Recognising Behaviour as Distress in Practice – a discussion paper

The National Autistic Taskforce

January 2024

Executive Summary

This discussion paper focusses on the current social care response to what is often called ‘behaviour which challenges’ in autistic people and the persistent issue of the inappropriate detention of autistic people in institutional care settings. We argue that current approaches are often distressing and, even, traumatic; and have been largely ineffective in reducing the number of autistic people in inpatient settings, and, more widely, at preventing placement breakdown and reducing the use of restraint.

We analyse the problem from an autistic perspective and consider how the problem can be productively reframed. We propose, as have others, a rights-based approach to care which focusses on quality of life. We also call for the widespread adoption of the National Autistic Taskforce’s autistic-authored ‘An independent guide to quality care for autistic people’ and particularly recommendation 7, which advocates recognising behaviour as distress.

We examine how this proposal could be realised in practice by exploring existing alternative approaches to responding to and preventing distressed behaviour in autistic people. We argue that care and support should focus on promoting autonomy, reducing stress and distress and supporting autistic people to have a meaningful life, rather than managing behaviour and risk. We critically examine the pre-eminence of Positive Behavioural Support (PBS) in adult social care. We explore what an overarching framework focussed on human rights and quality of life, rather than behaviour, and utilising alternative approaches from the education context, low arousal approaches and intensive interaction can offer social care practitioners working with autistic people.

We go on to explore the implications of these proposals for the social care workforce. We consider some of the current problems at the system-level, including commissioning and commercial pressures, the need for wider support services including accessible healthcare and the current context of staffing issues in social care. We argue that, even in the current

Foreword

Dame Stephanie Shirley CH

I founded the National Autistic Taskforce in 2018 to give autistic adults a stronger voice in the direction of their lives. Its 2019 report *An Independent Guide to Quality Care for Autistic People* addresses the key issue “

Section 1: Introduction

The problem

Autistic people using health and social care services can behave in ways that cause concern to those providing care. Responses from such services vary, but are widely focussed on the behaviour itself and intervening to minimise it. Autistic behaviour is seen as a source of risk and the response from health and social care services frequently involves increasing numbers of staff, restrictive interventions, movements to more restrictive placements, and the use of restraint and seclusion (Social Care Institute for Excellence (SCIE), 2023). This already unhappy picture is, all too frequently, compounded

the legal frameworks involved, including the Mental Capacity Act and Adult Safeguarding. We take a rights-based look at physical intervention. Whilst we argue that more needs to be done to explicitly trial and evaluate a fully-realised model of care based on these principles, this paper does not outline such a system. At this stage we offer a different way of thinking, which naturally leads to principles that will, we believe, be more likely to produce harmonious relations between autistic people and the services they depend on. The exact practical application of these will depend on individual circumstances, and we consider examples in our case studies.

We will look at the location of disability and argue for environment modification as the primary focus of change. We will consider and discuss important essential elements of autistic wellbeing, including autonomy, communication, meaningful activity and stress reduction. We examine the context of behaviour in order to better understand its causes, rather than merely proximate triggers, and seek to create conditions in which an autistic person can not only comfortably exist but positively thrive. We consider the implications for the workforce of social care workers and practitioners and how change can be achieved without necessarily requiring additional resources, much as those are needed as well. We argue that services that work in harmony with autistic people, supporting them towards a good quality of life at home and in the community, will over the long term, be less expensive than the current situation.

Section 2: Conceptualising a fundamentally different approach

Recognise when service policies, placement environments or particular staff are not the right match for the individual.

Identify when stretched public resources are leading to short term decisions which are unlikely to be cost effective in the long term.

Identify when behaviour is related to an unmet need, and meet the need.

In order to achieve real change, we need to completely rethink how care and support is provided to autistic people. We need to develop a model of care and support that results in fewer breakdowns of placement and far fewer autistic people experiencing crises, restraint and inappropriate detentions in inpatient settings:

simple and necessary for basic regulation – getting away from unpleasant sensory stimuli, avoiding stressful interaction, obtaining certainty.

Behaviour has a basis in a complex mental life involving feelings, sensations, values, autistic adults of all abilities to take control of their own lives. This means genuinely shifting power from those providing the care and support to those receiving it.

This recommendation is rooted in recognition of human rights and ensuring equality for disabled adults. This approach is widely supported in adult social care, including by the Care Quality Commission (CQC, 2020). It uses concepts and values from human rights law, primarily from the European Convention on Human Rights (ECHR) as incorporated into UK law in the Human Rights Act 1998. The recommendation is also influenced by other sources which have not yet been fully incorporated into UK law, most notably the United Nations Convention on the Rights of People with Disabilities (UNCRPD) and the United Nations Convention on the Rights of the Child (UNCRC). What has been agreed to be important about all human life has been codified into these Human Rights laws.

The distinguishing feature of a rights-based approach is that it treats each human individual as a valuable person in themselves, not as a means to some other end. This fundamental tenet can be challenging to maintain in any care environment where the competing priority of managing resources can conflict and cared-for individuals can come to be seen in terms of the income they attract to the organisation. This may be especially true in care environments which are explicitly ‘for profit’. Non-profit making care environments are not immune from the commercial demands of contracting with commissioners, focus on inspection outcomes, and focus on issues like encouraging donations and reputation management

We argue that these competing priorities should be acknowledged and challenged and that care services should focus primarily on supporting autistic people to make their own decisions and take control of their own lives (ECHR Articles 5 & 8 and others, UNCRPD Article 12), a rights-based approach. For a very rough comparison of what might constitute a rights-based approach as opposed to an approach which is not rights-based, see the following table.

Human rights-based values (drawn from the UNCRPD guiding principles and articles)	**Values which are not consistent with human rights**
The opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement	Having to live in a residence and/or with people not of your own choosing
Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices. This includes both positive risk taking and protection from harms that are important to the individual (e.g., uncertainty, sensory stress, too much interaction).	Risk averse practice due to (largely unfounded) fears of liability and/or of the impact on service reputation or inspection outcomes.

Non-discrimination, including respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.	Discrimination. This does **not** just mean being nasty to disabled people. It also means disadvantaging autistic people, even unintentionally. For example, excluding autistic people from opportunities assuming they will be ‘too stressful’ (without asking the person themselves), not

is, on the face of it, troubling, human-rights based reasoning can help to work out where the priority needs to lie. Staff should consider whether the behaviour is or is likely to actually infringe another person's right to life (ECHR Article 2), or their right to privacy (Article 8) or any other rights, and whether taking steps to prevent this behaviour would infringe the service user's right to liberty (Article 5) or their right to freedom of expression (Article 10) or any other rights. Often there will be rights implications on both sides, and, in that case, a balancing judgement has to take place, in which competing rights need to be weighed up considering both the severity and the likelihood of any infringement of rights. This approach is completely in line with legal duties on care services, including adult safeguarding, duty of care, proportionality, and the Mental Capacity Act 2005 (Dunn, 2020).

It is important to note that there is no legal requirement to always make decisions that are the safest options, nor even to take decisions that are, in retrospect, correct. This includes best interests' decisions taken on behalf of an individual who lacks capacity to take a decision. If the risks are substantial to important rights, such as the right to life (ECHR Article 2), then it may be appropriate to ask the Court of Protection to resolve any disagreement in relation to a particular best interests' decision. But that does not mean that court authority is needed to empower positive risk taking at a less extreme level in a person's best interests.

Similarly, adult safeguarding is often misused or misunderstood as requiring staff to keep adults safe from all harm, when in fact this is not the case. Staff and managers need not be overly fearful of mistakes as long as they can show they have taken a rights-based approach and thought about the potential harms and benefits on **both** sides of the issue, including emotional wellbeing. Within this approach, people are protected from harm in a reasonable way that is proportional to the severity of the harm while supporting the right of autistic people of all abilities to take risks and make decisions (UNCRPD Article 12). Focussing on rights can help to ensure that autistic people are not unreasonably prevented from Iing difficulty and even harm that can be a source of excitement, interest, value, colour, learning and reflection for both the autistic people and those who support them. Case Study 9 illustrates the beneficial effect of the removal of an unnecessary and disproportionate restriction of a service user's right to liberty.

Working with, rather than against, the autistic person

> *meant I have managed to avoid getting upset in the first place. Like when*
> *support workers who work with me now no*
> *when I say I need to leave somewhere, and they help me find a way out,*
>
> Case

Case

be used, as a failure. This is because this is the same basic reality that non-disabled humans live in. Most non-disabled people never experience being restrained in their lifetime. Those few, non-disabled, people who do, experience it in the course of some extreme circumstance, such as being temporarily and severely impaired by alcohol or drugs, and/or in a situation of extreme threat, such as to remove them from the path of a fast-moving vehicle. This same standard should be applied to disabled people as well, on the basis that autistic people have the same human rights as others. Our position, as outlined above, is that there is nothing about autism which inherently causes dangerous or rights-infringing behaviours.

So, should restraint have to be used, then this rare and exceptional occurrence should prompt a staff meeting to discuss how to avoid the same happening in future, as well as acknowledging to the autistic person that this occurred not because of their disability or personal failing, but a failure of those around them to accommodate their needs. Case Study 8 describes distressing and disproportionate restraint on a service user from the perspective of an autistic support worker who has successfully avoided using physical restraint due to the relationship of trust they have with the service user. Previous attempts to reduce and minimise the use of restraint, such as the restraint reduction standards (Restraint Reduction Network, 2022), which apply to all training that includes training in how to undertake restrictive interventions, and the ‘positive and safe’ initiative (Department of Health and Social Care (DHSC), 2014), despite good intentions, have not actually succeeded in significantly shifting practice. Unfortunately there are few statistics on the use of restraint as they are not collected, however it seems clear from anecdotal evidence that various forms of restraint and restrictive practice are still widespread.

Continuing to accept, without robust and effective challenge, the assertion that some autistic people **require** restraint due to their behaviour, reinforces the underlying assumption that the problem is located within the autistic person – an assumption that we unpicked at the start of this chapter. We believe that a more radical approach is needed. Challenging the location of the problem within the autistic person requires challenging the premise that restraint (including sedating medication to manage behaviour) is a necessary response to that problem at all.

Section 3: Alternative Approaches

powerlessness. So, support to develop functional communication is likely to alleviate distress:

> *supports and enables communication throughout the lifespan. Staff need the skills, confidence and support to use and respect alternative forms of*
> *9, p. 14)*

	as a safety net during times of dysregulation
Teach developmentally inappropriate communication skills or skills that are not clearly functional, such as rote repetition of pictures	

app, and may help autistic adults who have been taught to use them in the past or show interest in utilising them in the present.

Signing is another non-speaking approach which is available to empower functional communication. Si 0 508866 .98 r/98 rongs avempowsysteunihe pr training can only go so far. When supporting vulnerable people, their overall well-being and happiness should be an important factor, as people are less likely to engage in behaviours of concern or ‘meltdown’ when they are in a happy and stress-free environment. Whilst most support systems tend to focus on reacting to behaviours which are considered ‘challenging’, our philosophy regards these behaviours not as concerns,

Ensuring that people have routine access to sensory protection strategies e.g., noise-cancelling headphones, ear defenders, sunglasses, sensory retreat/quiet room, and calming sensory equipment, e.g. weighted vest, rocking chair.
Adapting physical environments, including staff behaviour and policies (e.g., around the use of strong-smelling hygiene products), to reflect sensory challenges and preferences[8]
Considering the suitability and appropriateness of a placement for the sensory

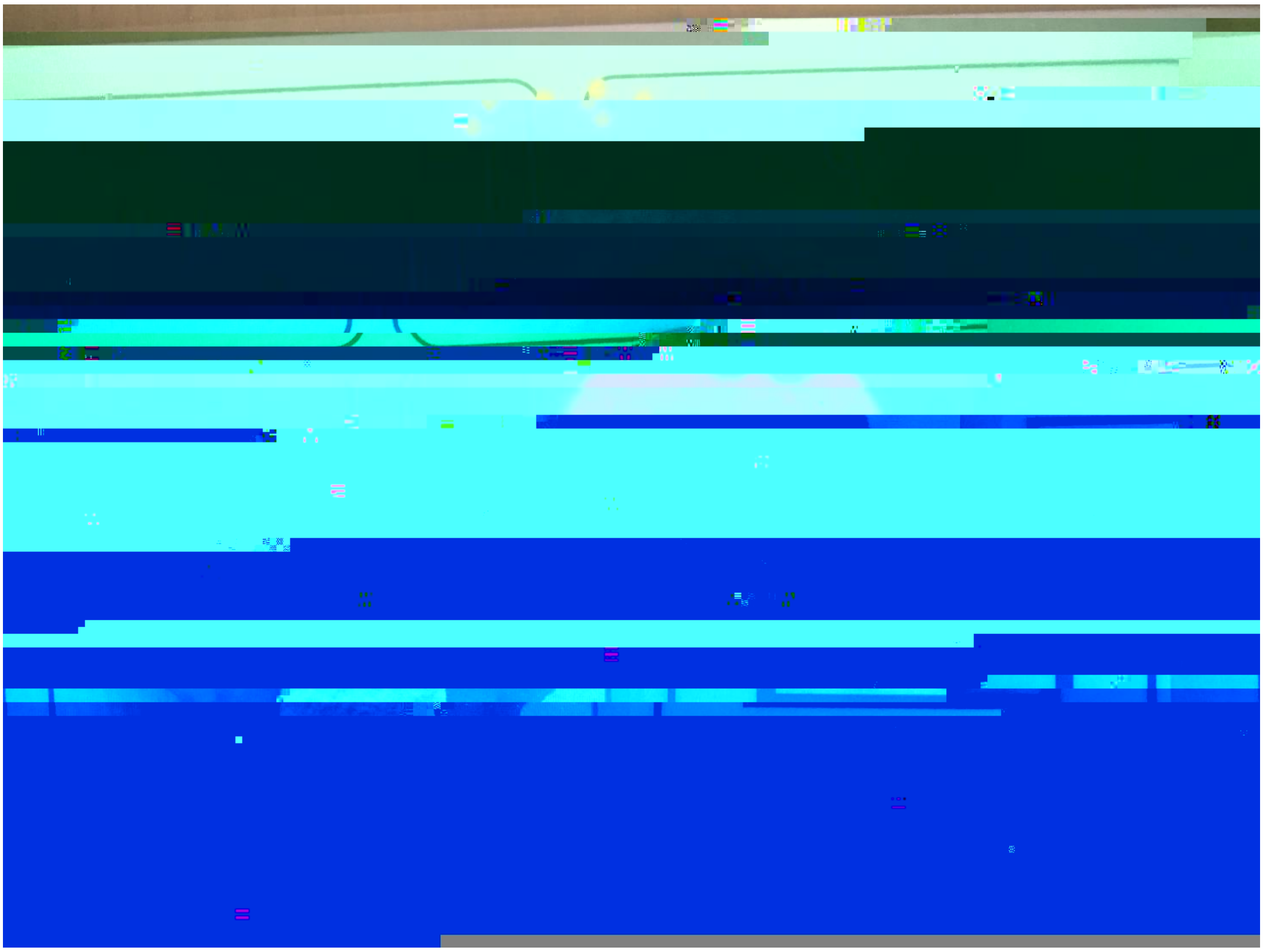

Fig. 1

Choice boards (see fig. 2 for example): with pictures of things the autistic person can choose, whether foods, or activities, or chores. This can provide some (limited) independence and autonomy.

Fig. 2

> *having the police called altogether.*
>
> Case–Study 4 - Tomas

Clinical Psychologist Bo Hejlskov Elven (Elven, 2010) describes how training staff to use a low arousal approach elicited positive responses without resorting to restraint or seclusion, using the method to ‘step away from distress and towards calm, improving the quality of life of everyone involved.’ Staff need to know the people they care for, and be aware of signs of their mounting anxiety, so that they can act to support them.

Initially, every attempt should be made to evade the distressing situation. Adults, including those who need support, have a right to make decisions about their preferred activities and environment (see section on autonomy above). If an autistic adult resists a specific activity, most often the correct response is to back down and stop trying to get them to do that thing. For situations where choice is not possible, redirecting the demand to something they may find easier to tolerate may be helpful.

Distractions and diversions may be helpful. Often an autistic person will be able to relax and regain control if they are able to engage in a preferred activity. Changing the staff member when tension has built may also ease the situation, as long as the new member of staff is also known to the person and relates well to them. The new staff are more likely to be calm, and to show the person that they can help them to feel calm too (Elven, 2010).

Autistic people often become more distressed when confronted with interaction, communication, decision-making or other demands. Where an adult is already distressed, if at all possible, back off, stop talking, and give the person space. Wait the situation out without reacting to it.

> *situation; every contact results in chaos. They need to be left alone to be able to stay calm and keep self- , 2010)*

Non-threatening body language will also help to avoid escalating fear and anxiety responses in the distressed person. Some non-threatening behaviours include:

Keep calm. In order not to spread anxiety, someone working with an autistic person must keep a controlled exterior. This is not unlike how emergency and health care workers must keep shock, distress and disgust in check to avoid distressing their patients. Try to avoid tensing muscles, direct eye contact, or other postures that may appear dominant.
Respect personal space. Their ‘personal space’ may be much larger than a non-autistic person’s. This can be achieved by physical distance between individuals, but also by avoiding standing face-to-face.
Sit down.

> *would never dare to do so. They would risk being kicked in the head. I usually say that in that case they have sat down too late. You have to sit down when the service user is getting wou (Elven, 2010)*

> Speak calmly or use no language at all. Some autistic adults are non-speaking or have limited speech, but even those who are normally fluent may lose their ability to use or understand language when distressed. In such cases, stop any attempt to communicate if it is realistic to do so. If communication is absolutely necessary, it is helpful for staff to have ready access to non-speaking methods of communication, such as wearing a key ring with a few visual signs on it that include those things that have worked in the past to help the person self-regulate.

After the situation has resolved, plan recovery time for all involved. Autistic people may need a particularly long time to recover from a highly stressful experience. Consider what has led to the situation and how it could be avoided in future. When looking for causes of distress, consider cumulative stress, not just immediate ‘triggers’. Has the individual

Meaningful life

where clear progress is being made is important to positive self-image. Discriminatory assumptions about what the person could or could not do should be avoided and replaced by gradual development and opportunities to try and experience a range of things, including experiences of failure and times when things do not go well. Engaging in activities which are meaningful and genuine and which, to the extent desired by the autistic person, contribute to society is preferable to ‘make work’ activities which simply keep the person occupied.

In order to create this sort of rights-based practice, it is necessary to prioritise staff understanding of autism from autistic perspectives. This general knowledge then needs to be supplemented with developing understanding of each autistic person’s individual strengths and difficulties, so that each individual can be approached differently, according to their needs and preferences. This approach is rooted in understanding and empathising with the reasons for behaviour, rather than observing and noting the form that the behaviour takes. It involves staff recognising that experiences and interactions which may

perspectives, work with rather than against the autistic person and are founded on the development of trusting relationships between care staff and autistic people who need support would, we believe, have the best chance of achieving significant progress in preventing and addressing the issues discussed in Section 1.

this paper should be attractive to both commissioners and care providers. Less distress amongst service users results in less need for additional staffing to ‘manage risk’. Lower levels of distress also mean happier and safer work environments for staff. Better support and pay for staff results in improvements in retention and less need for expensive agency staff. Difficult as it is for hard-pressed Local Authorities and NHS Trusts to resist

Wider support services

For high quality, ethical care and support for autistic people to be consistently realised, wider support services beyond adult social care are needed to support good health, minimise stress and distress and avoid placement breakdowns. One of these is accessible health services. Mental Health services are a particularly relevant issue, as autistic people are at much greater risk of experiencing a range of mental health needs than non-autistic people (Autistica, 2022). There is a great deal of evidence that early intervention in mental health difficulties is cost effective and reduces hospital admission (Mental Health Foundation, 2023). For autistic people, these should include:

> Commissioning community-based mental health services that meet the needs of autistic people, including autism-adapted and accessible counselling and low-level psychological therapy. These should work closely with specialist autism teams in

> Ensure that there are sufficient independent advocacy workers with specialist training in autism and learning disability available promptly when required by the statutory duties in the Mental Capacity Act, Mental Health Act and Care Act. This requires advocacy to be sufficiently well-funded for advocacy organisations to be able to fund autism-specific, as well as legal, training for advocates, and for advocacy duties, particularly under the Care Act, to be adequately resourced and fully implemented in line with the statutory requirements.

Real change requires a system-wide commitment to the principle that no autistic person requires long-term institutional care and making real, effective and measurable progress in experience, can understand what they have experienced and can alter the environment to minimise this risk occurring again and enable the person to develop confidence that they are in a safe environment. The current response to risk is invariably to add more staff (2 to 1, 3 to 1 and more), with the implicit expectation that physical restraint may be required and that more staff are needed in order to physically overpower the service user. Instead, emphasis should be placed on the quality, skills, person-specific knowledge, attitudes and consistency of the staff working with a supported individual who is experiencing distress. For a similar, or lower cost, more staff, could be replaced by fewer, more skilled staff with improved retention and consistency.

At least part of the solution to staff shortages and high turnover is frustratingly simple. If we want high quality care, we need high quality staff.

> *Supporting people with learning disabilities and complex needs is a skilled role, which can be challenging; staff therefore need to be well trained and well supported, and pay scales should reflect the importance*
>
> *2)*

To recruit and retain people with the right skills and temperament, we need to pay frontline care and support staff much higher wages than at present and provide them with high quality training and support, such as supervision and reflection time, and respectful, supportive managers. Remunerating and supporting staff well will minimise turnover and ensure retention of staff with the right values and skills. High quality supervision, management, support and training all matter, as outlined below, but pay **is** crucially relevant. Pay will often not be the prime motivator for committed care staff but

However, there are alternatives to depending entirely on large, existing care providers. One alternative option is to use Direct Payments flexibilities. This option is often overlooked because, for adults with needs for care and support, the process of being a Direct Payments employer is often too complex and onerous to undertake. An autistic adult may not have any family members who feel able to manage the responsibilities and demands involved either. However, this could potentially be mitigated by commissioners giving serious consideration to funding roles such as support brokers or case managers to provide independent sourcing and management of Personal Assistants (PAs) and a

practice[14] on the new legal requirement to train staff on autism and learning disability may provide a starting point (CQC, 2022). However, much training is strongly health-focussed discussed in this paper. Training should provide key skills to implement the principles described in Section 3 above, i.e.:

Supporting autistic people to safeguard themselves against abuse, whilst also empowering them to be autonomous adults (DHSC, 2019, Capability 15).

Using a range of appropriate tools to support and develop and support functional communication (DHSC, 2019, Capability 4).

Implementing environmental and practice changes to create structure, routine and sensory suitability to reduce causes of stress and distress (DHSC, 2019, Capabilities 5 & 7).

Support a meaningful life consisting of meaningful activities and trusting relationships. This will also include understanding autistic issues with planning and carrying out their intentions (Buckle et al., 2021) and effective approaches to prompting, as well as being sensitive to the potential for autistic people to become overwhelmed by external demands (DHSC, 2019, Capabilities 3 & 11).

In addition, key skills for staff include:

Understanding that autistic people experience high levels of stress and may have limited resources to respond to external demands (Iemmi et al., 2017).

Understanding autistic differences in identifying and communicating about physical sensations and emotional experience, and how to oroutine and encounter accessibility barriers and discrimination in the community and other services (DHSC, 2019, Capability 14).

Support, supervision and reflective practice

Training by itself is not sufficient to embed changes in practice. It is also essential that staff are well supported to reflect on their practice, individually and together:

> *through supervision and training, and have opportunities to discuss and*

prioritise the needs of service users over any risks or perceived risks to the service in terms of liability or reputation. Leaders need the knowledge and confidence to reassure staff with legal literacy around positive risk taking, best interests, and safeguarding,

Section 5: Conclusions

The distress of autistic people and the struggles of services in supporting us are not inevitable, even in underfunded services. It should be possible to create an environment which meets the needs of service users while also constituting a safe and fulfilling work environment for staff, managers and professionals.

Meeting the needs of autistic people can be achieved by adapting the physical, cultural and social environment: recognising that autistic people are a different kind of worthwhile person rather than a defective neurotypical person in need of fixing. Acceptance, and even promotion, of non-typical behaviours, lifestyles and ways of being, encompassing, for example, stimming, clothing, interest, personal space, activities interests etc are a key part of recognising that an autistic person can thrive and develop in the right environment. We need to seek: to understand the causes of stress and remove those causes as far as reasonably practical; to understand the causes of problematic behaviour and address the underlying causes rather than the behaviour or just its immediate ‘triggers’; to take advantage of the natural understanding of autism that autistic people have; to ensure access to autistic space[16] and culture; to support genuine adult decision-making and promote autonomy, not merely tokenistic ‘choices’; to understand individual communication needs, adapt to these and seek to develop functional communication; and to allow relationships to develop. We need to do all of these thing, even though they may involves risks and challenges, as well as rewards

Supporting staff, managers and professionals to provide effective services can be achieved by involving autistic people (from both within and outside a service) in the design and provision of services, by ensuring legal literacy around positive risk taking so that staff feel confident to support positive risk taking and autonomy, without fear of criticism, by understanding and practising rights-

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Appendix 1: Case Studies

It is one of the strengths and unique aspects of the National Autistic Taskforce that it is an organisation led by autistic professionals in the fields of Education, Health, Social Care and Law, both in practice and academia, who also have lived experience of receiving support and a range of support needs, for themselves, friends and family members. The authors have both a professional as well as a personal lived experience perspective on the issues in this paper. Additionally, we have collective involvement with the international autistic community going back more than 20 years, which has given us access to collective autistic knowledge, drawn from the experiences of a very broad range of autistic people right across the spectrum and explicitly including autistic people with intellectual disabilities, non-speaking autistic people, autistic people who have been detained in institutional settings, autistic people who have been deemed to lack capacity to make important decisions, autistic people considered to have complex needs and autistic people who have experienced restraint.

The case studies outlined here draw on those elements from the broad range of experienced autistic authors working together and involved in writing this guide. With the exceptions of Tomas' example (case study 4) which is published with his explicit permission, and excerpts from media reports which are in the public domain, the individuals have been anonymised and details altered to protect the individual, or individuals, concerned. In a few cases, we have constructed composite case studies based on more than one individual. None of these stories are unusual, and indeed, we feel confident that many of our readers will have encountered similar situations in practice.

Papers such as this are always open to criticism for being theoretical and removed from

company offer a different home in their portfolio, further away from where Shafiq wants to live and at a significantly higher cost to the local authority. However, Shafiq’s family strongly object, stating that the safeguarding review was at best a way to divert attention from their mismanagement of the situation, or at worst a cynical ploy on the part of the care company to increase revenue, and that they did not deserve to care for Shafiq. The Local Authority query the care provider’s ‘safeguarding’ concerns. Shafiq is placed in a supported living setting under a different provider which is less restrictive, and closer to where he wants to live. Shafiq is happily settled in his new placement.

employing support workers by means of a direct payment (which fails because of difficulties covering staff holidays and absence), and following a stressful period of insomnia after medication changes, Jian is temporarily placed with the college’s recommended service who prove able to meet Jian’s needs. They create a low arousal environment and Jian successfully lives there for two years. His parents visit him regularly.

Jian’s placement is in jeopardy because, despite his high support needs, his family are told that the eligibility criteria do not give sufficient weight to needs related to his autism and OCD, instead focusing mainly on physical disability. If he is moved, his family fear he will become highly distressed and will be at high risk of being sectioned. Given that his needs are being met in his present setting sectioning is entirely unnecessary for him.

Jian’s current placement meets h][illegible] eeate a rg I ч reets h]" lege’s

I lost a lot of years, as well, to medication especially antipsychotics.

My mum talks about the time she remembers when I was barely conscious. I remember struggling to keep my eyes open and sleeping a lot.

Over time we've learnt better ways to manage some of that now. And it's helped for me to understand why it happened and find out other ways to deal with things.

Thank you.

Case Study 5: Several Newspaper reports on one case

“Patient A is stuck inside a system the government vowed to fix in 2011, after the abuse of autistic adults with severe learning disabilities was exposed by the BBC's investigations programme, Panorama. Last year, Patient A was being prepared for discharge from hospital, but at the last minute the provider that had promised a house – and a care team to support him – pulled out. Experts such as Dan Scorer, head of policy at the Mencap charity, say that for some autistic people being confined in a unit like Patient A's can exacerbate aggressive behaviour. They become trapped in a vicious cycle of overmedication and ever more draconian restrictions of their liberty. ‘People can deteriorate because the environment is not right for them, and that can make their behaviour worse,’ Scorer says. ‘This means it is harder to get them discharged, as they continue to be seen as a risk to themselves or others.’ The answer, according to the government's own experts, is supported housing in the community.”

January 2nd, 2022)

“A young autistic man has been kept in a secure apartment made from a hospital's old file room for the past four years, it has emerged. The 24-year-old has his movements constantly tracked by CCTV cameras and is permitted contact with his family and the outside world only through a hatch in the wall. His placement sets the taxpayer back an estimated £20,000 per week. His mother, Nicola, 50, from Liverpool, says her son frequently begs to go be allowed to go home. ‘His behaviour has got worse because of where he is,’ she says. ‘He needs to be in home, not in a hospital. What care and treatment are they giving my son through a serving hatch?’”

“A young man sits in solitary, drugged and terrified, with only a PlayStation for company. But this is not prison. It is ‘care’.” (Sunday Times Investigation, January 2nd, 2022)

‘On Christmas day 2011 Nicola (Patient A's mother) had to hold her son round the waist on the kitchen floor whilst he tried to attack his 61-year-old grandmother. Desperate, she called the police, as she had been advised to do by staff at Alder Hey Children's Hospital. ‘I just needed help,’ she says, her eyes full of tears. ‘I couldn't drive him to hospital in my care because he was grabbing at the wheel. It wasn't safe.’ Nicola asked the police to approach quietly: ‘I told them: ‘Don't come with the blue lights on.’ ‘I just needed help with getting him to hospital". But the officers 'turned up in a yellow riot van' with lights flashing. Terrified, Patient A ran at the officers and was promptly restrained. 'They floored him. I was hysterical. I was crying 'Please get off him!' but they only see the behaviour, not the disability.' When they got to hospital, Patient A 'was still locked in a Perspex cage in the back of the van'. The police took him into the hospital. 'Then a doctor came with a big syringe of diazepam and pumped it into him. And that was it.'

Guardian, January 3rd, 2022)

"The family of an autistic man confined to an apartment and fed through a hatch are

as a healthy willingness to regulate his feelings, and not a danger in any way. Then she took him to car parks with slow moving traffic. Angus was clearly aware of cars and would wait for them to pass. Soon, with graded experiments, Ayla judged that Angus had sufficient awareness of physical danger to not need to be led around arm in arm at all, ever. Ayla was never inclined to chat, she did not see the point, and did not assume Angus would be interested, and thought it would likely stress him out. Angus always complied with Ayla's sparing, quiet, clear guidance. Ayla's autism meant that she found being late very stressful, and she was usually a few minutes early and would wait outside in the car until it was time to start, and Angus would leave the house at exactly the start of the shift. When she was late, she understood how Angus would be feeling, so she would text ahead with a realistic time of arrival. When late she helped Angus reduce his stress for the rest of the day by suggesting less stressful activities. Ayla has worked with Angus for many years with no significant incidents and has been able to work on developing communication and other skills.

Case Study 10: Justin and Asil

Justin is autistic adult without a learning disability and has two support workers. Justin hides in his room while his support workers are there because they do not listen to him nor take instruction well. The support workers always communicate face-to-face in real time and Justin always agrees to what they suggest because he can't process the information quickly enough to fully understand and appreciate what is being said. The support workers have been told that Justin prefers email and text but they ignore this. The support workers talk to each other and between them decide what to do for Justin. Justin has little control over his support. Justin feels powerless and that he has no control over his own space, nor can he use his support workers to help him improve his life in the way that he wants.

Eventually these support workers leave and a new support worker, Asil, arrives. Asil reads the introductory materials to the job, which indicate that Justin prefers to communicate by email. Asil always communicates with Justin about any complex issue or important decision by email. Asil never makes decisions for Justin unless the issue is urgent and Justin is too impaired to make the decision at the time. When this happens Asil always checks afterwards that she did the right thing, and she discusses with Justin what should be done to prevent the loss of capacity in the future. Justin employs another support worker. Asil and Justin discuss measures to prevent loss of control in the future. It is agreed that Asil and the new support worker must not routinely communicate with each other, and if they do they must include Justin in the communication. Asil and Justin continue to put in place systems and routines to aid communication and prevent loss of control over Justin's support.

Case Study 13 - Jasmine

Jasmine is autistic and has recently transitioned from school to a supported living placement in the community. She has high support needs and 24 hr support in her home. Support workers change shifts in the morning, afternoon and at night. As this is a working environment, support workers naturally have the lights on even on the handover to the night shift, they do their paperwork, they discuss the day's events, do whatever chores may be outstanding from the day shift, interact with Jasmin enthusiastically because they have not seen her for a day or two, they put the washing machine on, wash up, and then prompt Jasmine to begin her bedtime routine. Jasmine finds it extraordinarily difficult to settle even though she is very tired. Jasmine frequently has meltdowns, has trouble getting

Appendix 3: Sex and relationships resources

SAAIL: Supporting Autistic Adults' Intimate Lives is a participatory research project funded by NIHR School for Social Care. SAAIL has conducted an analysis of English Health and Social Care policy and guidance documents pertaining to autistic people to investigate how they represent and prioritise intimate lives. We have produced a short report, a journal article and a press release sharing these findings.

To help practitioners include intimate lives in social care assessments, SAAIL has produced this guidance and this practical topic menu resource.

Further resources:

Family Planning Association (2007) Jiwsi: A pick 'n' mix of sex and relationships education activities

Autism and appropriate touch

All about us manual *Family Planning Association*

Hartman, Davida Sexuality and Relationship Education for Children and Adolescents with ASD

Kate Reynolds Sexuality and Severe Autism

Kate E. Reynolds

What's happening to Tom (puberty)

What's happening to Ellie

Tom needs to go (public toilets)

Ellie needs to go

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