for families.

`... | 1 Battle of the Experts | 2 System Culture & Hu Rights | 3 Good Ord Lives | 4 Funding Squab | 5 Crisis | 6 Info Comms Guid | 7 Transition | ⊕`

Relevant Word Searches
SELTCP Council Websites 1 and 2

Search 1		
Bromley		
Learning Disabilities	• Housing and support schemes for people with learning disabilities • Disabilities • Learning disability ; Living with a disability • Joint Strategic Needs Assessment (JSNA) learning disabilities • Day opportunities for people with learning disability – EIA	**3980 results**
Autism	• Choice Support autism • Social and communication difficulties including autism in Bromley • Healthwatch Bromley – autism survey form • National Autistic Society • Healthwatch Bromley – autism survey	**1590 results**
Transitions	• Moving from child to adult social care • Transition plan • School – transition between schools downloads • + final internal audit report education, care • Information, Advice and Support Service (IASS)	**2940 results**
Challenging Behaviour	• Guidelines for managing challenging behaviour • Positive behaviour management in early years practical advice • Guidelines on managing challenging behaviour – pack • What is early help for families • Parenting courses – Bromley Children Project	**1460 results**
LD & Autism	• Advocacy for all • Disabilities and learning needs choosing a school • Children and young adults with disabilities and learning needs • Health support – children with disabilities and learning needs • Rewarding and fulfilling lives: a strategy for people with autism	**653 results**
LD & MH	• Emotion wellbeing and mental health – health support – children with • Contacts for Bromley Council – media contacts • Education care and health • Freedom passes for people with disabilities • Committee details – adult care and health portfolio	**2380 results**
LD & CB	• Supported living – learning disability scheme – decision • Budget pressures on adults with learning disabilities – appendix 3 • Supported living – learning disability scheme – decision • Issue – items at meeting – supported living – learning disability • Hollybank – Community Provided Unit	**809 results**
Autism & CB	• Hollybank – Community provided unit • Budget pressures on adults with learning disabilities – appendix 3 • Short breaks for children/young people with autistic spectrum • February AHDC – newsletter pa • Parenting courses – Bromley children project	**226 results**
Autism and MH	• Community and special dental care – SEN • Inclusion support advisory team – SEN • Bromley joint strategic needs assessment 2018 • Bromley CCG transformation plan children and young people's • Special needs	**546 results**

Search 1		
Bexley		
Learning Disabilities	• Bexley learning disability strategy • Day activities for adults with learning disabilities • Help for people with disabilities • Bexley twofold • Polling stations	**486 results**
Autism	• Support for people with autism • Specialist teaching service (STS) • Adult social care • Bexley adult autism strategy • Autism awareness training strategy	**34 results**
Transitions	• Specialist teaching services (STS) • Transition strategy – survey for carers and stakeholders • Day activities for adults with learning disabilities • Transition strategy easy read questions for survey • Preparing for adulthood strategy 2017-2022 draft changes	**111 results**
Challenging Behaviour	• Services • Antisocial behaviour • Bexley education traded services (BSN) • Community safety and antisocial behaviour • The community right to challenge	**350 results**
LD & Autism	• Support for people with autism • Bexley learning disability strategy • Day activities for adults with learning disabilities • Adult social care • Disability sport and activities	**488 results**
LD & MH	• Bexley learning disability strategy • Asylum seekers • The Bexley contract register • Day activities for adults with learning disabilities • Bexley among winners at 2019 London health workplace awards	**756 results**
LD & CB	• LD & CB • Bexley learning disability strategy • Services • Day activities for adults with learning disabilities • Support for people with autism • Antisocial behaviour	**611 results**
Autism & CB	• Support for people with autism • Antisocial behaviour • Community safety and antisocial behaviour • Services • Community trigger	**237 results**
Autism and MH	• Support for people with autism • Bexley among winners at 2019 London health workplace awards • Asylum seekers • Services for children, young people and families • Ageing well strategy	**574 results**

Search 1		
Greenwich		
Learning Disabilities	• Community Learning Disability Team | Help for people with learning disabilities • People with disabilities • Advice for disabled jobseekers • Learning disability housing strategy 2017-2022 • Support for dyslexic adults learners	**1504 results**
Autism	• Community learning disability team – help for people with learning disabilities • Lego-thon raises awareness of autism • New equipment for Blackheath/Westcombe autism support • Outside space improvements at Blackheath/Westcombe autism support • Who can get a Blue Badge – apply for or renew a blue badge	**12 results**
Transitions	• Sing up to learn more about adoption – adoption information events • Vehicle seizure notices • Pest treatment service standards • How business rates are calculated • Social mobility delivery plan	**24 results**
Challenging Behaviour	• Emergencies and urgent incidents – report anti-social behaviour • Request an anti-social behaviour review – anti-social behaviour community trigger • Victim and witness support – report anti-social behaviour • What can I expect when I use the community trigger? • Ways we deal with anti-social behaviour	**231 results**
LD & Autism	• Community learning disability team – help for people with learning disabilities • Learning disability strategy 2017-22 • Advice for disabled jobseekers • People with disabilities • Support for dyslexic adult learners	**606 results**
LD & MH	• Adult mental health services • Community learning disability team • Health and wellbeing • Support for children and young people • Learning disability housing strategy 2017-22	**2903 results**
LD & CB	• Community learning disability team • Learning disability housing strategy 2017-2022 • Advice for disabled jobseekers • People with disabilities • Support for dyslexic adult learners	**778 results**
Autism & CB	• Emergencies and urgent incidents – report anti-social behaviour • Request an anti-social behaviour review • Victim and witness support • What can I expect when I use the community trigger • Community learning disability team	**229 results**
Autism and MH	• Adult mental health services • Health and wellbeing • Support for children and young people • The drug and alcohol and mental health integrated commissioning team • Adult care and health	**2786 results**

Search 1		
Southwark		
Learning Disabilities	• Learning disabilities • Learning disabilities JSNA 2018 • Next People with learning disabilities • Learning disability – easy read translation • People with learning disabilities	**10953 results**
Autism	• Autism (x 4) • Autism friendly • Southwark autism strategy • Autism friendly • The autism project	**1153 results**
Transitions	• EYFS – Transitions from EYFS to KS1 – 19/5/20 • Council Spending August 2018 • Kyle provision map • The journey from early years for children who have experienced a difficult start in life • Council spending November 2018	**339 results**
Challenging Behaviour	• Challenging Behaviour Foundation • Behaviour • Challenging your services • Contact Anti-social behaviour • Report anti-social behaviour	**3395 results**
LD & Autism	• Learning disability • Adult learning disability • Autism • Learning disability mortality reviews (LeDeR) • Adult Learning Disability Activity Pack	**8260 results**
LD & MH	• Learning disability • Mental health • Adult learning disability • Southwark mental health learning disabilities service (MHLD) • Health SEN/Disability	**15485 results**
LD & CB	• Adult learning disability • Learning disability mortality reviews (LeDeR) • Adult learning disability pack • Disability • Behaviour	**9498 results**
Autism & CB	• Challenging behaviour foundation • Autism • Behaviour • Autism friendly • Southwark autism strategy	**4149 results**
Autism and MH	• Mental health • About your mental health • Mental health foundation • Heath mental/foundation • Mental health practice	**12946 results**

Search 1		
Lewisham		
Learning Disabilities	• Privacy notice – adults with learning disabilities and transitions • Children with disabilities, learning difficulties or life-limiting conditions • Services for children with disabilities, learning difficulties or life-limiting conditions • Supported learning courses for adults with learning difficulties • Supported tenancies for people with disabilities	**57 results**
Autism	• Kaleidoscope drop in – autism support • Information for parents of children with autism • Support groups for families and carers of children with SEND • Brent Knoll School • Speech and language development	**19 results**
Transitions	• Privacy notice – adults with learning disabilities and transitions • 14-19 year old learners with special educational needs • Improving and maintain attendance and engagement in school • Moving children's social care to adult social care • Moving from child to adult social care	**32 results**
Challenging Behaviour	• Child behaviour • Privacy notice – fair access • Babysitting • Privacy notice – challenging needs service (day opportunity) • Building safe communities	**9 results**
LD & Autism	• How we determine if a child has a disability • Specialist provision and specialist schools for primary-school-aged children with an education, health and care plan • Educational support for children with autistic spectrum disorder (ASD) • Joining the disability register • Redeveloping the Mayow Road Warehouse	**6 results**
LD & MH	• Aids, adaptations and equipment for children and young people with SEND • Moving from children's social care to adult social care • Community services directorate structure • How we determine if a child has a disability • Privacy notice – adults with learning disabilities and transitions	**16 results**
LD & CB	• Privacy notice – challenging needs service (day opportunity) • Making sure your child with SEND gets the right amount of sleep • Candidates for young mayor 2019-20	**3 results**
Autism & CB		**0 results**
Autism and MH	• Support groups for families and carers of children with SEND • How we determine if a child has a disability	**2 results**

Search 1		
Lambeth		
Learning Disabilities	• Learning disabilities • Living with a disability or illness • Learning disabilities • What are special educational needs and disabilities • Focus on autism	**4530 results**
Autism	• Autism pathway 0 to 25 years • Lambeth autism advisory service • Focus on autism • How are children and young people assessed for autism • Autism advice and support groups	**2170 results**
Transitions	• Children with disabilities • How our help from social care changes at 18 • Preparation for adulthood programme coordination directorate • LB Lambeth children and young people's service • Adult social care	**3970 result**
Challenging Behaviour	• Lambeth family information director • LB of Lambeth • Job description template • Mental health for children and young people • Towards inclusion	**2940 results**
LD & Autism	• Focus on autism • What support is there if I'm a18 or older? • Living with a disability or illness • Special schools and resource bases in Lambeth • The children and young people disability register	**472 results**
LD & MH	• Learning disabilities • Focus on autism • Mental health for children and young people • Shared lives • What support is there if I'm 18 or older?	**2910 results**
LD & CB	• LB of Lambeth • Mental health for children and young people • Lambeth family information directory • Black Caribbean underachievement in schools in England • What are special educational needs and disabilities?	**1130 results**
Autism & CB	• Lambeth family information directory • Mental health for children and young people • Lambeth family information directory • Lambeth family information directory • Lambeth family information directory	**286 results**
Autism and MH	• Focus on autism • Mental health for children and young people • Autism advice and support groups • What support is there if I'm 18 or older • How are children and young people assessed for autism	**719 results**

Search 2		
Bromley		
Difficult behaviour	• Guidelines for managing challenging behaviour • Positive behaviour management in early years practical advice and … • What to look for when visiting a childcare setting • A strategy for improving the behaviour of young people in Bromley	**2130 results**
Behaviours of concern	• Antisocial behaviour • Raising concerns at Bromley council • Educational psychology • Consultation – have your say about community safety • Review of the promoting positive behaviour strategy	**3290 results**
School exclusion	• Exclusion from school • School – exclusion of pupils • School – exclusion of pupils forms • Provision for pupils who are excluded from school • School – exclusion of pupils downloads	**1790 results**

Reference / link to	• https://bringingustogether.org.uk/publications/survival-guides/
	• Family Survival Guides
	  - Care & Treatment Reviews – no
	  - Crisis Prevention – no
	  - SEND Education – no
	• Nothing came up in the search on the Bromley council website, but when I did a search via Bringing Us Together the following came up: https://www.bromley.gov.uk/LocalOffer
		0

Search 2		
Bexley		
Difficult behaviour	• Antisocial behaviour • Community safety and antisocial behaviour • Services • Community trigger • Domestic abuse	**316 results**
Behaviours of concern	• Community trigger • Antisocial behaviour • Educational concerns and complaints • Education welfare service (EWS) and child licensing • Bexley obesity strategy	**482 results**
School exclusion	• Bexley Educated Traded Services (BSN) • Bexley Targeted Youth Service (TYS) • Have your say on Bexley Children's Services • Inclusion services • Services	**820 results**

Reference / link to	• https://bringingustogether.org.uk/publications/survival-guides/
	• Family Survival Guides
	  - Care & Treatment Reviews – no
	  - Crisis Prevention – no
	  - SEND Education – no
	• Nothing came up in the search on the Bexley council website, but when I did a search via Bringing Us Together the following came up: http://www.bexleylocaloffer.uk/#
		0

Search 2		
Greenwich		
Difficult behaviour	• Emergencies and urgent incidents • Request an anti-social behaviour review • Victim and witness support • What can I expect when I use the community trigger • Ways we deal with anti-social behaviour	**167 results**
Behaviours of concern	• Issues you can report • Worried about someone you know? • Victim and witness support • Domestic abuse x 2 • Emergencies and urgent incidents	**255 results**
School exclusion	• Proofs of identity • How to register for Greenwich homes • Who can arrange a burial • Free school meals, clothing and school trip grants • Admissions during the school year	**2572 results**
Reference / link to	• https://bringingustogether.org.uk/publications/survival-guides/ • Family Survival Guides - Care & Treatment Reviews – no - Crisis Prevention - no - SEND Education – no • Nothing came up in the search on the Greenwich council website, but when I did a search via Bringing Us Together the following came up: https://greenwichcommunitydirectory.org.uk/kb5/greenwich/directory/home.page	**0**

Search 2		
Southwark		
Difficult behaviour	• Behaviour x 2 • Challenging behaviour foundation • Contact anti-social behaviour x 4 • Report antisocial behaviour • Challenging behaviour foundation x 2	**3923 results**
Behaviours of concern	• Cause for concern x 4 • PHE (2016) high impact area 2 – reducing risky behaviours x 2 • Teacher recruitment and retention from LCOGS news x 2 • London safeguarding children board (LSCB) thresholds x 2	**1754 results**
School exclusion	• Exclusion • 1. Exclusion from school • Exclusion • Exclusion process x2 • Next reasons for exclusion	**9023 results**
Reference / link to	• https://bringingustogether.org.uk/publications/survival-guides/ • Family Survival Guides - Care & Treatment Reviews – no - Crisis Prevention – no - SEND Education – no • Nothing came up in the search on the Southwark council website, but when I did a search via Bringing Us Together the following came up: https://localoffer.southwark.gov.uk/	**0**

Search 2		
Lewisham		
Difficult behaviour	• Smacking • Behaviour worries • Child behaviour • Making sure your child with SEND gets the right amount of sleep • Information for parents of children with autism	**7 results**
Behaviours of concern	• Behaviour worries • Counselling for children and young people with SEND and their families • Recognising and reporting child abuse • Why report hate crime • Exclusion from school	**8 results**
School exclusion	• Exclusion from school • School exclusions for children and young people with SEND • Penalty notices for school absences • Abbey Manor College • Key priority areas for our children and young people's strategic partnership	**11 results**
Reference / link to	• https://bringingustogether.org.uk/publications/survival-guides/ • Family Survival Guides Care & Treatment Reviews – no Crisis Prevention – no SEND Education – no • Nothing came up in the search on the Lewisham council website, but when I did a search via Bringing Us Together the following came up: https://lewisham.gov.uk/localoffer#/	**0**

Search 2		
Lambeth		
Difficult behaviour	• Access free parenting courses and support • Black Caribbean underachievement in schools of England • Anti-social behaviour on estates – guide • Have your say on our street gaming and street gambling PSPO • Appendix 2 – summary of feedback and council's response	**4100 results**
Behaviours of concern	• London Borough of Lambeth • Safeguarding and adult abuse – guide • Report neglect or abuse of an adult • Dealing with empty properties • Lambeth safeguarding websites	**7510 results**
School exclusion	• Apply to review a permanent exclusion from school • School exclusions in England • Schools and education • Black Caribbean underachievement in schools in England • Application for a permanent exclusion review - form	**3110 results**
Reference / link to	• https://bringingustogether.org.uk/publications/survival-guides/ • Family Survival Guides Care & Treatment Reviews – no Crisis Prevention – no SEND Education – no Nothing came up in the search on the Lambeth council website, but when I did a search via Bringing Us Together the following came up: https://www.lambeth.gov.uk/send-local-offer	**0**

Proxy measures for assessing risk of institutional abuse

Environment

Environments which are hospital-like or have characteristics of prisons: Small cells, cramped wards and dormitories, reduced natural light, no beds, no furniture/furnishings, no personal belongings or other forms of personalisation.

Environments which are isolated and not overseen: built in non-residential areas, on the edge of towns, at a distance from shops and amenities, no passers-by, walled or screened by trees, separated by large grounds or long driveways.

Reasonable Adjustments

Absence of competent, informed, personalised communication with the patient: patient's basic healthcare needs cannot be understood and are at risk of being neglected; assessment or exclusion of mental illness as a cause of symptoms is delayed or prevented; causes of behaviour that challenges the service not understood, managed, reduced or prevented.

Absence of awareness of the needs of people with autism and/or learning disabilities: inappropriately small, busy, noisy, chaotic environments; insensitivity to effects of hypersensitivity or hyposensitivity to sights, sounds, smells, tastes, touch; failure to understand the unique causes of behaviour that challenges; failure to recognise and account for physical and sensory disabilities; absence of ordinary routines and structures; absence of meaningful activities; failure to support, prompt or encourage daily living activities where needed e.g. getting washed and dressed.

Absence of understanding and competence in behaviour that challenges: blaming rather than understanding the patient; not understanding the form and function of behaviour and therefore unable to develop pro-active and reactive strategies or reduce behaviours; engaging patients in inappropriate cycles of challenge and restraint which traumatise.

Absence of understanding and competence in trauma-informed care: inability to recognise that behaviour that challenges can be unconscious and related to trauma; that detention, segregation, seclusion and restraint can cause trauma; that unmet basic healthcare needs (pain, physical discomfort) can cause distress and traumatise.

Restrictive Interventions

High incidence of segregation: patients isolated from human contact and interaction for long term to manage risk of violence i.e. dealing with the effect of behaviour, not its cause.

High incidence of seclusion: patients isolated from human contact and interaction for short periods to manage risk of violence from them or to them; using seclusion to manage understaffing.

High incidence of physical restraint: patients physically restrained regularly, illegally, inappropriately, instead of compassionate care, instead of using positive pro-active support, instead of less restrictive interventions.

High incidence of chemical restraint: patients chemically restrained regularly, illegally, inappropriately, without diagnosis, experimentally, to reduce demands on staff, instead of compassionate care, instead of using positive pro-active support, instead of less restrictive interventions.

Access, Leave and Inclusion

Access highly restricted: Family, advocates or third parties cannot visit frequently or unannounced. Visits to wards or accommodation is not permitted. Visits frequently cancelled. Understaffing or behaviour episodes frequently constitute reason/excuse to cancel visits.

Leave highly restricted: Low incidence of home visits and Section 17 leave; relatives report frequent cancellation home visits and Section 17 leave; patients or their advocates report leave used as punishment or reward.

Inclusion of the patient, family or advocates in decision-making is absent, limited and/or inept: planning and review meetings held without the patient, with the patient present but with no means to communicate; ignoring patient's wishes and views when expressed. Exclusion of family members or advocates by failing to invite, inviting at short notice or cancelling meetings. Ignoring or dismissing the expertise and opinions of family members and advocates.

Lengths of Stay or Detention

Lengths of stay incompatible with therapeutic role: high incidence of stays in excess of six months; high incidence of voluntary admissions become compulsory; high incidence of serial sectioning on grounds of violence/aggression (when it is an expression of stress and distress or incorrectly managed behaviour that challenges).

Lengths of stay incompatible with diagnostic role: Extended failure to exclude mental illness; medication to manage the effects of extended detention rather than treat symptoms of an identified mental illness; frequent failure to diagnose mental illness at all or correctly.

Incompetent or Dangerous Healthcare and Care

High incidence of injury, serious injury, and harmful medication errors: Serious injuries resulting from the use of force; overdose or over-use of anti-psychotic and mood-stabilising drugs; use of anti-psychotic drugs in the absence of a diagnosis of psychosis;

Life and health of patients compromised by shortcomings in basic healthcare: failure to monitor, treat or manage risks relating to unique, common and life-threatening conditions (e.g. epilepsy, constipation, infection, allergies); failure to treat injury or illness (whether caused by accident, self-harm or physical and chemical restraint); failure to ensure adequate nutrition and hydration;

Presentation and appearance of patient shows a lack of care and respect for dignity: failure to support, prompt or encourage daily activities e.g. getting washed and dressed, personal grooming; wearing other patients clothes; patients routinely unclean, unkempt wearing dirty clothes.

Commercial Conflict Of Interest

Extended detention and serial sectioning generates excessive shareholder profit (private sector): patients with a high financial value subject to repeat section and delayed discharge by directly employed clinicians without independent safeguards.

Extended detention and serial sectioning funds excessive executive and non-executive salaries (including private, not-for-profit or charities): patients with a high financial value subject to repeat section and delayed discharge by directly employed clinicians without independent safeguards.

Personalised Health Economics

For a child or adult in ATU/PICU or at risk of detention, CCGs use the following formula to calculate Personalised Health Budget:

1. They take the figure which represents the national or regional average length of stay in an ATU e.g. national is 5.4 years (2020).

2. They multiply this by

   i) (For those already detained) the actual cost per week of the ATU

   ii) (For those at risk of detention) the mean or median cost per week of an ATU.

3. The total (e.g. 5.4 x 52 x £13,500 = £3.8m) is the person's budget for the next five years and can be spent in a flexible front-loaded and tapering way on highly personalised and bespoke accommodation and support solutions (including capital spend).

4. Supported by relevant health and social care professionals, it involves the child/adult and their families/advocates at the centre of decision-making about what the solutions might be and how the budget might be spent.

5. As the solution is personalised, it uses money which will otherwise be spent on harmful detention on setting up a good ordinary life with preventive dimensions (the right accommodation in the right place, intensive support for recovery and transition, an ordinary, full and aspiring life, well-trained and competent staff, structures and approaches for managing behaviours of concern, personalised contingencies for crisis prevention).

6. The human rights case for this solution stands on its own merits. However, the health economics point and broader business case is that from five years onwards, the sustainable personalised solution costs health much less than detention in an ATU. At that point the Local Authority can pick up their share of costs which have already been managed down.[6]

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6 The authors are aware that the current financial framework does not accommodate this kind of solution but as the Funding Transfer Agreement and all other measures have failed to 'transform care' believe that CCGs and LAs should press for radical changes to the framework

Notes

Notes