National Autistic Taskforce
Bolder Voices, Better Practice

Recognising Behaviour as Distress in Practice – a discussion paper

The National Autistic Taskforce

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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 context, productive change is possible by focussing on small, consistent staff teams instead of routinely managing risk by increasing staff numbers in anticipation of the need for restraint. We conclude that our proposals are likely to be cost-effective at the system level.

We also explore the service-level implications in terms of training, supervision and support for staff, service leadership, policies and recruitment. We argue for radical shifts in power to maximise the autonomy and control of autistic people receiving care and support. We see the need for a much greater focus on supported decision-making and, when necessary, high quality best interests' decision-making that is not unduly risk averse. We consider the benefits of seeking to develop smaller, more bespoke care providers and a

focus on seeking to recruit staff with experience and characteristics which make them more likely to empathise with autistic perspectives.

This paper offers something that has all too often been missing from debates in social care about the care and support of autistic people - an autistic perspective.

About The National Autistic Taskforce

The National Autistic Taskforce was established in January 2018 to give autistic adults a stronger voice in the decisions and directions of our own lives – especially those with highest support needs and, often, least autonomy. We draw on deep knowledge of rights and obligations, already enshrined in law but not reliably respected in practice, to increase autonomy in autistic lives. We seek to ensure autistic voices are included alongside those of families, policy makers and professionals. We seek to draw on the collective knowledge and experience of autistic adults to inform and improve care and support, especially for autistic adults whose own voices are rarely heard.

The National Autistic Taskforce is an innovative autistic-run body that aims to improve the chances for autistic people to have control over their own lives. Our role is to challenge government and local communities to deliver the support, services and opportunities that autistic people are entitled to. We have a particular focus on issues which are of most relevance and importance to 'The Other Half': those autistic people who are less able to directly advocate on their own behalf.

In April 2019, we published [An Independent Guide to Quality Care for Autistic People](#), the first independent and autistic-authored guide to what good quality care and support looks like, for autistic people of all ages and right across the autistic spectrum.

Note about the use of pronouns

Throughout this discussion paper, when referring to both autistic people and those providing care and support, the authors have sometimes used first person pronouns (e.g. us) and sometimes used third person pronouns (e.g. them). This variation is deliberate and reflects the multiple and overlapping identities of autistic people broadly, and those involved in writing this paper, as recipients and providers of care and support. This paper is written from an autistic perspective and, while fully supported by Skills for Care as points in a discussion paper, they do not necessarily represent Skills for Care's position and should not be considered guidance or advice from Skills for Care.

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 "*what is a good autistic life?*" What is normal for neurotypicals may not be acceptable for neurodiverse people who do, however, share an avid desire for autonomy as the opposite of dependence.

Caregivers aim to use meaningful interactions to tease out people's preference and dreams; to find out and use what works for each person – not try to get the person fit some unreachable criteria.

This paper embraces the full range of autism spectrum disorder (from learning disability to erstwhile Asperger's). It is pragmatic. And supported by the most recent references. I wish it had been available when my autistic son was living in the community.

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 when some 'care' environments become abusive – Winterbourne View, Mendip House, Whorlton Hall and many more.

Approaches focussed on behavioural intervention have been developed, and strongly promoted to government and the health and social care sectors. From an autistic perspective, much of the focus within health and social care services seems to be on managing the 'problem' of autistic 'behaviour'. Many years of extensive plans, starting with Transforming Care and leading to the current Building the Right Support Action Plan (Department of Health and Social Care (DHSC), 2022), despite aiming to promote good quality support in the community, appear to have been based on the perceived need to manage and contain 'behaviours'. These 'behaviours' are seen as inherent to the autistic person and a matter of 'complex needs'. They are assumed to require specialist 'intervention' – generally from medical specialists and often involving the inappropriate use of psychotropic medicines to keep people 'safe'. Multi-disciplinary teams, consisting of non-autistic health and social care professionals focus time, effort and professional skill on managing 'behaviour'.

And yet, despite all of these interventions, specialists and multi-disciplinary teams, the persistent long-term detention and restraint of autistic people in inappropriate placements continues. Recent data suggests that 61% of inpatients with 'barriers to discharge' are autistic (Ince *et al.*, 2022). Some 'behaviours' are 'managed' but little really changes.

In this paper we shine a light on some of the assumptions which underpin existing approaches. We highlight how common approaches can be expensive, time-intensive and ultimately ineffective in actually improving the situation. Moreover, we argue, common approaches can also cause distress and harm to the autistic people involved, and merely contain rather than resolve problems.

We propose a fundamentally different approach, founded on rights, and seeking to promote the quality of life of autistic people, rather than focussing on 'behaviours'. We highlight the role of factors external to the autistic person in causing 'behaviours' and suggest an approach which focuses on building empathy with autistic perspectives. We explore the barriers and opportunities such an approach faces in the current social care climate, and consider the implications for the social care workforce.

We draw on many sources in exploring approaches, including those found in the education sector. However, this paper is primarily focussed on social care provision for autistic people and, to a lesser extent, healthcare for autistic people. Wherever funding comes from, we would hope to see less of the day-to-day care of autistic people (even those with the most 'complex' needs) being led by and founded in the medical model of healthcare services and much more of the day-to-day care of autistic people being led by and founded in the ethos of social care. Social care support is best placed to take forward the rights-based model of support outlined in this paper and support all autistic people to live ordinary lives in our communities.

An autistic point of view

One purpose of this paper is to explore what 'success' means from an autistic perspective as well as the perspective of services. Interventions in current use in social care have, generally, been developed by non-autistic people. By contrast, this paper is written primarily by autistic people with a range of personal and professional experience and with varying levels of support needs for us, our families, our close friends and our community. It is informed by more than 20 years of international autistic community and a wealth of collective knowledge and understanding which comes from having an autistic perspective. Many of the case studies in this paper directly express the point of view of an autistic person, either the user of a service themselves, or an autistic person working with the autistic service user. While our knowledge is necessarily incomplete, the authors of this paper collectively have a wide experience and knowledge of the variety of autistic experience, including what it feels like to be the subject of interventions. The authors also have knowledge and experience of providing environments in which autistic people are a natural fit, and in which problematic behaviours do not occur to any significant degree.

What are we offering in this paper?

In this paper we survey and critically examine the existing landscape of interventions and approaches, in which there are to be found many positives we can support. We draw on previous work done by autistic people on this subject. We ground our approach in law so that services can have confidence that the approach we outline is entirely consistent with

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

Introduction

It is clear, as set out in Section 1, that, despite pockets of good practice, much of current practice in health and social care services is not working well for autistic people (Ince et al., 2022; SCIE, 2023). In this section we will discuss how a fundamentally different approach can be conceptualised, based on recommendation 7 of the National Autistic Taskforce's An Independent Guide to Quality Care for Autistic People (NAT Guide) (NAT, 2019): **Recognising behaviour as distress**, which recommends the following practice for care providers:

- Treat the use of any physical intervention, pharmaceutical control of behaviour or any other forms of restraint as failures and seek to create a service free from physical interventions and pharmaceutical control of behaviour.
- Don't blame autism. 'Challenging' behaviours are not an inevitable consequence of autism.
- Don't label people as 'complex', seek to understand and empathise with their perspective.
- Do not remove choice and control from an autistic person.
- Challenge proposals/decisions to remove an autistic person from their local community.
- Modify the environment to meet needs, look for underlying causes not just triggers.
- Work with, not against, the autistic person – supporting them to manage stress and recover from distress.
- Avoid focussing on behaviour 'management' at the expense of meeting needs.
- Accept and accommodate autistic behaviours that do not infringe on the rights of others.
- Support autistic people to find practical ways to meet their needs which minimise overall harm to themselves and respect the rights of others.

- 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:

> *"Supporting people in community settings … may well require a different way of understanding and managing the concept of risk. Tackling misconceptions about autism … Discrimination and inequality are also both likely to contribute to heightened levels of anxiety, with the danger that someone might get trapped in a never-ending cycle of uncertainty, anxiety, and concerning behaviour." (Iemmi et al., 2017, p. 34)*

The DHSC *Core Capabilities Framework for Supporting Autistic People* (DHSC, 2019, p.16) identifies the values that staff working with autistic people should have:

a) Demonstrate positivity, recognising the strength and abilities of autistic people.

b) Gain an understanding of each autistic person's perspective and personal preferences.

c) Be patient and really listen to what is being communicated by the autistic person.

d) Recognise the presentation, behaviour and identity of autistic people – and respond with respect and compassion, without judging them or labelling their behaviours in unhelpful ways.

e) Value and acknowledge the experience and expertise of autistic people, their families and support networks, enabling choice and autonomy and protecting people's human rights.

f) Act with integrity, honesty and openness, seeking to develop mutual trust in all interactions with autistic people, their families, carers and communities.

g) Be committed to integrated current and future care and support through working in partnership with autistic people, teams, communities and organisations.

h) Value collaborative involvement and co-production with autistic people to improve person-centred design and quality of services.

i) Recognise, respect and value autistic people's differences and challenge negative stereotyping.

j) Take responsibility for one's own learning and continue professional development and contributing to the learning of others.

Social model and location of the problem

To most non-disabled people, disability appears to be a problem or deficit that makes someone unable to function in a 'normal' or typical way. This is called the 'medical model of disability'. Naturally enough, the way to help people with disability conceived in this medical way is to treat them to make up the deficit, or fix the broken bit, just as you would try to treat someone with a broken leg by fixing the leg to get them back to normal. While that approach is quite appropriate for some conditions, including some that often occur alongside autism (such as epilepsy), it is not appropriate for autism itself, for two reasons:

(1) Autism cannot be corrected or changed. It is impossible to turn an autistic person into a non-autistic person. Autism is essential to a person genetically, neurologically, physiologically and psychologically. Removing someone's autism would be to destroy the person, as observed most famously and powerfully by Jim Sinclair in his seminal presentation "Don't Mourn for Us" (Sinclair, 1993):

> *"Autism is a way of being. It is pervasive; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person — and if it were possible, the person you'd have left would not be the same person you started with."*

Few people (autistic or not) truly want to be someone else.

(2) There is nothing intrinsically bad about being autistic. Autism does not entail suffering in and of itself, and the autistic way of being is valuable in its own right. The first part is relatively simple; most people basically value who we are, and autistic people are no exception.

The question then arises as to why, if there is nothing wrong with being autistic, autistic people experience so many difficulties with social inclusion, employment, behaviour, and other issues? An explanation for this is provided by the 'social model of disability'. Yes, autistic people are disabled, but that is not solely because of something intrinsically 'wrong' with them. Autistic people are frequently, even usually, disabled by having to live in an unsuitable environment, just as a fish is disabled on dry land. There is nothing wrong with the fish. The fish does not need prosthetic wheels and breathing apparatus, counselling to reduce its stress and anxiety, nor does its attention-seeking behaviour need to be ignored. It needs to be back in the water where its needs are met.

Similarly, there's nothing wrong with an autistic person who is distressed. What's wrong is that the autistic person is frequently in an environment with chronically high sensory inputs for prolonged periods, many sudden changes and transitions, very high degrees of uncertainty, a huge burden of interpretation, baffling mix of expectations, frequent uncontrollable touching, no means of escape, and so on. A medical model approach would seek to change the autistic person, perhaps through a reward system and/or medication, to tolerate the environment like everyone else. Medical models also tend, in assuming that 'behaviour' is an inherent part of a condition such as autism and/or learning disability, and even while stating that they are seeking to reduce restraint, to ultimately normalise and

provide justification for restrictive interventions and reactive strategies, including restraint, seclusion and segregation (see for example NICE, 2023; Hollins, 2023). A social model approach would instead seek to design environments that are accessible to everyone, not just those who have the most common types of needs. As a fish is in water, so is an autistic person in autistic space[1] and culture, for example at Autscape[2]. This approach does not threaten the individual's personhood or subject them to aversive conditions, thus it is arguably more ethical. Case Study 9 provides an example of the impact on autistic person's behaviour of this sort of fundamental change towards providing an accessible, non-distressing environment.

There is an intrinsic element of impairment to most disabilities that will not be completely eliminated by favourable environments. However, modification of the environment, including the social environment, is particularly effective for difficulties seen as 'behavioural'. Environment modification should nearly always be the primary 'intervention' to respond to distressed behaviour in autistic people. Case Study 5(a) describes the negative impact and cycle that results from inappropriate environments and case studies 3(b) to 3(d) describes changes in environments and their effect on an autistic individual.

The basis of 'behaviour'

Before any intervention can be applied effectively, the underlying reasons for the behaviour must be understood. Sometimes behaviour is treated as if it just popped out of nowhere for no reason. Sometimes 'behaviours' are assumed to be inherent to autism itself, which risks normalizing distress. Sometimes it is recognised that desires and goals are the causes of behaviour, but often the goal is not respected, as if the person is unreasonable in having a will of their own, and that if this will is indulged there will somehow be a slippery slope and they will become out of control. Sometimes motivations based on typical assumptions are wrongly attributed to neurodivergent people, such as that behaviour is intended to annoy or manipulate the other person. In these circumstances, the presence of a neurodivergent worker or advisor can be extraordinarily beneficial to help in interpreting such behaviour. Case Study 1 illustrates the negative and harmful spiral that can occur when behaviour is poorly understood and misattributed.

Expression vs. communication

Some progress has been made towards recognising behaviour as a source of information about how the person is doing. This is often phrased as 'all behaviour is communication'. While this is preferable to treating behaviour as a problem without any internal driver, it is less often recognised that behaviour is not necessarily goal-directed or communicative. Often, behaviour is just expression of feeling, as it is for anyone. For example, laughing, crying, or stimming[3] do not necessarily have any communicative intent, but this behaviour still carries important information about a person's inner life. Some autistic goals are very

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[1] See https://nationalautistictaskforce.org.uk/about/autistic-space/ for an explanation of the term 'autistic space'
[2] http://www.autscape.org/about/concept
[3] Stimming is short-hand for sensory stimulation behaviours, such as rocking or flapping

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, beliefs, impulses, desires, and so on. Just because we have stopped someone's behaviour by imposing external pressures does not mean that these feelings go away. Training people to hide all this by altering their behaviour will ultimately fail, as the behaviour is likely to resurface at some later point, or find another means of expression. Keeping it suppressed is hard work, and unnecessary, like stopping a high-pressure leak without turning off the stop-tap. Instead, if we focus on meeting people's needs, acknowledging feelings, supporting people to realise their aims (where doing so will not infringe rights), not only will autistic people have far better outcomes from their own point of view, the causes of problematic behaviour are removed, and therefore the behaviour itself has no reason to occur. Case Study 3(f), Case Study 4 and Case Study 9 all show how behaviour changes positively when needs are understood and met.

Distressed (challenging) behaviour

These principles apply even to 'challenging behaviour', which usually arises from distress. In our experience, autistic people are only more likely to behave dangerously when exposed to environments, practices or people which do not work well for them – this shifts the focus to prevention and puts the onus on services and staff to adapt to autistic needs. Research suggests that the 'fight, freeze or flight'[4] reaction, which is a normal, human neurobiological response to perceived threat, is more frequently and readily triggered in autistic people (Caldwell, 2014). This reaction causes an 'autonomic storm' (Ramachandran, 2011) which has both physical and psychological effects.

> *"When I get overwhelmed or distressed, I tend to hit my head or bite my hands and this can lead to the police being called, and ending up being restrained by them and others, and eventually into hospital." Case Study 4 – Tomas*

Case study 3(a) describes 'challenging behaviour' caused by distress. Case Study 5 contains newspaper reports of what can happen when an autistic person is highly distressed. Case Study 9 describes 'challenging behaviour' caused by inappropriate support.

The relevance of human rights as a foundation

The NAT Guide (2019) places a heavy emphasis on the development of autonomy of autistic people of all abilities in all care settings. The NAT recommendation goes considerably further than conventional person-centred practice in recommending that care and support services should not merely promote 'choice', but meaningfully empower

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[4] Or additional trauma responses such as 'fawn' or 'flop' (PTSDUK, 2023)

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 giving disabled children access to expert subject teachers, failing to make adjustments for an autistic person to be able to enter a building and attend an appointment.
Full and effective participation and inclusion in society, including access to interpersonal relationships.	Discriminatory exclusion e.g., assuming that supported individuals are not interested in/cannot possibly access wider society (e.g., voting, joining user-led groups, accessing peer support, being educated and informed about wider issues, being an active citizen). 'Protecting' people from emotional attachment and the extra vulnerability that can result. Prioritising organisational needs over the needs of service users.
Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.	Othering – viewing people who need care and support as fundamentally different from themselves (e.g., as a problem to be managed, as 'suffering', as 'having behaviours' or as a source of self-worth for those supporting them).
Equality – this includes respect for uniqueness of individuals, prioritising an individual's values.	Normalisation – focusing on an external idea of a 'normal' life and prioritising inspection outcomes, commissioning preferences or family perspectives (for adults).
Equality of opportunity – this includes opportunity for individuals to contribute to society and be valuable in ways that are important to the individual.	Assuming disabled people are of little use and must always be the passive recipients of help. 'Including' people by focusing on 'normal' ways of being included, without considering the individual's strengths and desires.

A human rights-based approach is consistent with a person-centred approach. However, being person-centred is not sufficient to achieve a rights-based approach.

A compass on a starless night

A human rights-based approach can be a very useful and reassuring way for staff and managers to work out how to act ethically when in doubt. If an autistic person's behaviour

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 ling 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

> *"Although there's been lots of bad times, there's also been lots of times when people have taken the time to listen and be understanding. It's meant I have managed to avoid getting upset in the first place. Like when support workers who work with me now notice I'm getting overwhelmed or when I say I need to leave somewhere, and they help me find a way out, meaning that I don't get too distressed, and it avoids having the police called altogether." Case–Study 4 - Tomas*

> *"a genuine collaboration with an autistic person to seek to identify and resolve or manage the underlying source(s) of distress". (Dunn, 2020, p.205)*

Fundamental to this approach, consistent with Human Rights as a foundation and recognising behaviour as distress, is the principle of allowing autistic people to be ourselves and accepting us for who we are. This includes accepting and accommodating autistic behaviours that do not infringe on the rights of others (Bradley & Caldwell, 2013). It may seem odd to have to state a principle of allowing people to be who they are, for in most settings in society this is widely taken for granted. And yet there are beliefs, therapies, educational and care approaches commonly in use in health, social care and education settings where autistic people are not allowed to be who they are, but are encouraged to stop doing harmless things that they enjoy and that bring them comfort, in an attempt to minimise the autistic part of themselves and to accentuate what is described as normal behaviour.

For example, autistic behaviour often includes stereotypical movements, described in the diagnostic criteria for autism (DSM-5) as:

> *"Restricted, repetitive patterns of behaviour, interests or activities, repetitive motor movements, use of objects or speech." (American Psychiatric Association, 2013)*

The diagnostic criteria do not say that these things are wrong, merely that they are an observable trait of autistic people. Autistic people who are able to communicate about our lived experience of autism explain that these actions, often known as stims or stimming, are their ways of self-comforting. They are therefore a very useful self-soothing mechanism, in itself an invaluable life skill. Unless these stims infringe the rights of others or cause or risk causing the person serious harm, which the vast majority do not, they should be not only accepted but encouraged as sensible coping mechanisms, rather than being seen as negative behaviours to be eliminated. As Mills & McCreadie (2018) say:

> *"You can't change underlying neurological differences by getting rid of behaviours. Even if it was desirable, effective intervention that changes the behaviour of another human being is elusive. This is evident from the host of unsuccessful approaches and continuing need for so-called 'specialised services'. Changing the behaviour of another human being by 'doing things to them' is incredibly difficult. On the other hand, an understanding of one's own beliefs, behaviour and coping skills through guided self-reflection and self-awareness is achievable. It is more likely to result in a better and healthier relationship for the worker and for the person receiving support. In this, an understanding of the impact of the psychological and physiological factors at work is critical and will enable a more effective and healthier mind-set and outcome." (p.8)*

The approaches described in (the next section of this paper) are fundamentally at odds with any methodology that looks to remove 'autistic deficits' by changing behaviour.

Restraint as a failure

A human rights-based approach requires resorting to restrictive physical or chemical intervention, or indeed any form of restrictive or coercive intervention, in only the most exceptional of circumstances, and to regard each time that it does, exceptionally, need to

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

Introduction

In this section, we show how the standards, values and principles of a human rights-based approach to care and support for autistic people can be applied, and are already being applied in some settings and through some approaches, in practice. These approaches were selected on the basis of their compatibility with the conceptual principles set out in section 2 above. We identify four overriding principles which emerge from these approaches:

- **Develop and support autonomy**. This includes supporting and developing decision making skills and providing opportunities to make decisions, including making mistakes and learning from them.
- **Develop and support functional communication** Supporting and developing functional communication is essential for effective expression of autonomy in any but the most basic aspects of life. Not being able to communicate will, preferences, wants, needs or views is very frustrating.
- **Reduce causes of stress and distress**. The behaviours which lead to placement breakdown are almost always a result of unmanaged stress leading to distress. Reducing and managing stress in the physical and social environment, and by minimising uncertainty will inevitably result in happier, calmer autistic people.
- **Support a meaningful life**. For most people, a good life requires more than just being calm and happy. A life should include activities and relationships that are meaningful to the individual. This applies no less to autistic people with any level of

disability or support needs. Trusting relationships are part of a meaningful life, and the development of trusting relationships also supports autonomy, stress reduction, meaningful activities, and all aspects of good care.

Develop and support autonomy

Autonomy is a core element of a rights-based approach and the first recommendation of the NAT guide. This is because autonomy, control over one's own life, is so fundamental an experience that most human adults take it entirely for granted and barely even notice that they have it. When autonomy is compromised, humans typically experience distress – for example at being trapped, imprisoned or unable to assert their own wishes. Autonomy is at greater risk of being compromised when an individual has needs for care and support, because the experience of being dependent on care or support from others risks shifting power in the relationship, away from the person being supported and towards those providing, managing and commissioning care and support.

Autistic adults with and without learning disabilities, even those with the most profound disabilities, should be fully recognized as adults. Staff should never demand compliance, but rather recognise and respect full adulthood in those they support, even when those individuals may need a lot of support to effectively realise their autonomy by making choices and exerting control.

At its most basic, autonomy means having real choice and control over decisions that affect your life. This includes:

- Choosing who you live with
- Having control over your physical space, including decoration, furniture, equipment and being able to ensure that these accommodate your sensory needs
- Having an influential voice in who is recruited to support you and selection of particular staff who support you
- Not being required to live in or attend communal settings or any other activity unless you want to be there
- Empowering self-management strategies such as:
    - interaction-free access to sensory protection or stimulation
    - encouraging/permitting repetition and sameness
    - developing skills in requesting and obtaining information to increase certainty and predictability
    - using timetables, schedules, planners and ensuring easy access to these
    - supporting the person to develop systems and rules which work for them and ensuring that those supporting them respect these rules and help to maintain these systems
- Effective supported decision-making, including support for the development of decision-making skills and experience (Hennessy, 2023)

Case Studies 10 and 3(f) illustrate how respecting a service user's preferred method of communication can transform the control they have over their life.

Promoting autonomy is entirely consistent with the Mental Capacity Act and case law on the meaning of 'best interests' (See for example DY v A City Council & A NHS Trust [2022]).

> *Physical health and safety can sometimes be bought at too high a price in happiness and emotional welfare. The emphasis must be on sensible risk appraisal, not striving to avoid all risk, whatever the price, but instead seeking a proper balance and being willing to tolerate manageable or acceptable risks as the price appropriately to be paid in order to achieve some other good – in particular to achieve the vital good of the elderly or vulnerable person's happiness. What good is it making someone safer if it merely makes them miserable? (Mr Justice Munby in Local Authority X v MM [2007])*

Autistic adults need to be empowered to take positive risks and their rights as adults respected, whether or not they have capacity to take their own decisions. Positive risk taking has a secure legal basis and social care services need cultural change around understanding what duty of care really means and how unlikely liability in negligence is if positive risks taken to benefit the individual were to result in harm. Legal literacy is essential to fully implement a rights-based approach – particularly of the Human Rights Act[5], Mental Capacity Act, duty of care and what 'safeguarding' really means, as set out in the Care Act Statutory guidance:

> *Organisations should always promote the adult's wellbeing in their safeguarding arrangements. People have complex lives and being safe is only one of the things they want for themselves. Professionals should work with the adult to establish what being safe means to them and how that can be best achieved. Professionals and other staff should not be advocating 'safety' measures that do not take account of individual well-being. (DHSC (2023) para 14.8)*

All staff working in care need to really understand that 'best interests' and safeguarding mean focussing on a person's balanced rights, not prioritising welfare at all costs.

Develop and support functional communication

For those autistic people who do not have a practical, reliable means of functional communication, developing functional communication should be a priority. Not being able to communicate your will, preferences, wants, needs or views is very frustrating and limits the expression of choice and control. If staff can find a way to help autistic adults to communicate their needs and wants, this is likely to alleviate feelings of frustration and

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[5] Which applies in full to regulated services under s.73 Care Act and is likely in many instances to apply to unregulated services on the basis that they are fulfilling a function of a public nature (that is the Care Act s.18 duty to meet needs delegated to the provider by a local authority)

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

> *"A good service for autistic people is one which actively and effectively supports and enables communication throughout the lifespan. Staff need the skills, confidence and support to use and respect alternative forms of communication." (NAT, 2019, p. 14)*

Case Study 11 describes an ongoing process of supporting an autistic person with a learning disability to develop their functional communication in order to improve the choice and control they have.

SCERTS (Social Communication, Emotional Regulation and Transactional Supports) (Prizant *et al*, 2007) is a communication approach written entirely for use with autistic people. The section on social communication helps practitioners to recognise what level of communicator (or 'partner') any particular autistic person is, and how to respond to and develop that level of communication. Whilst it is designed for autistic children, many of the principles of SCERTS are just as pertinent for autistic adults, particularly those with reduced language skills and understanding. As an exemplar, we have listed here the "Do's and Don'ts" of interpersonal support in the SCERTS model, which sets out how autistic people should be treated[6]:

Do not . . .	Do . . .
Focus on compliance, respondent training, and passive learning	Encourage initiation, spontaneity, and active learning
Teach communication skills exclusively in one-to-one teaching	Support the development of a person's communicative abilities with different partners in varied social contexts
Ask too many questions or give too many directions	Comment and expand upon a person's initiated communication and focus of attention
Persist in making a person "say the whole sentence" or focus on correct grammar	Respond to and expand on functional communication to support a person's self-confidence as a communicator
Remove visual supports as a person begins to speak or becomes familiar with a routine	Continue to use visual supports to enhance a person's communicative attempts, to build language, to support attention and to serve

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[6] We have substituted the word 'person' for the 'child' used in the original SCERTS Do's and Don'ts

	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 or reading flash cards	Support the development of communicative skills that are developmentally appropriate and that will have an immediate impact on a person's life in everyday activities
Focus primarily on labelling and requesting	Support a person's ability to communicate for a wide range of purposes
Teach fragmented skills in a repetitive, drill-like format outside the context of meaningful and logical activities	Support a person's communicative growth in meaningful and purposeful activities that can be understood and make sense for the person.
Make social-communicative activities stressful for a person (e.g., by withholding food or preferred activities until the person speaks)	Create motivating activities with many needs and opportunities to communicate, with modelling and support provided as needed
Ignore, punish or extinguish echolalic speech or other unconventional communication	Respond to echolalia or unconventional communication specific to the functions that it serves for a person and model/teach more conventional means
Ignore a person's emotional regulation and emotional state or dismiss a person's behaviour as non-compliant if he or she is dysregulated.	Always monitor a person's emotional regulation and make the necessary accommodations or modifications to support emotional regulation, attention and learning.

The Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) approach (Mesibov *et al.*, 2004) is another educational approach developed for autistic children, but which is just as applicable to adults in social care contexts. TEACCH recommends using visual structures to organise the environment and tasks when supporting autistic people and this approach is likely to help many autistic people to communicate and to increase their functional vocabulary.

The routine use of objects of reference, photos, diagrams and written information, alongside speech, are basic adaptations and adjustments that can make communication significantly more accessible for autistic people across the spectrum (Dunn, 2020, p.33-35). There are many specific visual communication tools which can be used. Symbol-based systems, such as PECS (Picture Exchange Communication System), Talking Mats, Boardmaker and others, can be made available in paper/card form or on a tablet using an

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. Signalong is a system that is consistent with and can be developed into full British Sign Language, whilst Makaton is a signing system which is in widespread use within the Learning Disability community. Individuals may also develop and use their own signs spontaneously and this should be both encouraged and taken as an indication that supporting the learning and use of recognized signs from Signalong or Makaton is likely to be worth exploring with the person.

Reduce causes of stress and distress

Stress reduction is a vital part of a human rights-based approach to working with autistic people since it is a humane response to distress caused by a highly arousing environment. While behaviour-focussed approaches do often consider the immediate antecedents or 'triggers' of behaviour, we see a need to go much further to identify deeper causes and focus more broadly on stress reduction. While there are a number of approaches which may be loosely grouped as 'low arousal' approaches (see for example Elven, 2010; McDonnell, 2022), the primary focus of these is most often on the way that those working with and interacting with autistic people present themselves. We argue that stress arises largely from sensory issues, unpredictability or uncertainty, and social demands, and that each of these provides opportunities to limit stress, which in turn limits distress.

Should all of these fail, and the autistic person becomes distressed, a calm approach which empathises with the autistic person's perspective and experience can de-escalate the situation quickly and safely without the need to resort to physical intervention. The key elements of these approaches are highlighted in the NAT Guide (NAT, 2019, p. 34):

> "A good service for autistic people is one where staff try to put themselves in an autistic person's shoes, get to know each person as an individual, and maintain a relationship with the person based on trust and respect. A good service for autistic people works with them to modify their environment to meet their needs and minimise distress. A good service for autistic people offers regular opportunities for 'quiet' or downtime (but does not use this punitively) and offers regular opportunities to meet sensory stimulation needs."

They are also identified amongst the core capabilities health and care staff are expected to have for working with autistic people:

> "Seek to develop and promote preventative strategies that work with the autistic person to minimise the need for reactive strategies." (DHSC, 2019, Capability 8 Tier 2)

Studio 3, who specialize in low arousal approaches, "believe in the power of positive psychology when supporting individuals with additional needs. Physical intervention

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, but as signs of distress which can be pro-actively prevented by anticipating their causes"[7] (McDonnell, 2022). Over-arching frameworks which are consistent with reducing stress have been developed by various providers, including the National Autistic Society's SPELL (Structure, Positive approaches and expectations, Empathy, Low Arousal, Links with Parents) framework and Scottish Autism's attempts to embed low arousal approaches in services (Harkins, 2015). However, reliable implementation of these frameworks in day-to-day practice still has some way to go. Case Study 12 illustrates how the combined stress caused by sensory overload, unpredictability and social demands can result in the breakdown of a placement, and how finding solutions can require going outside of 'normal' approaches.

Reduce sensory stressors

In its diagnostic criteria for autism, DSM-5 (APA, 2013) refers to hyper- or hypo-reactivity to sensory input, which can lead to significant confusion and distress, and which can be to an extent ameliorated by reducing arousing factors of the environment. One of the NAT Guide's (2019) recommendations is to "Tackle environmental and other stressors" and it draws on the report of the National Autism Project which highlights:

> "The very nature of autism leaves people exposed to much higher risk of stress from external demands, and a more frequent and severe experience of it. […] Tackling misconceptions about autism, improving awareness of how environmental factors and aspects of the built environment can easily become major stressors and providing appropriate structures and support are all necessary responses." (Iemmi et al., 2017, p. 34)

Genuinely empathising with and seeking to meeting an autistic person's sensory needs is likely to reduce distress:

> Autistic people's sensory needs and preferences should be accepted and understood; they should be embraced as being a fundamental part of the autistic person. The focus should be on the environment; what is available in terms of activities, food and drink, exercise, walks outside, and to staff responsiveness to help out and reduce distress rather than the autistic person's behaviour. Sensory experiences should be understood from the perspective of autistic people ourselves (Bogdashina, 2003).

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[7] 'Causes' here refers to going significantly beyond the immediate antecedents or 'triggers' of distress, to understand the deeper underlying causes of stress and distress in the autistic person's life.

Staff should be aware of an individual's sensory needs, and proactively offer sensory solutions when they see the first signs of sensory stress. If sensory strategies that an individual finds helpful in alleviating distress are noted, they can be applied again by other staff, or by the autistic person themselves. Ideally this work should be overseen by an Occupational Therapist with autism and Sensory Integration training, who can write sensory profiles and programmes which are then carried out by care and support staff. However, it is possible for effective support to be provided by staff working directly with the person, experimenting, and engaging in sensory 'play' with them to learn their needs/likes/dislikes. Sensory approaches should be incorporated into routines (e.g., alternating activities that provide movement with those that are seated), and sessions to meet sensory needs proactively provided for in care and support planning. All sensory equipment, for protection, stimulation or calming, as well as spaces for the person's individual needs, must be accessible without any interaction or communication (e.g., having to communicate with a member of staff to ask for something) being required and should not be restricted or limited in any way.

The PAVE (Promoting Autism Favourable Environments) approach is accepting and adapting to the unique neurobiology of autistic people through environmental adaptations (Bradley & Caldwell, 2013). They recommend a systematic review of the circumstances that give rise to stress for the autistic person and supporting the individual to develop a cohesive sense of self and the daily environment. "Essentially it views the world from the perspective of the person with autism, rather than imposing our non-autism frame of reference" (Bradley & Caldwell, 2013, p. 18)

The TEACCH approach (Mesibov *et al.*, 2004) includes many aspects which create an organised and low-arousal environment to reduce perceptual and motor difficulties autistic people frequently experience. This is likely to include using quiet and calming colours; staff speaking in quiet voices; clear visual delineation of areas, with quiet areas, group areas and social areas; and a lack of unnecessary visual distraction. This is in contrast to many social care environments which often include displays and noticeboards for the benefit of staff, which may be very cluttered and chaotic, and are, often, designed with practical and cost issues and/or with the aesthetic preferences of visitors as the foremost consideration.

In practice, an informed approach to autistic sensory experience should include some or all of the following:

- Having an up-to-date sensory assessment/profile for the individual, and ensuring all staff refer to it frequently.
- Avoiding practices based on desensitisation, acknowledging that painful stimuli are likely to remain painful, despite warning and repeated exposure
- Ensuring that people have routine access to sensory stimulation opportunities which meet their needs (e.g., outside space, trampoline, soft play/sensory rooms) and include time for these in care plans.

- 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 needs of the individual, acknowledging that some autistic people may not be able to function in some sensory environments (including, for some, living with other people at all or even living in an urban environment)
- Using checklists written by autistic people to consider potential sources of distress, including undetected health problems and experience of abuse

Case Study 13 describes a successful implementation of a low arousal approach to reducing stress in a supported living environment which involved noticing and altering sensory demands.

<u>Reduce the stress of uncertainty</u>

Many autistic people are particularly sensitive to the stress of uncertainty. Providing structure and routine, to the extent compatible with the individual's choice, is well established and widely recommended good practice with autistic people. An organised, low-distraction and predictable environment can help to compensate for processing difficulties and give meaning to an otherwise confusing and stressful environment (NAS, 2023).

In addition to sensory aspects of the environment, TEACCH also includes the use of clear visual supports for communication and the provision of information. These are likely to include:

First/Then or Now/Later boards (see fig. 1 for example): a very simple visual device to help autistic people to know what will happen next. . For example, a picture on 'Now', of making a bed, and a picture on 'Later' of looking at books or researching on the internet a topic of interest to them.[9] Though it's important that these are not used as a form of coercion / reward but to explain planned activities or natural consequences (such as the need to travel to get somewhere).

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[8] When carrying out a project in a residential care home for autistic people, autistic members of the project team immediately noted creaking doors and numerous other sensory challenges in the environment and reported these to the staff. The staff had not previously noticed these issues.

[9] It is important that these are used to communicate factual information about what will happen. They should not be used in any way that seeks to offer reward or coercion.
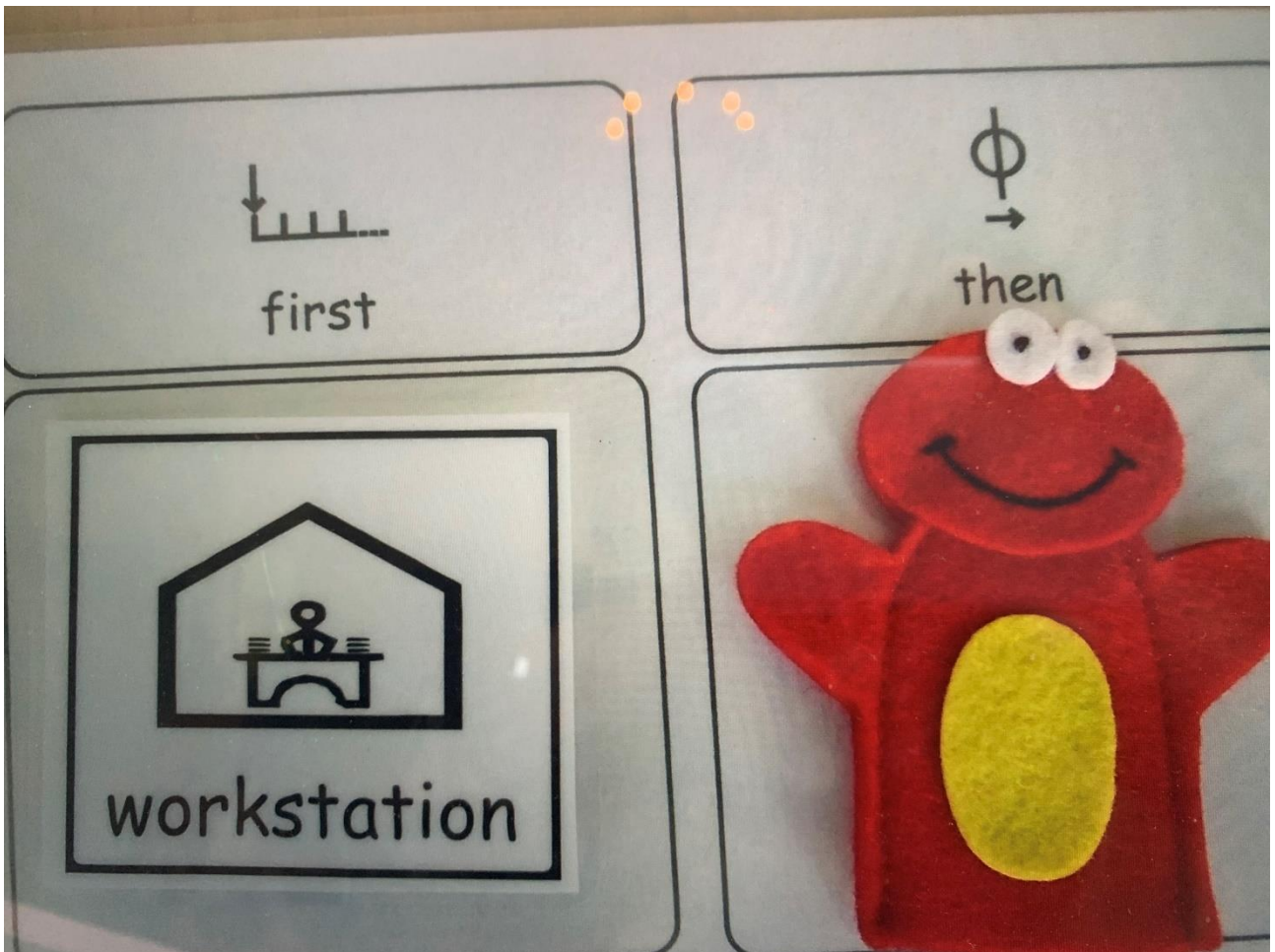
Fig. 1

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

Schedules (see fig. 3 for example): a list of what is planned to happen in the course of the day, using photos and/or symbols where needed to help understanding.
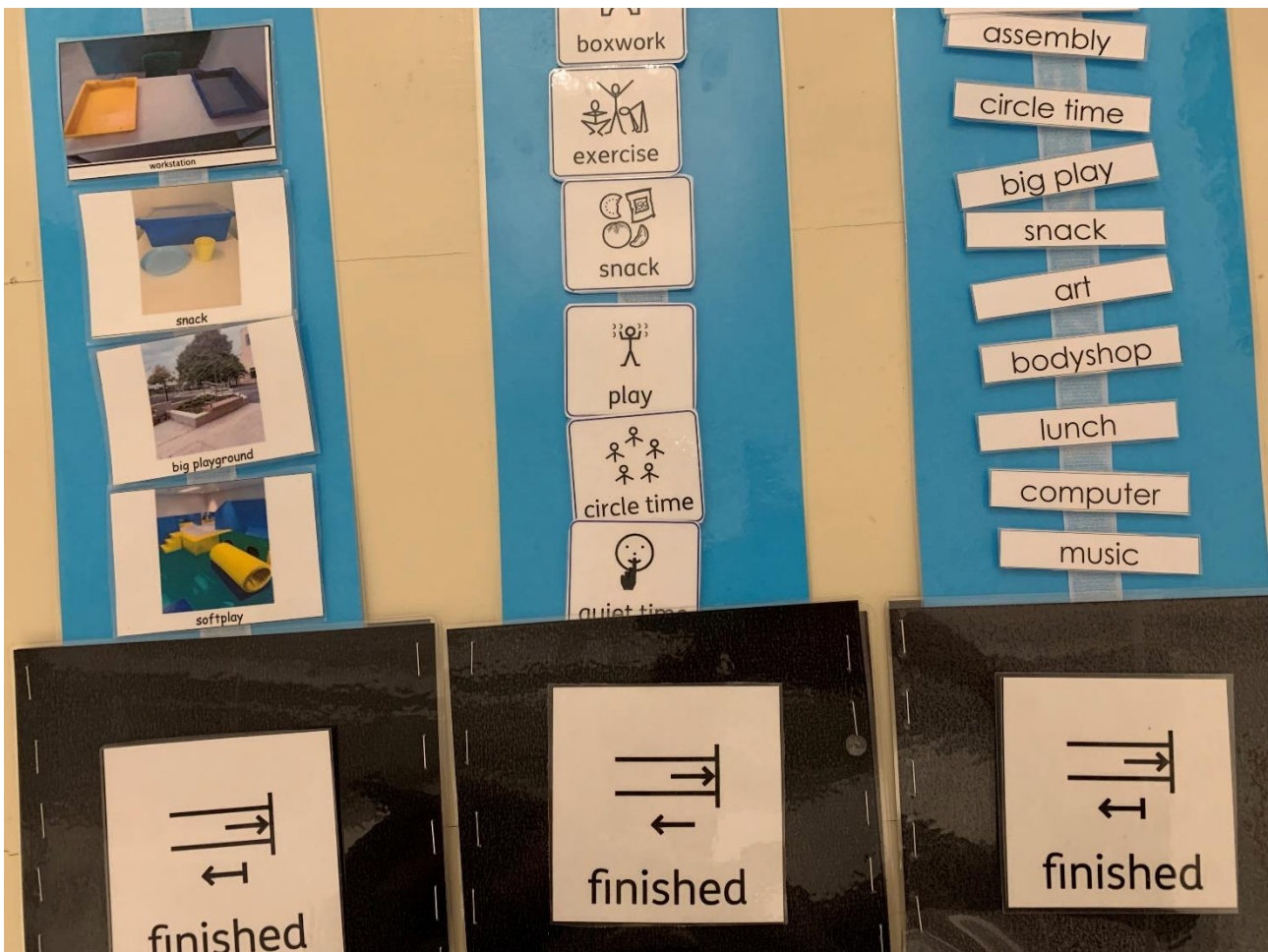
Fig. 3

For some people, just having this to hand as a visual reminder is helpful. For others, it may be useful to have the list made up of photos or icons that are attached to the list with Velcro, so that the person can take the icon – perhaps of brushing teeth – and place it in a 'finished' pocket when done. Both research and experience indicate that this supports autonomy, the feeling of independence, and through understanding the list, it helps the person to know what they can expect, when things might end, and when preferred activities will be coming up.

These approaches can, and should, be developed over time to enhance and develop the person's understanding and knowledge. For example, adding a 'yesterday' column and moving the current days' activities into it. Once that is established, 'tomorrow' can then also be added and the daily schedules moved along between the columns to support learning of the concepts of yesterday and tomorrow. Over time, as appropriate to the individual's developing understanding, this can and should be further developed towards a weekly planner and even the use of diaries, calendars and year planners. All too often, such development is never undertaken simply because of an assumption that the person is incapable of learning, and without sufficient efforts to use different teaching methods and trying repeatedly over time.

<u>Reduce social and emotional stress</u>

A vital part of reducing stress is the way staff behave with those they are supporting. The goal is to avoid the raised stress that causes the fight, flight or freeze response, with raised levels of adrenaline, raised heart-rate and faster breathing. This requires staff to be trained to empathetically observe the people they care for, so that they can be alert to any indications of increasing stress levels and act to support the person to avoid the source of stress (which might be the presence or behaviour of the staff themselves), and to access stress reduction strategies that work for them, which may include being left alone, staff stopping talking, stimming, engaging in or talking about a passionate interest (Phung *et al.,*2021).

The Synergy approach[10] (Mills & McCreadie, 2018) focusses on the behaviour of staff, rather than that of the autistic people being supported and is underpinned by evidenced practice derived from established psychological and physiological theory. A short, intensive practical course focused on mind sets and behaviours of workers supported by mentors has been demonstrated to promote a well-being culture and a changed narrative across a range of services. The program takes a 4-stage approach:

1. Self-awareness and self-control: The instinctive brain v the thinking brain. The importance of narrative
2. Verstehen: Deep understanding
3. Learning theory: Role Models and mentoring
4. Understanding stress and physiological arousal

Synergy demonstrates that:

> *"an understanding of one's own beliefs, behaviour and coping skills through guided self-reflection and self-awareness is achievable. It is more likely to result in a better and healthier relationship for the worker and for the person receiving support. In this, an understanding of the impact of the psychological and physiological factors at work is critical and will enable a more effective and healthier mind-set and outcome." (Mills & McCreadie, 2018, p.8)*

Autistic people can be sensitive to 'catching' emotions from those around them, sometimes called 'emotional contagion' (Engelbrecht, 2022). Autistic adults are also likely at times to become anxious and scared for reasons that are not always apparent to staff, due to our different autistic perceptions of the world around us. If staff who are caring for them display panic or fear, then this can increase the anxiety and fear of the autistic person, worsening the situation and increasing the autistic person's distress. If, by contrast, staff are trained and led to behave in a calm, understanding, low arousal way themselves, then the autistic person is more likely to be able to become calm and to trust staff to support them to recover from their distress.

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[10] https://www.atautism.org/

The SCERTS model has already been mentioned in the context of communication support and it can also be applied to support emotional regulation rather than trying to change behaviour out of context. Within the SCERTS model, in order to teach understanding of emotions and their regulation to autistic people, The Queensmill Trust[11] (a specialist education provider supporting autistic children and young adults) uses Zones of Regulation. This, or similar tools, can be used to support autistic people to better understand and communicate about our own emotions. Most powerful in this is being able to support autistic people to recognise our own signs of distress and know what we can do to help ourselves to return to a calm state, and who they can turn to in order to help them with this. Having some sort of reminder of what has helped us in the past, a walk outside in the garden for instance, or going to a quiet room, or listening to music, will help cue us in to our own self-soothing strategies.

Using trained staff to observe closely and to notice early signs of distress and potential risk-factors for these, enables a focus on supporting emotional regulation rather than changing behaviour. Support strategies can then focus on ways of managing the environment and creating structure and certainty, to better support an autistic person's needs.

Autistic people can express pain and/or distress differently. Low arousal approaches support staff to learn the individual's 'language' around pain and/or distress. With that understanding, stressful situations can be avoided, and staff can be "vigilant, to know signs of mounting distress in each of our adults, and to respond to the situation before it escalates" (Elven, 2010). Such a response may be by adjustments in the carer's behaviour, what is on offer, or the level of support. The more staff are trained and practised in this way of working, particularly in times of escalating stress, then the less likely will be times of severe distress for autistic adults, and life will be easier and more enjoyable both for them and for those who work with them. This can also include recognising when particular staff are or are not a good match for supporting a particular individual. Case Study 9 describes how a change of support worker, to one who was more able to empathise with the autistic person's perspective, drastically reduced the supported person's social and emotional stress.

Responding to distress

All of the approaches we have described should, if applied well, dramatically decrease the occurrence of distress for an autistic person. However, no strategy is perfect, or will be perfectly applied, and no life is completely without distress. When an autistic person becomes distressed, communication challenges are exacerbated and the approach by those surrounding the autistic person can make the difference between successful de-escalation and the police being called.

> *"Like when support workers who work with me now notice I'm getting overwhelmed or when I say I need to leave somewhere, and they help me*

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[11] https://www.thequeensmilltrust.com/

*find a way out, meaning that I don't get too distressed, and it avoids
having the police called altogether.*

I haven't been in hospital for a few years now." 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.

> *"Some service users cannot manage any contact at all in a troubled
> situation; every contact results in chaos. They need to be left alone to be
> able to stay calm and keep self-control" (Elven, 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.

> *"Sometimes when I tell this to staff, there is someone who says they
> 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 wound up." (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 indicated previously that they find something distressing? What have you done about it? Avoiding a recurrence is as important as dealing with distress when it happens. Where the cause is difficult to fathom, observation may yield clues. Spend more time with the individual (if they will tolerate it) when they can't articulate what is driving their decisions or reactions. The clues need to be picked up by careful observation going back further than the immediate antecedents. Detailed timelines need to be built and deductive work undertaken, using autistic-created checklists[12] as a guide. If this demands more than the skills of the staff working with the individual, then it needs to be worked on by someone with the knowledge and skills needed. However, that should not automatically be a medical practitioner. It is particularly important to consider the benefit of consulting other autistic people, in addition to friends and family who know the person well, in trying to empathise with and understand the individual's perspective, as discussed further below.

<u>The compatibility or otherwise of Positive Behaviour Support (PBS) and functional approaches to 'behaviour'</u>

Positive Behaviour Support (PBS) and, more broadly, functional approaches to analysing and intervening in 'behaviour' are widely believed by health and social care commissioners to be the only 'evidence-based' approaches to supporting individuals with behaviours which challenge – many of whom are autistic people, with or without accompanying learning disability (NHS England (NHSE), 2015, 2017; National Development Team for Inclusion (NDTi), 2010; NICE Guideline, 2023). High level endorsements of PBS, as in the Transforming Care Model Service Specification (NHSE, 2017), have had a knock-on impact on care commissioning by creating and reinforcing this impression. For example, Wiltshire's adult social care Market Position Statement (as required by the Care Act) states *"We will expand provision of services such as Positive Behaviour Support for young people with behaviour that challenges and their families."* (p.3). Cheshire East Borough council's current procurement exercise for providers cites "*the nationally recognised self-assessment for Positive Behavioural Support*" (p.32, Appendix A1) as a way to meet the requirements of the Transforming Care Programme.

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[12] See for example https://wearelikeyourchild.blogspot.com/2014/05/a-checklist-for-identifying-sources-of.html

While there are some autistic individuals, parents and family members in favour of PBS, a significant proportion of the autistic community, many other parents and family members have concerns and feel that PBS is not aligned with the priorities and values of autistic people as outlined in this paper. PBS has its origins in Applied Behavioural Analysis, which has been the subject of substantial critique from the autistic community due to its fundamental focus on reducing behaviours of concern, essentially training autistic people to 'mask', rather than empathising with autistic perspectives (Milton, 2018).

Evidence about PBS is mixed and there are several studies that challenge the robustness of Positive Behaviour Support as an evidence-based approach to supporting people. . One recent cluster randomised controlled trial concludes that PBS is *"insufficient to achieve significant clinical gains beyond [treatment as usual] in community intellectual disability services"* (Hassiotis *et al.*, 2018), although this study has been criticised for not examining the direct practice occurring in the services. Another study, including a large autistic sample, concludes a *"lack of clinical effectiveness for PBS"* (Strydom, 2020). An earlier systematic review and meta-analysis found evidence of impact on staff and reduction in challenging behaviour, but "*no evidence was found for Positive Behavior Support training having a positive impact on quality of life for service users"* (MacDonald & McGill, 2013). In a recent "State of the Nation" report on PBS in the UK, the authors share their concerns about the *"indiscriminate use of PBS"* and notes the risk of "*PBS being associated with attempts to deny neurodivergent people a part of their identity or to conform to "societal" or neurotypical preferences"* (Gore *et al.*, 2022).

The approaches advocated in this paper involve moving away from behaviour management approaches. There are at least three reasons for this:

(1)   Behaviour management approaches result in a focus on the behaviour itself, rather than the underlying distress the autistic person is experiencing. The immediate, apparent 'trigger' for a behaviour, is not necessarily the genuine source of distress, particularly where cumulative stress is a factor. This also means avoiding focussing on counting and recording sheets to monitor behaviour, and on ABC analysis, as this promotes a focus on the behaviour itself over the person's experience.

(2)   Behaviour management approaches tend to imply that the behaviour was volitional, that the autistic person engaged in this behaviour wilfully and that they had a choice to do so or not so, when this is unlikely to be the case. (Ming *et al.*, 2004; see also Buckle *et al.,* 2021; 2023; Welch *et al.*, 2018).

(3)   Behaviour management approaches imply that 'behaviour' is a necessary and inevitable consequence of autism, which risks legitimising autistic people's distress in inappropriate care environments (NAT, 2019, Recommendation 7) (Dunn, 2020, p.209-10).

Meaningful life

Low arousal, in the approaches discussed in the previous section, does not mean 'no' arousal. Everyone should be exposed to activities and interactions that they enjoy. Again, good communication with the autistic person to the extent possible, accompanied by observation by staff, is crucial here to identify when the environment is becoming too overwhelming.

Engagement in meaningful activities

> *"Everyone needs to feel fulfilment by engaging in activities which are of interest to them. Nurturing our interests by engaging in activities such as music, sport or hobbies can help us achieve a sense of 'flow' – contented immersion in an activity. For people in supported living, engaging in immersive activities is especially important as it can help to reduce stress and promote happiness." (McDonnell, 2022)*

Staff should be aware of each autistic adults' passionate interests, so that they can support them to engage in them on the internet, through books, and activities. This immersion in an interest leads to calm contentment for autistic people.

> *"Having meaning and purpose in our daily lives is crucial for cultivating happiness and well-being. Focusing on creating meaning can have positive implications both for service users and their supporters, helping individuals to become more motivated and fulfilled in their work and their lives." (McDonnell, 2022)*

This should include, where the individual may or does enjoy doing so, supporting individuals to participate meaningfully in their interests in the wider outside world. For example, volunteering at a heritage railway rather than merely looking at pictures of trains, or joining a retro computing club, not merely looking up information about computers. Sometimes, perhaps often, this will require advocacy and challenging discrimination to achieve, as well as strategies to cope with accessing challenging environments, that the person might wish to access. It also requires regular review to ensure the person can experiment with different activities or change their interests.

Positive approaches and expectations should be based on careful assessments of where the autistic person is functioning at present and what would be helpful and pleasurable for them to learn next.

> *"Focusing on positive emotion by recognising achievement, recording happy moments, generally being positive and optimistic about the future is a key factor in a person's overall happiness." (McDonnell, 2022)*

However, it is important for this positivity to be real and not forced or artificial. Treating autistic adults like children and patronising them with excessive positivity does not enhance happiness or respect rights. Genuine moments of joy should be celebrated, and autistic people allowed to spend time on enjoyable activities, avoiding everything being focussed on 'therapy' and improving at things the person finds challenging. Spending time doing things that the person can excel at and progressing at activities

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 keeping with the low arousal behaviour described above, it is possible to be positive and optimistic without being loud and overwhelming.

> *"Achievement has been shown to produce positive response in our psychological well-being, and this is no less true for individuals who may have some difficulty in accomplishing their goals. By nurturing environments in which supported individuals are able to achieve small daily goals and broader life goals, we can push these individuals to thrive and flourish, bringing meaning into their lives and boosting self-esteem."* (McDonnell, 2022)

Trusting relationships

An approach built on the foundations outlined in Section 2 requires building trusting relationships between autistic people and those providing care and support. On a practical level, trusting relationships allow staff to recognise stress before it becomes distress, as described above. This cannot be done unless staff genuinely respect and value autistic people for who they are, which includes assuming that 'behaviour' is not inherent to autism and supporting the person to learn any skills they may need to manage their needs and feelings. Trust depends on staff behaving in ways which demonstrate that autistic people are valued and respected, including being honest and transparent. This means avoiding easy 'white' lies for staff convenience, such as telling someone they are going on a 'holiday' when moving placement, claiming that a valued staff member is 'on holiday' rather than that they are seriously ill, or sheltering them from the realities of discrimination by telling them that an activity would be 'too stressful' for them, rather than being honest that other people are scared of people who seem too different and sometimes exclude people.

This also extends to how staff talk about, as well as to, autistic people. Words such as 'complex' are often applied to autistic individuals (Brenner *et al.,* 2018). However, these words are typically a signal for more time, more information and/or more resources. Perhaps the paperwork that was supposed to have come with the individual was incomplete or very sparse; perhaps the staff feel that they lack the skills to respond to a particular need; perhaps there is insufficient space, money or other resources to meet the person's needs effectively; perhaps there is a dispute between public bodies about who is responsible for funding a person's needs. If so, these issues need to be made explicit and prompt steps taken to rectify them (University of Birmingham, 2023), rather than allowing the issues to be hidden and loaded on to the autistic person through terms such as 'complex', 'high support needs', 'dysregulated' and 'behaviours'.

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 seem innocuous to them, such as banter and small talk, can be overwhelming and distressing for an autistic person. Focus on trust and human rights leads staff, in working with autistic people, to recognise the distress an autistic person can experience, to empathise with their perception of the world and to actively avoid the situations and experiences which cause distress. When staff behave in this empathetic and trustworthy way towards autistic people, it enables people to feel safe with those providing care and support, to trust them, and to increasingly turn to them for help and support.

> *"Putting oneself in the shoes of the other — taking an inside-out perspective demands that we really know ourselves and listen attentively to the other. By standing back and being in touch with our own mind-set and in control of our responses we can begin to learn to listen and understand the world of the other person." (Mills & McCreadie, 2018)*

Seeing the world through the eyes of autistic people is essential in working with them (McDonnell, 2022). Empathetic and trust-based practices are also identified amongst the core capabilities health and care staff are expected to have for working with autistic people:

> *"Consult the autistic person and their family/support regarding what causes distress or anxiety in order to understand and respect an autistic person's perspective." (DHSC, 2019, Capability 8 Tier 2)*

> *'As human beings, we thrive off our relationships with other people and for autistic people this can be a particularly challenging area of life. This model proposes that nurturing strong and healthy relationships with those around us is a significant contributing factor towards our overall happiness.' (McDonnell, 2022)*

This level of empathy will always be easier when we listen to autistic people who are able to tell us their experiences and listen, by observing and reflecting, to those autistic people who aren't able to tell us their experiences. If we observe what autistic people do when they are happy, when they are distressed, what they enjoy, what interests them, we are beginning to empathise with them and will be better able to help them and to earn their trust (Mesibov *et al.*, 2004). Staff must be able to really listen to, show respect for autistic people, to value them and have fun with them. Case studies 8, 9, 10 and 11 all describe the benefit experienced by an autistic person when a support worker develops this sort of trusting relationship.

Intensive Interaction is an approach devised by Dave Hewett (Intensive Interaction Institute, 2022) to encourage and develop social communication in people who have yet to develop pre-speech skills. It is generally used with autistic people who also have

significant learning difficulties, have limited ability to communicate or may be socially very withdrawn and isolated. It is a way of communicating playfully with autistic people who use sounds or gestures or some repetitive speech, responding to them so that they know that we value their communicative intent, and showing them the purpose of social communication as a way of interacting with other people and the enjoyment that can be had from reciprocal exchanges. It follows the person's lead, helping them with turn-taking, and communicating with them in a way they understand.

The principles of intensive interaction can be applied more broadly to work with autistic people across the spectrum. The fundamental approach is one of empathy with and attunement to autistic norms and ways of communicating, which is consistent with the development of trusting relationships between autistic people and those who support us.

<u>Safeguarding</u>

One factor that can lead to high levels of restrictions and constraints placed on the lives of autistic adults receiving care and support, is that many autistic adults are potentially vulnerable to abuse and exploitation and can also be at risk of (often inadvertently) behaving inappropriately towards others (see Dunn, 2020, Chapter 8). However, this reality should lead to additional support for autistic people to learn how to stay safe and where to turn for support and help if experiencing abuse or exploitation, rather than restrictions on the autistic person's rights and freedoms. So-Safe (So Safe, 2023) is a comprehensive package of materials which can support staff to develop the communication and self-protective skills of autistic adults to enable them to protect themselves more effectively, avoiding unnecessary constraints on autonomy and freedom. The materials are available in written and pictorial form, whichever is more accessible to the autistic person. The materials can be used to show each autistic adult their own network of known people whom they can trust and turn to for help. It shows steps to relationships and ways to move into intimate relationships in a safe way. There are also a wide range of other resources available for actively teaching autistic people how to stay safe and develop healthy relationships (see Appendix 3).

Many of the specific tools mentioned in this chapter were developed with children and in educational contexts and may need further work to be fully adapted to the context of adult social care. However, all of the approaches mentioned above could potentially be used in adult social care environments.

Conclusions

We believe that focusing on developing and supporting autonomy and functional communication; reducing causes of stress and distress; and supporting autistic people to have a meaningful life and trusting relationships would move practice closer towards achieving the recommendations of the NAT Guide (2019), particularly recommendation 7. We acknowledge, however, that this would require significant shifts in current practice. Achieving a shift of this type is likely to face some system-level issues, and these will be discussed in Section 4. Nevertheless, approaches which are fully human rights-based, which are supported by autistic people and respect the value of autistic experience and

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.

Section 4: Workforce Implications for Social Care

System-level implications

There are substantial systemic barriers which impact on the quality and nature of support for autistic adults. Currently, action taken is often far too late and is reactive rather than preventative. There is a need for services to be proactive and agile to prevent placement breakdowns and the sort of inappropriate admissions and use of restraint and restrictions discussed in Section 1.

Cost effectiveness

A setting where 'challenging behaviour' is common, and physical intervention is also common, will be an expensive one. The cost of injury, trauma and damage to all concerned, and those around them, will be considerable. The experience of The Queensmill Trust, having adopted similar methods to those described above to largely eliminate the use of restraint, is that the setting becomes less expensive to maintain. This also chimes with the potential for 'diagonal accounting' savings highlighted by *The Autism Dividend* (Iemmi *et al.*, 2017). The potential cost effectiveness of the proposals outlined in

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 redirecting any savings to other services, investing some of the resultant savings in resources that support the model, such as fresh and new resources for adults to use for their leisure and interests, meaningful activities, clean and attractive surroundings, improved pay, support and training for staff, are also likely to enhance service reputation and staff retention, in addition to the obvious benefits for supported individuals.

Commercial and commissioning issues

The commercial pressures of the adult social care market can actively encourage care providers to prioritise the needs of their organisation above the needs of the individuals supported (CHPI, 2016). The long-term under funding of adult social care means that most providers are in a constant battle for survival and find it difficult to offer high enough pay to recruit and retain sufficient staff, let alone equip them with autism-specific skills and training and the stable support needed to sustain committed social care staff in key roles (Institute for Government, 2023). Local Authorities, faced with diminishing budgets and despite the requirements of the Care Act, are tending to 'ration' care (Institute for Government, 2023) and there is evidence of a focus on personal care needs to the exclusion of vital support for autistic people (and others with needs for care and support) to have good and fulfilling lives (Autism Alliance, 2023). Commercial fears around care provider reputation risk issues not being raised with commissioners until a placement is already unsustainable. Due to the current systemic lack of care provision and high levels of unmet need (Institute for Government, 2023; Autism Alliance, 2023), it is much easier for an organisation to give notice on an individual's placement and swap a 'challenging' service user for someone who is easier to look after, than it is to really change the approach of the organisation, particularly if this would require better trained, supported and more highly paid staff. However, this readily results in those individuals who care services find more 'challenging' entering a cycle of their placement being at perpetual risk. Repeated short-notice changes of placement, combined with high staff turnovers, mean relentless causes of distress, leading to further placement breakdown, as autistic people experience constant changes of support staff and shifts from provider to provider. This increases the likelihood that they will end up in more secure services or a more restrictive environment when, inevitably, they reach a moment of crisis where no provider can be found to provide a community placement. In the current market, with care services a scarce resource, commissioners can be placed in the position of needing to avoid challenging the decisions of providers who give notice on 'difficult' people, in order to secure placements at all. These tensions too often lead to poor quality care and act in ways which increase the risk of inappropriate hospital admissions (Hatton, 2014; Autism Alliance, 2023).

<u>Wider support services</u>

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 each local area.
- Considering the development of pathways for particular groups of autistic people, e.g., those with eating disorders. This could involve screening for autism in eating disorder services.
- Contributing to and developing community-based crisis services that meet the needs of autistic people when placements or family situations breakdown or acute distress is being experienced, to provide an alternative to detentions in ATUs and on psychiatric wards.
- Ensuring that all staff in Child and Adolescent Mental Health Services (CAMHS) and Community Mental Health Services are aware of their responsibilities under the Equality Act and are aware that it is discriminatory and likely to be unlawful to use autism as an excluding factor when making decisions about access to support for people with mental health conditions.
- Developing a clear pathway for young autistic people to access mental health support that begins at referral for an autism diagnosis. This should be focused on preventing the escalation of need.

More broadly, a preventive and rights-based approach to care and support for autistic people would include the following systemic changes:

- Working with commissioners to create individualised settings for people in the community before, as well as when, they are needed – the Care Act already requires local authorities to engage in 'market shaping' (although the resources needed for local authorities to effectively do this are lacking). This also requires sufficiently knowledgeable commissioners[13].
- Improve practice around Community Care and Treatment Reviews by providing autistic people and their families with greater clarity on their rights and entitlements to them.

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[13] Training is available via the Learning disability and autism version of Principles of Commissioning for Wellbeing Level 5 Qualification, see https://www.skillsforcare.org.uk/Developing-your-workforce/Qualifications/Level-5-Commissioning-for-Wellbeing-Qualification.aspx

- 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 each and every service towards all autistic people living in the community (NAT, 2019; UNCRPD Article 19). All parties in the adult social care system should have a responsibility to challenge decisions or proposals which involve removing an autistic person from their local community (NAT, 2019, p. 33; Milton *et al* 2016) in order to ensure such proposals are always subject to the maximum possible scrutiny and professional challenge. Services need to be routinely challenged as to whether they have really assessed the impact on the person's right to respect for their home and family life when considering terminating a placement.

Sector-wide staffing issues

Staffing issues and instability are currently widespread in all social care services. Inevitably these are also a significant factor in producing poor practice in care for autistic adults:

> *"Reviewers found that staff were under pressure because of a high staff turnover, lack of appropriate training and high use of agency staff. In addition, we found poor staff cultures, and there was often a disconnect between the multidisciplinary team and frontline workers." (CQC, 2020, p. 13)*

Importance needs to be placed on a stable and consistent workforce – which requires workforce planning and adequate funding, including to raise pay. Jian's mother (Case Study 3(a) and 3(b)) recognises that the care package for her son works for him because of the care and skills of the staff who provide for him. She says she is 'humbled' by their care and love for him. She said, "Care is such a skilled job, but the money and status it attracts does not reflect this.". Care providers need to do all that they can to minimise any unnecessary change and disruption to staff whom the autistic adults know and trust, and also to allow for the continuance of the same consistently high level of autism-specific skills and understanding. If services are to provide care which is autistic-person centred, as recommended in the NAT Guide (NAT, 2019, recommendation 3), services must "ensure a minimum of staff variation and match staff to autistic people on the basis of shared interests and mutual compatibility wherever possible." (NAT, 2019, p.17).

Where autistic people have previously experienced abuse, restraint and/or inappropriate placements, they may have experienced trauma (Mehtar & Mukaddes, 2011; Rittmannsberger *et al.*, 2020) and need staff who know the detail of their history and lived

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 of the work they do." (MacDonald, 2018, p.42)*

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, along with consideration of other factors, such as shift patterns, locations and staff travel options, pay does need to provide an adequate standard of living. Staff who can't pay their bills or afford food or childcare will not be able to sustain providing good care and support. Of course, the level of wages is not merely a decision made by the care provider themselves, but is significantly influenced by the rates local authorities and the NHS pay for care, which are themselves primarily a result of political decisions taken at central government level.

Nevertheless, even without substantial increases in central government funding for social care, much could be done by commissioners seeking to redistribute existing resources from funding large numbers of expensive agency staff, the profits made by some providers in the industry, and insistence on increasing staff numbers working with an individual to 'manage risk' towards bespoke packages focused on funding small teams of well paid, highly skilled staff directly supporting autistic people.

Size and structure of provider

In our view, large care providers are not necessarily the most suitable organisations to provide appropriate and bespoke care for autistic adults, as they can be limited in the degree of flexibility they can offer and it is often difficult for an adult's family and friends to be closely involved in their support. Much can be done, even in large services who have their own pressures and interests, to support autistic people better and, consequently, reduce 'challenging' behaviours by shifting practice in the directions highlighted in this paper.

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 personal budget on behalf of the supported adult. Another possibility is that of PAs directly supporting the service user to manage and employ their PAs. This requires due consideration to the conflict of interest issues and how such arrangements can work for adults who may lack capacity to fully direct their own support; nevertheless it is a potentially workable model which has been achieved in a number of care co-operatives (see below).

Direct Payments creates person-centredness inherently as a result of its structure. The supported individual is not merely the recipient of the support, but also the commissioner and overseer of that support. As a result, there are fewer conflicts of interest (such as the reputational, regulatory and commissioning priorities discussed above). There are also simply fewer people involved and no hierarchy distant from the service user. Support workers working directly for a service user, their relative or a case manager overseeing the package on the supported individual's behalf are freer to develop a unique trusting relationship tailored to the needs of that supported individual, rather than being driven by organisational pressures, general policies and the instructions of managers.

In many areas of the country, there is an uncomfortable gap between a Direct Payments-funded bespoke package, as outlined above, and 'off the peg' placements from large providers. However, in-between options do exist and could be developed further. Individual Service Funds can offer many of the flexibilities of Direct Payments, but, at present, these are too often rather tokenistic and managed, remotely from the supported individual, by the same large care provider organisations.

Further innovative options exist. The 'small supports' programme (NDTi, 2022; Lancashire, 2022) aims to support local areas to create the best environment for small supports to emerge and flourish and to work with existing and emerging small supports organisations to develop and share approaches. Organisations have to commit to a set of principles, which include the person having as much control as possible and that control increasing. People choose where they live and who supports them. Small Supports Organisations don't withdraw support or sell services on to larger companies. They stay relatively small and don't grow by more than 3-5 supported individuals per year. These principles are rights-based and accord with the principles set out in this paper.

Another model of care is that of care co-operatives. One approach involves user members (the supported individuals), employee members (the PAs), and supporting members (anyone who doesn't fit into the first two groups e.g., parents/family members of user members). The co-ops are kept small – generally less than 10 user members in each, sometimes only 1. As a result, each individual member is able to exercise a voice and all

members are involved in governance on a one member, one vote basis. Employee members are a small, self-managing team, who are delegated a lot of trust to deliver care, but also experience flexible employment benefits, greater autonomy and job satisfaction. User members know all the employee members which enables PAs who normally support one user member to provide cover without significant disruption and change (North West Care Co-operative, 2022).

However, these types of services are not currently available in all areas and demand greatly outstrips supply. Strategic, long-term thinking by commissioners, taking account of the potential long-term cost savings through diagonal accounting, is needed to encourage growth and development of these types of options at a level to meet demand.

<u>'Professional behaviour' culture and its impact on staff-service user relationships</u>

Good support workers empathise with and care about the people they support. However, personal connections between staff and users are widely discouraged as 'unprofessional' and on the assumption that such blurring of boundaries poses safeguarding risks to supported individuals. However, as described earlier, where service users and support staff develop trusting relationships   these unique and sophisticated relationships can be an important space for development, good mental health and autonomy. The reality of autism and learning disabilities is that often support staff are supported individuals' only friends and are the source of vital emotional connections. That is a fact that should be recognised and accepted, even with the complications and issues that may come with it (Williams, 2021). Boundaries can be important for the prevention of abuse, but there is no reason legally why policies and conventions designed to prevent abuse need to be taken to such extremes that they prohibit healthy and positive human relationships (see The Local Authority v A & Ors [2019]).

Whilst it is important for support plans to deliver consistency and predictability, there is no need for a support plan to dictate staff behaviour and circumscribe the interpersonal relationships that develop between service users and staff. Support staff should not be required to be emotionally distant and impersonal at all times. For example, it should be acceptable for a support worker to answer an autistic person's enquiry about how they are honestly in most circumstances, even where that answer isn't particularly positive. It is valuable for service users to be exposed to open, honest, real people who are all different. This humanizing of staff is likely to foster empathy and help to counteract tendencies to dehumanize those receiving support (CQC, 2020).

Training and supervision

As outlined above, all too often, staff actually caring for autistic people day to day have had very limited training and support to understand autism. The forthcoming code of

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 and does not provide close to sufficient training for staff whose roles involve supporting autistic people to live ordinary lives in the community (mostly in social care). We recommend that such staff should additionally be trained, led and mentored in implementing the NAT guide, particularly recommendation 7, 'Recognising behaviour as distress' (NAT, 2019) and, as required in the draft code of practice, in line with the social care relevant sections of Tier 2 of the Core Capabilities Framework for Supporting Autistic People (DHSC, 2019).

<u>Training</u>

Improving the skills and knowledge of the social care workforce from support workers to senior managers is clearly critical to improving outcomes for service users at risk of restraint and secure placement. Professionals and care staff in social care often feel powerless and that they do not have the training, information, or support they need. There is commonly a lack of sufficiently specific, in-depth and ongoing training:

> *"Staff with knowledge about autism, particularly in terms of how it impacts people and the type of supports that might be required, would also be helpful." (MacDonald, 2018, p.42)*

Even where staff have received autism training, all too often it is focussed on diagnostic criteria and theoretical models and ill-suited to the practical context of supporting autistic people to live their lives in community settings.

> *"We were concerned to find examples of a lack of training for staff to be able to understand people with a learning disability and/or autistic people. For example, one service had training on the Mental Capacity Act, but staff were not trained in communication tools like Makaton or Picture Exchange Communication System (PECS) to help people with a learning disability to communicate. Other services did not provide training on autism" (CQC, 2020, p. 34).*

Staff should be trained in adopting an approach to care that is founded on human rights and an understanding of autism from autistic perspectives. In order to achieve this, we would suggest that autism training needs to be primarily created and led by autistic people and draw on the collective knowledge of the autistic community, to promote empathy with autistic perspectives.

Staff should be trained and have continuous mentoring and coaching to achieve a high level of reliable adherence to the agreed approaches, in a range of practical strategies that are demonstrably helpful in working with autistic people, such as some of the approaches

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[14] A draft for consultation is now available at https://www.gov.uk/government/consultations/oliver-mcgowan-draft-code-of-practice/oliver-mcgowan-draft-code-of-practice-on-statutory-learning-disability-and-autism-training#standards-for-training-and-related-guidance

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 help autistic people understand their own emotions and bodily experience and better regulate them (DHSC, 2019, Capabilities 4, 5 & 8).
- Reducing interaction and stimulation and all external stressors when an autistic person is in, or approaching, a state of meltdown or shutdown, including to stop talking, remove demands, leave them alone and, when they are able to calm themselves, attempt to engage with something predictable and comforting to them (DHSC, 2019, Capability 8).

Staff need training and refreshers (DHSC, 2019, Capability 8) to challenge assumptions that 'behaviour' and 'risk' are inevitable parts of autism which need to be managed, and support them in reframing issues from the perspective of the person themselves i.e. What may be distressing them? What do they not yet understand which they could be supported to develop? What changes in staff behaviour or organizational systems are needed to avoid causing distress?

In order to implement a rights-based approach advocated for in this paper, staff also need to be trained in equality, discrimination and the right to reasonable adjustments (Equality Act 2010). In our experience as disabled adults, it is remarkably common that well-meaning people struggle to recognise differential and discriminatory treatment and commonly believe that it is fine to say things like "It wouldn't be safe for you to do that because of your disability", regardless of evidence. Staff should understand and be able to apply in practice the care services' own duty to provide anticipatory reasonable adjustments for autistic people, including the Accessible Information Standards 2016. They should also become confident in advocating for people they support when they

encounter accessibility barriers and discrimination in the community and other services (DHSC, 2019, Capability 14).

<u>Support, supervision and reflective practice</u>

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:

> *"To support a positive staff culture, staff need to feel well supported through supervision and training, and have opportunities to discuss and learn from incidents through reflective practice." (CQC, 2020, p.15)*

To achieve the shifts in thinking discussed in this paper, training must be embedded through day-to-day processes of reflection and supervision. Staff should have opportunities to share best practice amongst local services through communities of practice (Long, 2020). A staff culture which constantly seeks to understand and empathise with the perspective of the autistic person needs to be developed. This will support staff to understand the interactions between the quality of a person's life (including autism-specific issues such as stress from uncertainty, change, interaction, and sensory issues) and behaviours that may be seen as 'challenging' (DHSC, 2019, Capability 8, Tier 2).

Staff must be supported to reflect on their own practice and have the time and resources to do so. This reflection needs to include how their own attitudes, values and behaviours affect both the behaviour of service users and their perceptions of that behaviour. This includes recognising that the actions of staff and carers can increase or reduce the likelihood of behaviour which challenges (DHSC, 2019, Capability 8 Tier 2), since research confirms that:

> *"Staff reporting of challenging behaviour in clients with learning disabilities may be explained by differences between staff" (Skills for Care, 2012).*

Autistic people should be able to have as much autonomy in their lives as we possibly can. This includes allowing autistic people to make mistakes, to support them to learn from them, and being wary of assumptions that a mistake means the person cannot understand or is not capable. Developing and sustaining the confidence of staff to stand back and allow autistic people to learn from our mistakes is likely to require peer and supervisory support, deep understanding of what 'duty of care' does and does not require (BASW, 2021), and encouraging reflection on how mistakes by non-disabled people are treated compared to those of autistic people.

Group and individual reflection need to include active consideration of whether an autistic person's behaviour is infringing other people's human rights and/or causing or risking serious harm to the person themselves or whether the behaviour is just 'not normal'. Staff who are less familiar with or empathise less easily with autistic perspectives are likely to need ongoing support to accept and accommodate autistic behaviour which they find difficult to fathom. If, despite all of these approaches discussed in this paper, things do go wrong and an autistic person becomes significantly distressed and an incident causing injury (or the use of restraint) occurs, a staff debrief should be called. This should trigger an open discussion focusing on contributing factors and, as part of this, a review of the

approaches staff are using with this person. The focus of this is to establish where best practice broke down and how this can be avoided in the future by staff making more adjustments to accommodate each autistic person's needs.

Service Leadership

All of the above can only be achieved consistently in services led by managers who know, understand and believe in the core principles set out in this paper:

> *"In one example, a new manager had created a culture where staff felt they could be open about how they felt after incidents and felt supported to raise concerns. As a result, there was a dramatic reduction in the number of restraints" (CQC, 2020, p. 37)*

We strongly encourage leaders to foster a culture of peer support and professional challenge, in which human rights are openly and regularly considered and any indications of the 'othering' of autistic people is spotted and addressed at an early stage.

Achieving the significant shifts in practice called for in this paper requires a noticeable shift in power away from service managers and staff and towards those using care services. We recognise that having a setting that feels under the control of the staff can be very important to both managers and staff. Managers may also fear that, if they do not intervene to prevent all potential harm, that will reflect on them, leading to embarrassment, or worse, accusations of negligence, and failing to protect. This is a powerful, but misplaced fear. As set out in Section 3, the legal frameworks underpinning adult social care, including the Human Rights Act, Mental Capacity Act and Care Act Safeguarding arrangements, strongly support positive risk taking and respect for the autonomy of disabled adults. If staff are trained and thoughtful practitioners, and they can demonstrate that they have thought about their actions and have acted reasonably, they have nothing to fear in terms of blame or liability (BASW, 2021). Ultimately, we believe, and our experience suggests, that approaches that are founded on the principles set out in this paper, are actually more effective in reducing 'challenging' behaviour and preventing placement breakdown than much of current practice. This avoids the lengthy paperwork and stress associated with 'behaviour incidents' and has the potential to lead to a more effective, efficient, and happier workforce, working in an environment that is more rewarding and satisfying:

> *"In a good service for autistic people, family members, friends and staff throughout the service are supported to understand and use rights-based thinking. A good service for autistic people is one where staff throughout the service believe that everyone can be effectively supported to live safely in the community, whatever their disabilities." (NAT, 2019, p. 30)*

Support for positive risk taking

Autistic adults need a workforce that is able and willing to recognise the legitimacy of positive risk taking and the rights of adults, and be willing to defend its actions on the basis of balance of human rights and in accordance with the Mental Capacity Act and the genuine meaning of 'best interests' as defined in case law (as discussed in 'Promoting autonomy' above). It takes ethical and committed leaders to ensure that service decisions

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, and unpick, rather than furthering, myths around duty of care and liability for harm. Leaders need to be committed to creating a culture in which staff are focused on balancing rights and supporting the development of autonomy, not on welfare at all costs. Regulators and inspectors need to accept and support the same principles.

Creating and maintaining service attitudes which focus on quality of life, the perspective of the autistic person and supporting them to live in a way which alleviates distress and enables them to manage stress, rather than focussing on managing risk and 'behaviours', requires leadership. Managers need to create policies for staff to respect the sensory needs of those they work with, such as staff avoiding using scented products, jangling keys or background music/TV. Respect for the needs, preferences and rights of autistic adults includes ensuring that the autistic people who use a service are involved in and have meaningful power in the recruitment and training of the staff who will work with them. The needs and preferences of the individual(s) being supported should be prioritised in decisions about the deployment of staff. When you depend on other people to empower you to go about the most basic aspects of your adult life, it is reasonable to have a substantial say in who those people are. It is also vital to autistic quality of life and minimizing distress to minimize change and uncertainty around who will be supporting an autistic person.

Restrictive practices

Leadership is also vital around risks and restrictive practices. Whenever a service places restrictions on an adult and, particularly, has one or more staff supervising them for prolonged periods, leaders should actively consider whether the constant presence of other people is itself distressing to the autistic person and accommodate needs for privacy. Again, empathy is key here. Leaders should encourage reflection on how those providing support would feel in their own lives if they were being watched/overseen continually, and the likelihood of proportionately greater distress to autistic people from lack of privacy.

Whenever concerns are raised about risks, leaders need to ensure that there is explicit, realistic consideration of the likelihood, as well as the severity, of whatever negative consequence is feared. For example, it is possible that a supported individual could die if they eat a non-food substance (Pica). However, it is highly unlikely. This doesn't mean that nothing should be done to reduce the risk, but likelihood should be carefully considered and weighed against the negative impacts of any potential protective steps. There are also other actions that can be taken to minimise the risk, without seeking to control the supported individuals' actions, such as providing the person with accurate, neutral information about a decision and offering less harmful substitutes.

> *"Human rights breaches are not inevitable in any setting. To uphold people's human rights, providers need to always assess and keep under review if there is a less restrictive option for the people they are caring for. Under the Equality Act 2010, all healthcare providers have a duty to make reasonable adjustments for disabled people. This includes, for example,*

adjustments to the environment and communication. The British Institute of Human Rights has highlighted that to achieve this, there needs to be a service-level culture change, where staff care for all people from a human rights perspective." (CQC, 2020 p. 10)

Before increases in numbers of staff working with a person are considered, thought should be given to whether the person needs more highly trained staff, lower turnover of staff, or a smaller pool of staff who work directly with them. The option of other changes to the environment to make it more suitable, should also be considered, including consideration of whether the person can or wants to live with other people and, if so, which other people. These changes may well require active modification of services to achieve, including by improving staff pay and conditions or other changes (such as to a single-occupancy properties), which may have cost implications:

> *"the quality of care people received [in the community] varied, and was affected by the numbers and skills of staff available." (CQC, 2020, p.32)*

Approach to care

Autism informed

Transformative leadership is needed to shift the focus of existing services from 'behaviour' to 'need' and quality of life (DHSC, 2019, Capability 8). This requires leaders who will constantly seek to create environments, systems and ways of working which are geared to autistic needs and norms – for example by increasing structure and predictability, adapting the sensory environment, and recognising the demands of communication, interaction and decision-making. Reasonable adjustments and adaptations need to be considered throughout the service and ways of working, including the accessibility of communication, provision of information in advance, and sensory adaptations.

Services should actively suggest and encourage the use of advocacy by service users and communicate effectively with advocates. With the person's permission, or as part of best interests decision-making processes, services should facilitate the involvement of family members as much as possible, learning from their individualised knowledge as well as seeking to support important relationships. However, services should also engage directly with those individuals supported themselves, seeking to increase their autonomy and involvement in major and risk-involving decisions, as well as day to day choices. This may at times involve challenging family members and advocating for autistic adults, to protect and further our independent rights as adults.

Services need to be designed and managed in ways which support positive mental health for autistic people as well as the staff who care for them. This means enabling time spent in enjoyable activities and activities the person is good at, avoiding everything being 'therapy' and focussing too heavily on tasks the person finds challenging. It should also involve actively reaching out to and facilitating contact with the wider autistic community, such as through autistic-run local and national organisations, attending events and conferences, fostering membership and community links. Both of these factors support the

development of a positive autistic identity by recognising and empowering autistic strengths, not just working on weaknesses.

Case study 8 illustrates how harmful even well-meaning care and support can be when it is not autism informed. The supported individual's distress was regarded as an inevitable consequence of his condition and changing circumstances. The assumption was that the transition was always going to be horrible, it just had to be got through, enforcing the new system, showing the supported individual that his behaviour would make no difference, and eventually he would accept the new reality. This approach may succeed in teaching an autistic person to passively accept their powerlessness and become compliant to all treatment, including abusive treatment.

Solutions are not easy, but working from an autism-informed perspective, it is possible to see alternatives. Perhaps a softer transition involving days out with support workers before leaving the family home would have helped, and gradations in easing the transition, starting with one night a week. A low arousal approach to the new environment may have helped, reducing noise and activity especially late at night with shift transitions. Perhaps paying attention to the provision of familiar smells and objects in the new environment would have helped. Perhaps informing a supported individual more clearly about what needed to happen and why, communicating honestly with him about the needs of informal carers. Supporting the autistic person to come up with a strategy for their own transition, so that they are in control of the process – an active participant rather than a passive recipient, is also an ethical, autism-informed option. This may involve gently challenging parents/family members/professionals who want to keep an adult in the dark about what is happening to them. Another possibility would hav55nvolve to involve other autistic people who have had similar experiences to help and advise. Perhaps the supported individual could have been facilitated to have access to games and media that he had at home and may have missed. There is a host of possibilities that could potentially make a transition less traumatic, with better outcomes for all involved, without necessarily being more expensive in terms of staffing or resources, perhaps cheaper if less distress was caused.

Achieving such transformation in approach requires leaders who listen to their staff as well as to autistic people. In Case study 8, an autistic staff member had concerns but did not feel able to raise them effectively. Staff need to feel able to discuss ethical challenges in their work and need their voices to be respected when they attempt to advocate for autistic people they know well.

<u>Person-centred practice</u>

Staff teams also need support to tailor their learning and practice to each autistic adult's specific needs:

> *"We also found that a lack of training and support for staff meant that they are not always able to care for people in a way that meets those individuals' specific needs. This increases the risk of people being restrained, secluded or segregated." (CQC, 2020, p.3)*

"It is vital that whenever an autistic adult comes into contact with a care professional, they understand how to meet their individual needs. They may be making very important decisions about people's care, or mental capacity. In the long term, support from care professionals who understand autism can make the difference between someone living well in their community and falling into crisis." (APPGA, 2019, p. 18)

As discussed throughout this paper, if an autistic person is behaving in a way which infringes others' human rights and/or causes or risks serious harm to the person themselves, the goal should be to work *with* the autistic person to understand their needs and meet them, and alleviate the cause of their distress, rather than just 'managing risk'. Episodes when the world becomes so confusing, overwhelming and frightening that a person is overtaken with distress are painful to watch as well as painful to experience and are likely to affect the wellbeing of others present including changing the way support staff behave. Care providers should be doing everything they can to reduce the chances of someone in their care experiencing acute distress.

Staff should know each autistic person well enough to spot signs of rising distress early on, communicate well and respond to 'he person's needs, change their own patterns of behaviour, their expectations, and the environmental aspects that are within their control in order to minimise that level of distress before it becomes overwhelming. This is the creation of a caring environment that aims to help each autistic person understand what is happening around them and how they can express their needs and wants.

Rights-focussed support ensures that individuals are supported with dignity, and that family strengths and community solidarities are not undermined (NAT, 2019, p. 18). This should include staff actively using information from an autistic person's sensory profile (as discussed above) in day-to-day care planning, such as taking noise-cancelling headphones when going out or planning 'quiet time' in the afternoon following being in a demanding sensory or social situation in the morning. Staff need to be aware that autistic people can experience and express pain and distress differently and be able to work consistently with an individual in order to be able to learn their individual 'language' around pain or distress.

Recruitment

"Essential in providing good support is having a skilled, motivated and enthusiastic staff team, who have a commitment to the work that they do, and who enjoy working with individuals with complex needs. The ability to see beyond any complex needs to the person themselves is essential, as is the ability to have a degree of empathy and understanding. Staff are required to have an understanding that challenging behaviour serves a function for the individual and is communicating a need." (MacDonald, 2018, p.42)

When ensuring the workforce has the right skills and knowledge, traditionally the focus has been on training rather than recruitment practices. We are, of course, in favour of developing training to equip social care workers with the kinds of skills and knowledge outlined above. However, we are also aware of the limitations of relatively short training

programmes in achieving the sort of cultural change discussed in this paper (Willis *et al.*, 2016).

Whilst we acknowledge that, at present, recruitment and retention of sufficient staff at all is a major issue in social care, nevertheless we see potential benefits from autistic people being supported by staff who are most naturally attuned to their perspectives. Both at the stage of recruitment and when making decisions about deploying staff within a service, the natural aptitudes of staff in terms of ability to empathise with the autistic people they support needs to be prioritised. We suggest developing recruitment practices which prioritise at least some of the following qualities:

- Neurodivergence. This applies, but is not limited to, conditions such as autism, ADHD, learning disability, dyslexia and dyspraxia. Service users and support staff who share these conditions can maximise natural understanding and rapport. In our experience, support staff who are also neurodivergent are more likely to recognise the needs of service users as real and comprehensible. Not all neurodivergent staff will be compatible with all neurodivergent supported individuals. Nevertheless, neurotypical staff have the additional hurdle of trying to understand what is, to them, an alien perspective, in the same way that there is always a difference between native and non-native speakers of a language. They may be able to do quite well on theoretical understanding of autism, but it will lack a level of intuition and natural 'accent' that is only accessible to native speakers. Recruitment which explicitly encourages neurodivergent people to apply for roles supporting autistic or other neurodivergent adults should be considered[15].
- Experience of having choice and control removed from them, in any context. Staff who know what it is like to lose control of their lives will be better placed to understand the perspective of supported individuals when this happens to them. Experience of this nature may help staff to empathise with the negative consequences of loss of autonomy, see the benefits of increasing autonomy and, possibly, be particularly motivated to take steps to prevent loss of autonomy, including avoiding the use of restrictive interventions.
- Self-awareness and the ability to reflect. Staff who are aware of their own behaviour and characteristics are more likely to be able to notice and change things they are doing that cause an autistic person stress. Reflection is the ability to review situations, analyse them and consider the impact of potential changes on those situations. This skill is essential to being able to notice patterns and modify the care and support environment.
- Experience of minority spaces and cultures, especially neurodivergent ones. Staff who have had the experience of what it is like to be in a minority group and how it feels as a member of a minority to be in a majority-controlled environment are likely

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[15] Where there is insufficient supply of neurodivergent people to be a significant presence in front line staffing, some of the same insight could potentially be provided by experienced and knowledgeable neurodivergent experts taking the lead in educating and training staff.

to be more able to empathise with an autistic person's perspective. It is likely that staff with these experiences would be particularly well-placed to recognise when policies, placements or staff are not a good fit for a service user.

Case Study 9 illustrates the impact on the supported person of their support changing from a staff member who did not have the above characteristics to one who did. Well-meaning support, which was not in line with the approach set out in this paper, caused distress and required a restrictive intervention. A less conventional, but more autistic-empathetic, approach provided the supported individual with comfortable, less distressing autistic space and resulted in fewer restrictions, minimized behaviour 'incidents' and enabled a better quality of life.

Conclusions

The specific recommendations advocated in this chapter are ambitious but achievable. All social care services are under enormous pressure and staffing remains a massive issue. Nevertheless, while investment and capacity building are of course critically important, much can be done by refocussing existing efforts from 'managing' behaviour and risk, to rights-based care focused on quality of life.

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-based support, and by recruiting people who have a natural understanding of the needs of autistic people. Commissioners, inspectors and managers need to recognise and respond positively to high quality care and support, recognising the value of staff standing back, allowing downtime, privacy and withdrawal from interaction, and the difference between a good quality of life and (non-autistic assumptions about) what a 'normal' life should look like.

It is possible to maximally align the interests of autistic people and the services that we depend on by creating environments in which both service users and those who support us may thrive.

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[16] https://nationalautistictaskforce.org.uk/about/autistic-space/

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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 practice. We hope that these case studies provide examples of both good and poor practice, which help to illustrate the practical application of much of what we have set out in this paper.

Case Study 1: Hannah

Hannah is an autistic young woman in her 20s without an additional Learning Disability. She has high support needs. She is articulate when not stressed but loses speech and dissociates when anxious. She reports previous assaults, sexual abuse/rape when vulnerable and in a dissociative state. She will not tolerate care provided by male staff as a consequence. She is able to articulate her sensory needs, and has quite a good understanding of her autistic profile and sensory requirements. Her request that the care provider put alarms on her door and window so that they are aware if she has a dissociative episode and wanders out of the property, are refused, and male staff are employed by the provider. She becomes so anxious that she starts self-harming. Antipsychotics are administered. She does not like them, they make her feel drowsy and

more vulnerable. Fear of male staff, and fear of wandering when in a dissociative state, coupled with the staff not believing her when she reports those fears and playing them down send her into a spiral of anxiety which could in itself trigger a dissociative state. The self-harm is one of the ways she tried to keep herself grounded and 'present'. She is diagnosed with borderline personality disorder (BPD), and staff use this to refuse to intervene when she self-harms. The BPD diagnosis effectively places Hannah in a state where any display of distress is not believed or acted upon. She reports banging her head for so long the skin split, and staff just ignoring her and leaving her bleeding, saying she is just 'attention seeking'. Her self-harm escalates to the point where the care staff say they cannot keep her safe and she is hospitalised under s.2 Mental Health Act. In hospital her concerns about the care she got from the care company prompt her to make a safeguarding complaint, which is downplayed because of her BPD diagnosis and staff in the hospital disregard her distress.

Case Study 2: Shafiq

Shafiq is an articulate autistic man in his late 20s with high support needs, though he does not have an associated learning disability. He has lived in care settings since his early teens and is now living in a typical residential home with 20 other residents who mostly have learning disabilities. One of the other residents, Diego, likes teasing the other residents by calling them names. Diego lives in an upstairs room with a window that overlooks the quad, so anyone walking from one area of the property to another can be seen. He often shouts and teases other residents from his room as well as when he is downstairs in the communal areas. Whilst Shafiq is by no means the only resident that is upset by Diego's behaviour, Diego particularly likes to hone in on Shafiq, and incidents happen 2 or 3 times a day almost every day for around 5 years. When Shafiq complains to the staff, he is told to ignore it, and that Diego does not understand that he must not do it. Staff assume that Diego does not have the capacity to understand that what he is doing is hurtful to Shafiq, whereas Shafiq is deemed to be more able to adapt and cope because he is clearly intelligent. When Shafiq asks why they do not block the view to the quad, he is told that it would infringe Diego's right to a view. As time goes by, even the sound of Diego's voice becomes triggering to Shafiq regardless of whether he is being shouted at or not. Diego on the other hand finds out where Shafiq's room is and starts escaping from the carers to go and bang on Shafiq's door or window and shout at him when he knows he is in there.

After another incident Shafiq's temper snaps and he attacks Diego. It takes 10 members of staff to separate them, they have to take Diego to A&E to stitch him up. Shafiq is restrained for about an hour.

A safeguarding review happens and Shafiq is asked what would have happened if they had not intervened and separated him from Diego. Shafiq states "I'd have killed him". Because of his answer, Shafiq is served notice and has to leave the facility. The care

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.

Case Study 3: Jian

Jian is a young autistic man of 22 years with Obsessive Compulsive Disorder (OCD). His family background is stable with appropriate support from his family and care provider. The move from child services to adult services led to a change in his respite service. Relationships broke down one weekend when parents dropped Jian off at the adult respite centre to find it empty. The staff and other residents were out on a visit and had forgotten about Jian's stay. Jian becomes highly distressed due to this unexpected change. He refuses to get back into the family car; his distress worsens and is expressed in his behaviour. Two police officers arrive. They listen to Jian's parents. They restrain Jian with minimum force to prevent harm to others. An ambulance is called. Jian's parents ask the police not to take Jian to hospital, and they agree. Eventually Jian is driven home with his mother in the ambulance. It takes an hour before Jian will get out of the ambulance once outside his home. This is a case in which the police and professionals act appropriately and effectively de-escalate a situation which could easily result, with different professionals, in Jian being restrained unnecessarily for longer.

Parents describe the changes from child to adult services as 'like dropping off a cliff'. Jian had to adapt to a completely new set of respite services which do not meet his needs as his previous service had done. His OCD rituals are not accommodated and lead to distress and risk of problematic behaviour, including vomiting at will. The poor quality of the respite service leads to Jian being placed in a residential service. The move to adult services makes access to clinical services much more difficult.

When Jian does see a psychiatrist, after a wait of 18 months, he is prescribed a high dose antidepressant for the OCD symptoms, which, whilst beneficial at first, trails off in its efficacy. He remains on that drug because it is seen as too complex to take him off one medication and trial another.

By this time, Jian's parents are both physically and mentally exhausted. They describe being dependent on the positive support from the college Jian attends. The college finds the supported living providers where Jian now lives. The understanding the college has of Jian's needs is essential in sourcing appropriate provision which meets Jian's needs. The local authority opposes the placement saying it is too expensive. After a failed attempt at

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 his needs. They provide a low arousal environment. They follow Jian's wishes, for example changing his communication methods from app-based to PECS symbols offered by staff. They welcome outside advice from people who have worked with Jian to ensure continuity of support. They keep the staff that work with Jian to a consistent group who know him well. In the two years Jian is at this placement, there are no incidents of restraint.

Case Study 4: Tomas

I was diagnosed with Aspergers in 1996, I was age 13. By the time I was age 13, things at home and at school were quite bad.

I try not to speak about things just for myself. Things need to change for everyone. Some of my friends have never had an adult life outside of hospital, having similar experiences to mine, autistic friends with and without learning disabilities.

When I get overwhelmed or distressed, I tend to hit my head or bite my hands and this can lead to the police being called, and ending up being restrained by them and others, and eventually into hospital.

Staff in hospital often don't understand how anxious I'm feeling and why I'm doing things. Because of this they often get angry and shout, or punish me by nipping me on purpose while restraining me.

Sometimes they'd push me to get upset because they're bored or laugh at me or hurt me in other ways.

A lot of bad things have happened in and out of hospital, by professionals. A lot of things that at the time I just accepted as how things were, but, looking back, really shouldn't have happened.

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.

A lot of the medications I was on, I didn't need to be on, but because I had side effects, I would end up on more and more.

I remember I was put on Quetiapine, and for months I kept telling people I was scared. They kept asking me "What of?", and I kept telling them "Nothing, I just feel scared."

They would tell me that there's nothing to be scared of. At the time I didn't know how else to explain it, my heart was racing constantly, I felt like really panicky, on edge and the closest word to me was "scared".

They thought I was paranoid and kept increasing the medication. I now realise that it was almost certainly a side effect from that medication. I'd had a side effect very similar previous to that, and it had felt very similar.

As soon as they moved me to another medication, the feelings of being scared lifted.

If they'd understood some of my language and communication skills, or read back in my notes, they probably could have worked out that I was describing the physical symptoms.

Although there's been lots of bad times, there's also been lots of times when people have taken the time to listen and be understanding. It's meant I have managed to avoid getting upset in the first place.

Like when support workers who work with me now notice I'm getting overwhelmed or when I say I need to leave somewhere, and they help me find a way out, meaning that I don't get too distressed, and it avoids having the police called altogether.

I haven't been in hospital for a few years now.

There's been a few changes, but one big thing that changed was that I happened to chat to an occupational therapist who was working on sensory needs and autism with someone else I knew. They were talking about deep pressure, and I was saying that, when I was a kid, I used to find being squished really calming.

And they mentioned about how it's sometimes the reason people can get restrained for long periods because it becomes a cycle of being calmed, but also being upset by being restrained and needing something to calm me down from that.

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

"A Broken System" (Sunday Times Editorial, January 2nd, 2022)

"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."

"Life in a Box: young autistic man confined in hospital's former file room" (Sunday Times, 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.'

"Family of autistic man to bring legal challenge over 'inhumane' conditions" (The Guardian, January 3rd, 2022)

"The family of an autistic man confined to an apartment and fed through a hatch are planning a legal challenge against his conditions, in a case that will increase pressure on the government to end the practice of keeping people with severe learning disabilities in 'modern day asylums'. A spokesperson for the Department of Health and Social Care said: 'We are determined to continue to reduce the number of autistic people and people with learning disabilities in mental health hospitals. That's why we are investing in community services and supporting discharges with £90m of additional funding this financial year.'"

Case Study 6: Newspaper report

"**Autistic man held with murderers in secure hospital**" (Sunday Times, April 10th, 2022)

"Robert Buckland QC, the former justice secretary, whose daughter Millie, is autistic, said: 'I remember going to Rampton. To think a young man is being held there who has committed no criminal offence to be there is horrifying. I had no idea this was happening, and it seems well out of date to me. This is not acceptable for someone who has done no wrong. Having learning disabilities and being autistic is part of who he is. But it is being treated like a mental health condition.'"

Case Study 7: Newspaper report

"**Council paid £60,000 a week for girl's 'wholly unsuitable' placement**" (Guardian, April 27th, 2022)

'A council in England has paid £60,000 a week – the equivalent of £3.12m a year – for a 'wholly unsuitable' children's home placement for an autistic teenager with a mild learning disability. The judge hearing the girl's case was so appalled that he ordered the education secretary, Nadhim Zahawi, to explain the government's position on what he called a 'national crisis' – the severe shortage of secure placements for vulnerable children with complex needs. The case, the first reported by the Open Justice Court of Protection Project, involves a girl who spent at least five months alone in the locked annexe of a

children's home.' 'Mr. Justice Poole said in a hearing 'This case is reflective of a national crisis. Support from central government is needed.'

Case Study 8: Ethan's transition

Ethan is a young autistic man with ADHD nearing school leaving age. His parents are struggling to cope with looking after him at home and arrange a residential placement for him with a large service provider. Ethan seems happy with moving out of his family home. However as soon as the placement begins Ethan begins to 'abscond'. Support staff accompany him and coax him back to begin with, but the behaviour does not change. The doors of Ethan's house are then kept locked so Ethan cannot leave. Times that he does leave the house accompanied sometimes involve incidents in which Ethan is restrained, locked in a car and driven back to his house. Ethan is extraordinarily distressed by this treatment and shouts and insults his support workers and the organisation they work for. One of Ethan's support workers, Ben, is autistic. Ethan does not know Ben is autistic, but Ethan excludes Ben from the insults, saying that Ben is not like the others. The service provision continues as before on the assumption that Ethan's behaviour is primarily an attempt to assert control and get what he wants, namely a return to his home, or some fast-food takeaway, or some other benefit outside his house. Ben reluctantly follows the agreed support plan for Ethan, but feels acutely uncomfortable in doing so. Ben has so far successfully avoided restraining Ethan, and dreads the day he may be expected to. Ben is not sure what he will do when that day comes.

Case Study 9: Angus, Donna and Ayla

Angus is a young autistic man with a learning disability who has recently left a special school placement. Angus has never spoken, nor does he write. Communication is very limited and all decisions are made by his family and carers. On leaving school his family employed a support worker, Donna, to take Angus outside the home. Angus was led around arm in arm to ensure safety at all times, at the recommendation of a social worker. Donna chatted to him, asked him how he was, told him about her life, and so on. Angus never responded. Donna was sometimes a minute or two late for work which upset Angus, Donna would say sorry but thought little of it as it was only a couple of minutes. Sometimes when physically let go Angus would run off and not return when called. The frequency of such incidents increased. One day Donna put her arm out to stop him moving forward into a road and he bit her arm. Shortly after she resigned saying that Angus would not follow her instructions and she could not keep him safe. The family then employed another support worker, Ayla, who was autistic. Ayla had no previous experience of support work. At first Ayla led Angus around arm in arm, but she wondered if this was necessary. She took him to safe spaces like parks and woods and would let go. Angus showed no signs of any risky behaviour. He stimmed vigorously, but she recognised that

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 11: Ayodele and Sara

Ayodele is an autistic man in his twenties. He does not use speech and has a learning disability. However, he does have a spiky profile and can understand some kinds of information well. At primary school he learned some Makaton and used it effectively. His secondary special school provision discontinued the use of Makaton, saying that it was pointless because few others in the outside world understood it. They did not develop his communication skills.

When Ayodele left secondary school, his development had progressed little from when he was at primary school. A support worker, Sara, was found for Ayodele. The job was described as taking Ayodele out of the house to access the community. Sara recognised that Ayodele had no meaningful control over his own support. All Ayodele could do was make noise and violent movements when he did not want to do an activity. Sara began to develop Ayodele's communication skills. She offered multiple choice options which he could choose by pointing. She worked out a plan for the day with Ayodele by drawing a flow chart, which allowed for decisions and contingencies, for example having an alternative plan if it was raining. Sara tried to use PECS but it was clear Ayodele did not like that. Then she tried using very simple emails. Ayodele responded well to this but it depended too much on his family for support and on Sara being very consistent and emailing in her own time, and this proved practically unworkable. Then Sara learned some basic Makaton which allowed Ayodele to communicate more spontaneously instead of always in response to a prompt. There is still a long way to go, but communication is slowly becoming more sophisticated, and Ayodele is gradually learning that he is able to exercise some control over his own life.

Case Study 12: Chen

Chen is an autistic child without a learning disability. Chen cannot understand what others are saying in noisy environments because he cannot separate out the streams of noise. Chen becomes overloaded easily and has difficulty understanding school customs and rules. Chen finds the uncertainty of school very distressing but he hides his distress and continues anyway because he thinks this is normal and what every child experiences. Eventually Chen finds he cannot force himself over the threshold of school. His parents only now understand that there has been a problem. After a number of unsuccessful attempts to include Chen in school his parents take him out. His parents find an online provider of remote educational materials which the local authority reluctantly agree to fund. It is unlikely they would have funded it had not Chen argued his case with the local authority himself, by email, and avoiding face-to-face meetings. The provision is not ideal, but he can access the materials from any quiet space with an internet connection and some prompting. Chen is now getting an education that he would not have otherwise had.

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 up in the morning, and has even been restrained to prevent damage to property.

A manager who recently had some training in sensory needs and 'low arousal' approaches suggests that no noisy work is done after 8pm. No washing machines or clattering about. All harsh lights should be turned off. Staff are to talk in low voices if at all and not run around trying to look busy. Doors should be closed quietly. The manager says it's fine to leave some chores for tomorrow. Interaction with Jasmine should be low-key. After this, bedtimes go much more smoothly and Jasmine gets better rest.

Appendix 2: Contributing Authors

Leneh Buckle MA

Leneh is autistic and a parent of four neurodivergent young people. Following degrees in neuroscience, psychology and bioethics, Leneh is currently undertaking a (funded) PhD looking at initiative deficits in autism. Her groundbreaking research on autistic inertia has been published in a peer-reviewed article. Being autistic herself has motivated a longstanding interest autism and human behaviour that has developed into a research career, she now finds herself juggling multiple roles as a research consultant. Leneh is a co-author of an important article on the implications of the neurodiversity movement for early intervention research in autism, as well as contributing a chapter about Autscape to Steven Kapp's recent book Autistic Community and the Neurodiversity Movement.

Leneh has experience of involving autistic people in the neurotypical-dominated domain of autism research. She has applied her expertise in participatory research, autism and quality of life to work on projects with organisations including: Mentaur, the National Autism Project, the National Autistic Taskforce, Autistica, and research teams at several universities. Leneh provides a critical voice from the autistic community in her service on Autistica's Scientific Review Panel. Her focus throughout her involvement in these diverse endeavours has been on setting aside assumptions, prioritising support for autonomy, and recognising that autistic people's priorities may differ from the typical. She often serves as a 'translator' between autistic experts by experience and neurotypical researchers as she is fluent in the languages of both communities.

Leneh has been involved in the autistic community for nearly 25 years. She has worked with autistic people since 2004, largely in a leadership capacity, to create and manage Autscape, a large annual residential event for autistic people. This has included accommodating the diverse needs of hundreds of autistic participants, including effective communication verbally and in text.

Josh Hennessy MA

Josh has been working in health and social care for autistic people in various roles for fourteen years, including supporting a range of autistic people. He is autistic himself. He has been a committee member of Autism Rights Group Highland since 2017. His academic background is philosophy and is currently studying law.

Jo Minchin BSc, MEd.

Diagnosed autistic in her late 30s, Jo has been employed as an Expert by Lived Experience by the NHS since 2014. Initially this was by a Clinical Commissioning Group to expand and improve services locally, but it quickly incorporated working in Care and Treatment Reviews as part of the NHSE Transforming Care programme. Jo's NHS work has since expanded to national work in NHSE as an autistic consultant and currently she is co-chair of the Midlands Autism Strategy Workstream. She is also vice-chair of the advisory group to the All Party Parliamentary Group on Autism.

Jo holds a Masters with distinction on autism in adults from the University of Birmingham, and has three adult neurodivergent offspring with differing support needs. She has an interest in national policy, and has been involved with the National Autistic Taskforce since 2019.

Jude Ragan CBE

Jude qualified as a teacher in 1970, and has worked for almost all of her career with autistic children and young people. She has been headteacher of 4 schools that specialise in autism, and was an inspector for a brief period. Her final headship was at Queensmill School in Hammersmith and Fulham, from which she retired in 2015. Since that time she has continued to work with The Queensmill Trust as a Trustee. She also works for parents, supporting their autistic child in mainstream school through staff training. She has taken on autism-related work in Albania, St. Helena, China and Nepal. She is an Honorary Fellow of UCL London Institute of Education, having worked with CRAE (Centre for Research into Autism Education) for some time. She was awarded a CBE for services to autism.

Yo Dunn PhD

Yo is a trainer and consultant who trains social workers, health professionals and the broader social care workforce in both autism and law. She has a thorough knowledge of public law and professional practice issues in health and social care in England for autistic people both with and without intellectual disabilities.

Yo's book, Social Work with Autistic People, is the leading text in the field. She was legal and policy consultant to the National Autism Project, served on the Steering Group for the Department of Health and Social Care's Core Capabilities Framework for Supporting Autistic People, which sets out the key capabilities for staff working with autistic people in all roles across the public sector in England, and is now a member of the National Mental Capacity Forum. Yo is strategic lead of the National Autistic Taskforce and led the development of the NAT Independent Guide to Quality Care for Autistic People. She is autistic, a parent of autistic children and was formerly company secretary of Autscape.

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

- Things Tom likes (sexuality and masturbation)

- Things Ellie likes

An Exceptional Children's Guide to Touch: Teaching Social and Physical Boundaries to Kids

The Growing up book for boys

The growing up guide for girls

The Mix: Sex and the law

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