A short-term "behavioural support" service for autistic adults without an intellectual disability: a pilot evaluation

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Abstract:

Purpose: A region's *Transforming Care Partnership* identified that autistic adults without an intellectual disability (ID) may be falling through gaps in services when presenting with a significant emotional and/or behavioural need in the absence of a mental health diagnosis. The region's Intensive Support Teams (ISTs) for adults with ID therefore piloted a short-term 'behavioural support service' for this population.

Design/methodology/approach: This study represents a mixed-methods service evaluation over a four year pilot period. The quantitative component examined referral rates and demographic data of accepted and declined referrals; and length of referral episodes and Health of The Nation Outcomes Scores (HoNOS) for accepted referrals. The qualitative component used thematic analysis to identify key themes relating to reasons for referral, clinical/therapeutic needs, and the models of support that most informed assessments and interventions at individual and systems levels.

Findings: The ISTs accepted 30 referrals and declined 53. Most accepted referrals were male (83%), and under 24 years old (57%). Average HoNOS scores were above the thresholds generally associated with hospital admission. Key qualitative themes were: (1) transitional support; (2) sexual risks/vulnerabilities; (3) physical aggression; (4) domestic violence; and (5) attachment, trauma and personality difficulties. Support mostly followed psychotherapeutic modalities couched in trauma, attachment and second and third-wave cognitive behavioural therapies. Positive Behaviour Support did not emerge as a model of preference for service-users or professionals.

Originality: This project represents one of the first of this type for autistic adults without an ID in the UK. It provides recommendations for future service development and research, with implications for *Transforming Care* policy and guidance.

Introduction:

Autism (or Autistic Spectrum Disorder) describes a range of life long neurodevelopmental differences, marked by difficulties with social interaction and communication, alongside restricted, stereotyped and/or repetitive behaviours (Tromans *et al.* 2018). It is estimated that

1.1% of adults could meet the diagnostic criteria for autism (Brugha *et al.* 2016). However, prevalence rates appear to be rising (Russell *et al.,* 2022), with evidence to suggest that future adult prevalence could be nearer to 2.76% (Maenner *et al.* 2023). Whilst autism is often associated with intellectual disability (ID), estimates suggest that 30-60% of autistic people do not have an ID (Emerson & Baines, 2010; p7; NICE 2018; p6). Brugha *et al.* (2016) report a widespread assumption within UK health and social care policy that half or more of autistic people do not have ID, suggesting that there may be more autistic people who do not have an ID than those who do. As autism is widely considered to be a developmental condition, the imperfect term 'intellectual and/or developmental disability' (IDD) will be used when referring to both populations at once (i.e. people with ID and/or who are autistic), usually within the policy context of *Transforming Care.*

Autistic people are more likely to experience mental health problems than the general population (Lai *et al.,* 2019) and at a greater severity (Newell *et al.,* 2023). A range of factors have been proposed to explain this difference, including biological mechanisms (Juranek *et al.*, 2006), barriers and adverse events associated with accessing mainstream health services (Doherty *et al.* 2022), and psychosocial factors such as stigma, trauma and difficulties 'fitting in' to neurotypical society (Cooper *et al.* 2017; Peterson *et al.* 2019; Beck *et al.* 2020). The same mental health services should exist for autistic adults without ID as they do for the general population, although many report difficulties accessing these services at times of need, and receiving support tailored to their autism (Crane *et al.* 2019; Doherty *et al.* 2022). Policy has long insisted that autistic adults with ID should be able to access specialist mental health support via their local ID services if and where this is indicated (DOH, 2001; p66-67). Where 'behaviours of concern' are present in the absence of a diagnosable mental health condition, autistic adults with ID will usually access these same ID services, that will specialise in a broad range of emotional and behavioural presentations regardless of how they are categorised. For those without ID it is less clear, as there appear to be few emotional or behavioural support services for autistic people who have neither an ID or mental health diagnosis that would otherwise qualify them for secondary services (Hassiotis *et al.* 2022; p45). This may represent a service-gap under *Transforming Care*, which is primarily concerned with the meeting the mental health and behavioural needs of all people with IDD within their communities (LGA & NHSE, 2014; Bubb, 2015).

A 'behavioural support service' for autistic adults without ID:

This service development can be traced back to 2017, when the, then, *Transforming Care Partnership* (TCP) for the authors' region identified a small cohort of autistic adults who were

struggling to access a specialist service for a risky and/or distressing emotional or behavioural need. This group were not well defined, other than they appeared to be falling through gaps in existing provision through having neither an ID or mental health need that qualified them for services (see Figure 1). Whilst the locality offers a specialist neurodevelopmental service for people without ID, this was primarily a diagnostic, signposting and consultation service. The locality also commissions an NHS Community Forensic Service for people with IDD, but only a minority of autistic adults experiencing mental health and/or behavioural difficulties meet risk and/or legal thresholds for forensic services. This created a mandate for the local TCP to develop a short-term behavioural support service for autistic adults without an ID, mental health and/or forensic need that would have otherwise qualified them for services. The TCP estimated a projected referral rate of around five to six individuals a year, based in part on rates of individual funding requests received from GPs for services not routinely offered by the NHS. When looking to existing services with specialist autism knowledge, and established expertise in the assessment and support of behaviours of concern, the locality's two NHS Intensive Support Teams (ISTs) for adults with ID were considered best placed to expand into this new role. This was due in part to the ISTs' skills and experience in functional behaviour assessment (FBA) as part of a wider *Positive Behaviour Support* (PBS) approach, in addition to a multi-modal support model that included trauma, attachment, sensory, communication and psychiatric perspectives on autism, risk and distress. This ensured that any adult referred to the service had access to a full multidisciplinary team that included specialist nursing, speech and language therapy, occupational therapy, clinical psychology, psychiatry and unregistered assistant and support roles.

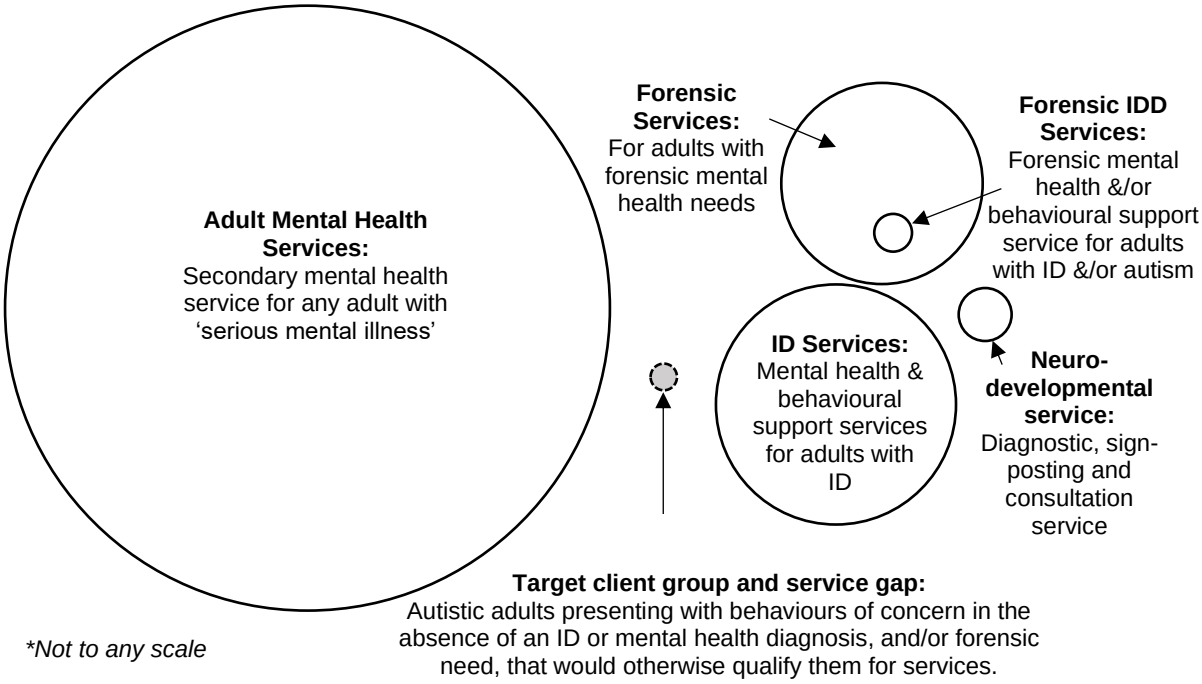
Defining the client group:

The service initially adopted an accepted definition of 'challenging behaviour' (or 'behaviours of concern') to operationally-define the types of difficulties its target population may be experiencing to meet service eligibility:

> *"Behaviour can be described as challenging when it is of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others and is likely to lead to responses that are restrictive, aversive or result in exclusion."* (RPsych, BPS & RCSLT, 2007).

It was on operationalising this criteria that the IST discovered how there are few to no mental health presentations that would not meet this definition of behaviours of concern. This

Figure 1: *Pre-pilot mental health and IDD service provision**



perhaps explained an early influx of referrals from colleagues across health and social care for autistic adults needing and/or seeking support for the distress behaviours associated with a mental health concern. Whilst the IST recognised the need for autism-sensitive mental health services for people without ID, this fell outside of the narrow remit of this short-term behaviour support service. This led to a revision of the referral criteria to ensure that any presentation that was better understood as a symptom and/or manifestation of a mental health need remained the therapeutic domain of adult mental health (AMH) services. In addition, the IST attempted to minimise further overlap with existing neurodevelopmental and forensic services by requiring an existing diagnosis of autism (so as not to be confused with a diagnostic service), and not working with individuals whose behavioural risks met the threshold for forensic services.

Study aims and objectives:

Service evaluation is an essential component of quality improvement, and done well can help identify problems, build knowledge and inform decision-making in the interests of all stakeholders (The Health Foundation, 2015). This is especially relevant to this service development, for which there appeared to be little to no prior precedent for delivering a short-term behavioural support service for this specific service-user population (Hassiotis *et al.* 2022; p45). This paper therefore aims to examine the nature of support requests for people referred to the service, and the broad types of approaches or interventions that they

received, in order to understand which of the ISTs' skills and models (or there lack of) most informed their support. This is with a view to informing future service-development.

Design and methodology:

The methodology was based in large part on Browning *et al's* (2016) mixed-methods evaluation of a new community forensic service for adults with IDD. In keeping with their methodology, key demographic data on accepted, but also declined, referrals were collected, combined with analyses of key case notes of each accepted referral where required. This included extracting key information and codes on discharge outcomes. Health of the Nation Outcome Scales (HoNOS) were collected for all accepted referrals, as an additional indicator of case-complexity at point of referral (Clifford & Kemp, 2020). Thematic analysis (Braun & Clarke, 2006) was used as the qualitative methodology for examining and extracting key information from referral documents and case notes, using elements of Robinson's (2022) tabular approach for investigating brief texts. The analysis adopted a largely inductive approach to ensure that themes were grounded, as far as possible, in the independent context of the text, although this would not have ruled out a theoretically driven bias where preferred terms and concepts would have undoubtedly influenced the shaping of the themes (e.g. Joffe, 2012; p215). Whilst referrals were often tracked informally by the researchers as embedded clinicians in the ISTs, key evidence pertaining to support models and/or approaches were confirmed by using key words as search terms in electronic records, and examining the immediately surrounding text.

Ethical considerations:

No identifying information has been included in the write-up of this research. All demographic details were extracted from NHS records and/or referral texts in accordance with the authors' NHS Trust's Research and Development protocols. Service-users would not have been aware that their demographic details and support themes were being anonymised and used for service-evaluation and service-development purposes. For this reason, very unique clinical presentations and/or therapeutic needs have been either omitted from the final-write up, and/or obscured slightly to preserve their relevance to the study findings whilst further protecting confidentiality and anonymity. Ethics clearance was provided by the authors' NHS Research and Development Department.

Results:

The total number of referrals over the pilot period was 83; split 36% accepted referrals and 64% declined referrals. These categories will be discussed in this order.

1. **Accepted referrals: key demographic and referral data:**

Accepted referrals for the evaluation period totalled 30 cases across 46 months (see Table 1). Given the small sample size, only basic analyses of demographic factors have been presented as part of this evaluation.

The ages of accepted referrals ranged from 17 (n=2) to 60 (n=1). It is relevant that 17.5 is the lower-age limit for IST service eligibility. This is exclusively for young people who have been newly referred to services, and for whom it would not be in their interests to be referred to Children's Services (CAMHS) for ≤6 months before transitioning into adult services. Table 1 illustrates that mode age for accepted referrals was 18 (n=7), followed by 19 (n=4). A result is that 43% of referrals were 17-19 years of age, with the majority of referrals (57%) being 23 or younger. The mean age across the study period was 26.3 (SD=10.8), with a median of 26.6 years old.

Table 1 shows that the ratio of males to females was 83% (n=25) to 17% (n=5). As far as the ISTs are aware, they worked with no individuals during the project phase who identified differently to their birth gender.

Length of referral episode varied greatly between 3 and 776 days, with accepted referrals averaging 183 days (SD=169.6). 10% of referrals were 8 days or less, with the remaining 90% being 46 days or more. Significantly shorter referrals were where the IST had agreed to provide some weekend support to an individual in the absence of their usual services (representing a flexing of referral criteria), or where a prompt and intensive piece of assessment resulted in a quick onward referral, but with some comprehensive formulation and/or support recommendations. 17% of accepted referrals were open for 365 days or more, with only 1 referral open for longer than 2 years. The majority of these longer referrals involved some sort of domestic violence, abuse and/or coercive and controlling behaviour (DVA) towards other householders, and all presented with eligibility issues about which service (if any) were best placed to provide ongoing case-management on discharge from the ISTs.

Table 1: *Key demographic and referral data for accepted referrals*

Year	Accepted Referrals	Age			Gender	Care episode (days)		Entry HoNOS-LD		Entry HoNOS-PBR	
	n	Range	Mean (SD)	Mode	M/F (%)	Range	Mean (SD)	Range (n)	Mean (SD)	Range A / T (n)	Mean A/T (SD/SD)
2018	11	18-38	23.9 (6.5)	19	11/0 (100/0)	8-776	187 (211.1)	21-29 (3)	25 (4)	11-22/17-66 (8)	15.6/35.1 (4.1/17.1)
2019	3	23-39	31.3 (8)	N/A	3/0 (100/0)	3-46	18.3 (24)	15-15 (1)	15 (0)	N/A (0)	N/A (N/A)
2020	9	18-60	27.7 (16.8)	18	7/2 (78/22)	57-530	175 (152.2)	30-69 (3)	45.3 (20.8)	10-20/21-35 (5)	16.6/28.8 (4.2/5.4)
2021	7	17-39	26.1 (8.4)	N/A	4/3 (57/43)	104-391	255 (118)	16-22 (3)	21.3 (5)	10-20/27-56 (3)	16.7/38 (5.8/15.7)
Total	30	17-60	26.3 (10.8)	18	25/5 (83/17)	3-776	182.5 (169.6)	15-69 (10)	29 (15.5)	10-22/17-66 (16)	16.1/33.7 (4.1/13.8)

In the absence of a HoNOS specific to this service-user population, the intention had been to use the *Mental Health Clustering Tool* (MHCT), which incorporates items from the original

HoNOS (Wing *et al.*, 1999) with the *Summary of Assessments of Risk and Need* (SARN) (Self *et al.* 2008), to provide both acute and historical ratings of individuals' mental health needs (NHSE, 2016). However, clinical habits can be hard to change, resulting in 33% of referrals (n=10) being rated with the HoNOS-LD (Roy *et al.*, 2002), despite the absence of an ID, and only 53% (n=16) being rated with the MCHT. 13% (n=4) had no recorded rating. In order to mark some of the similarities and differences between the HoNOS-LD and MHCT, both MHCT-*acute* (from previous 14 days) and MHCT-*total* scores (incorporating historical data) were collected; in contrast to a single score for HoNOS-LD (always based on last 4 weeks only).

Table 1 illustrates that HoNOS-LD scores at referral ranged from 15 to 69, with an average of 29 across the sample period (SD=15.5). Whilst scores should be treated with caution given the small sample size, and HoNOS-LD not being validated for people without ID, compared with available data for average HoNOS-LD scores for the ISTs' majority ID caseload in 2018 (n=231), this represents a higher average by 5.2 points, albeit with a wider distribution (Clifford & Kemp, 2020). A higher HoNOS-LD score is generally suggestive of greater case-complexity, with a global HoNOS-LD score of 21 providing a possible threshold for greater need across a range of domains that could result in hospital admission (Sandhu &Tomlins, 2017).

MCHT-acute scores ranged between 10 and 22, with a mean of 16.1; whilst MCHT-total scores ranged between 17 and 66, with an average of 33.7 (see Table 1). The distribution was considerably narrower with MCHT-acute scores (SD=4.1) compared with MCHT-total scores (SD=13.8). Given the small sample size, none of the variance of MCHT-acute or MCHT-total scores is explained by age (R^2=0.04 and R^2=0.05 respectively). There is some evidence to suggest that HoNOS ratings of around 13.5 or higher are associated with inpatient admission (Brooker *et al.* 2007), although no referrals were admitted to hospital during the project period (although around 17% were referred from inpatient settings to support community discharges).

2. Declined referrals:

Declined referrals totalled at least 53 across 46 months, accounting for 64% of all referrals (see Table 2). This will represent an underestimate of all referral enquires, as some will have been declined quickly and decisively by busy IST workers, and not entered on the evaluation database.

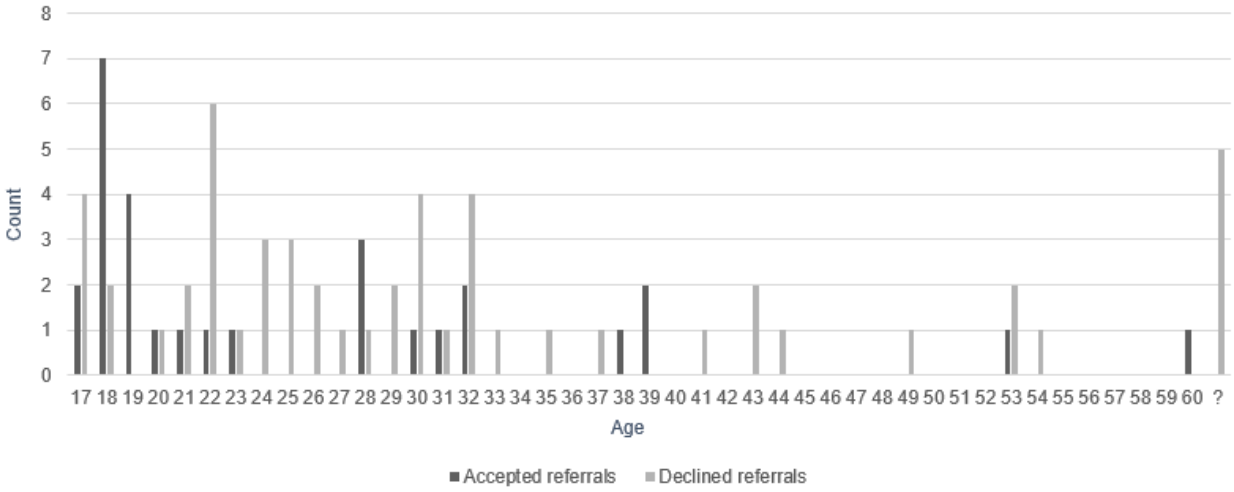
Table 2: *Available demographic data for declined referrals*

Year	Declined Referrals	Age				Gender	
	n	Range	Mean (SD)	Mode	Not recorded	M/F (%)	Not recorded
2018	9	22-29	25.4 (2.7)	N/A	3 (33.3%)	7/1 (78/11)	1 (11%)
2019	14	17-49	27.2 (9.7)	N/A	1 (7.1%)	10/4 (71/29)	0 (0%)
2020	13	17-54	27.6 (12.1)	22	0 (0%)	10/3 (77/23)	0 (0%)
2021	17	17-53	32.8 (9)	32	0 (0%)	12/5 (71/29)	0 (0%)
Total	53	17-54	29.1 (9.9)	22	4 (7.5%)	39/13 (74/25)	1 (2%)

Ages of declined referrals ranged from 17 (n=4) to 54 (n=1) with an average age of 29.1 (SD=9.9). The mode age of declined referrals was 22 (n=6), followed by 17, 30 and 32 (n=4). The ages of at least 5 declined referrals were not recorded. This represents a slighter higher average age than accepted referrals, perhaps explained by a comparatively higher number of people in their mid-twenties through to late forties (see Chart 1). A hypothesis in need of evidence is that these individuals had spent more time accessing (and perhaps struggling within) AMH services before they and/or their referrer approached a new specialist autism service that wasn't previously available.

Table 2 indicates that males and females where split 74% (n=39) to 25% (n=13) respectively, with 1 case note not recording or revealing a gender. The ISTs are unable to confirm whether any declined referrals identified differently to their birth-gender. Anecdotally, the slightly higher rate of females amongst declined referrals seemed to reflect a larger group of females with trauma, attachment and/or personality difficulties (diagnosed or not), where the individuals and/or their health or social care team felt they were not fitting well within AMH services due to diagnosed or undiagnosed autism.

Chart 1: *Ages of accepted and declined referrals*



3. Nature of 'behavioural support' needs amongst accepted referrals:

The full range of primary and/or concomitant assessment and support requests can be found in Table 3. For the purposes of this thematic analysis, the discussion has been limited to the five most common categories identified through the coding process. It was also decided to collapse 'trauma and attachment' and 'Personality Disorder' into a single category occurring across seven accepted referrals, given that these concepts are so often interlinked (Mosquera *et al.* 2014; Peng *et al.* 2020), and/or represent different professional terms or lenses to describe similar clinical phenomena (Herman, 2015; p123-126). Where overlaps in other themes occur, these have been reported in the findings.

A. Transitional support
B. Sexual risks and/or vulnerabilities.
C. Physical aggression
D. Domestic violence, abuse coercion and/or control (DVA)
E. Attachment, trauma and/or personality disorder

Table 3: *Range of identified needs and/or support requests documented in accepted referrals:*

Transitional support	Personal vulnerability	Needing FBA
Sexual risks/vulnerabilities	Drugs & alcohol	Needing PBS Plan
Physical aggression	Personality Disorder	Placement breakdown
Domestic violence, abuse, coercion &/or control	Anger	Multiple diagnoses
	Anxiety	Stalking
Self-injury	Property damage	Litigious/vexatious complaining
Anti-social behaviour	Violent threats	Paranoia
Trauma &/or attachment needs	Disengagement	'ARFID'
Forensic risks	Social isolation	Family stress
'ADHD'		

3a. Transitional support:

Around a quarter of referrals involved some sort of transitional support between services. This was a majority male population. These included supporting hospital discharges from secure care, or from acute adult and/or children's inpatient services, including Psychiatric Intensive Care Unit (PICU) settings. These also included support and transition between different hospital settings and specialisms. All of the people being discharged from secure-settings had sexual-offence histories, and none required any further MDT assessment from the ISTs. This was not the same for discharges from acute settings who generally had some outstanding assessment and support needs. The majority of people discharged from acute settings had been admitted due, in part, to some level of online or offline sexual risk to others, that had also contributed to breakdowns of their community placements. A very small percentage of people being discharged from a hospital setting had a previous history of 'serious mental illness', that was considered stable at point of discharge.

Other transitional support included working with individuals, families, providers and multi-agency teams to assist individuals' moves into new supported accommodations. These transitions were preceded by placement breakdowns, either in family settings or another supported placement. Community-to-community transitional support always involved some additional assessment, formulation and support tasks. These were initially to maintain placements in line with people's wishes and/or best-interests, but went onto inform something similar to 'PBS Planning' for receiving providers when this proved unsuccessful.

3b. Sexual risks and/or vulnerabilities:

Just over a quarter of referrals listed sexual risks as a primary or secondary concern requiring input. Reported risks ranged from online grooming with offline intent (also placing individuals themselves at risk of harm and exploitation); illegal online activity with no known offline risks; prosecuted and unprosecuted sexual assaults on others (e.g. family members, members of the public); voyeurism; allegations of illegal sexual interests and acts not previously covered; unorthodox, but not necessarily illegal, sexual interests generating concern around risk and vulnerability; vulnerability from sexual abuse and exploitation (with no risk to others); and combinations of the above in the histories of individuals being discharged from longer term hospital settings.

It is noteworthy that over half of the referrals identified in this category reported backgrounds of Adverse Childhood Experiences (or ACEs), such as sexual and/or physical abuse,

neglect, and multiple relationship and/or placement breakdowns. This seems clinically relevant given known associations between ACEs and health and wellbeing outcomes in later life (Hughes *et al.,* 2016).

Professional input usually involved some level of formal assessment of risk, vulnerability, knowledge and attitudes around sex and relationships, using a range of standardised instruments designed for people with IDD (e.g. Wilson *et al.* 1996; O'Callaghan & Murphy, 2002; Butler *et al.* 2004; Hart & Boer, 2010). This was either to inform interventions of a psychoeducation nature around safe, moral, legal and/or socially-acceptable on- and offline behaviour; and/or to inform capacity, best-interests and risk-management discussions amongst multi-agency colleagues (including Police).

3c. Physical aggression:

Physical violence and aggression towards others was a current feature of at least 20% of accepted referrals. These were all male. This mostly included physical aggression towards other family householders (covered in more detail in next section), but also included cases of recent physical assaults on members of the public, other service-users and inpatient and/or community support staff. Police had been involved at some stage in most cases, but only a minority went onto receive criminal convictions. Alcohol was a factor in just under half of cases, and presented a significant barrier to progress with a small minority of referrals

Assessment, formulation and intervention work focussed on individual anger-management and emotional regulation strategies for around half of these referrals. These tended to follow and/or combine secondary and/or third wave Cognitive Behaviour Therapy (CBT) models (e.g. Black *et al.*, 1997; Varela, 2014; Jahoda *et al.,* 2017; p181-207), attempting to connect background histories, stressors, thoughts, emotions and behaviours, and arriving at a set of individual coping strategies. (Similar work was undertaken with individuals under other support themes.) For individuals living in supported environments (e.g. hostels, residential care), support and guidance was also provided to staff, and summarised as PBS strategies.

3d. Domestic violence, abuse, coercion and/or control:

Around a sixth of referrals referred listed violence, aggression, coercive and/or controlling behaviour towards a partner or family members. All referrals under this theme were male. The majority of these referrals involved physical violence and intimidation towards a female parent figure. A minority also included unprosecuted sexual risks. Another minority of

involved physical altercations with other adult family members (male and female), where the individual was depicted as the primary aggressor. 80% of referrals in this category were received in the 22 months following the start of the UK's Covid-19 epidemic, rather than in the 26 months prior.

Cases of DVA and/or coercive and controlling behaviour all involved a delicate balancing of the needs, rights and responsibilities of all affected parties, but were usually led, at least initially, by the Safeguarding needs of alleged victims. This included completion of the *Domestic Abuse, Stalking and Honour Based Violence Risk Identification Checklist* (DASH-RIC) at the earliest opportunity, and making the necessary *Multi Agency Risk Assessment Conference* (MARAC) referrals. Input usually involved some level of safety planning with alleged victims, as well as emotional and practical support if/where feasible and/or welcomed. A consistent theme amongst alleged victims was living in near constant apprehension of their relative. Victims usually described coping patterns of keeping stress and demand to an absolute minimum around the autistic adult, whilst also trying be as present and responsive to them as possible. In just over half of cases, victims' inability to separate or withdraw from their relative under some extremely oppressive and risky conditions appeared driven, in large part, by an overwhelming sense of personal moral duty, and fear for the autistic person's safety and wellbeing. These patterns were usually accompanied by reports of extreme carer burnout*,* and victims seeking independent mental health support from their GP or secondary services, as has been found amongst parents of autistic children with complex needs (Khutuk *et al.* 2021).

Assessment, formulation and intervention work under this category followed a predominantly CBT approach to anger-management, emotional-regulation and/or unorthodox beliefs. Where a CBT approach was adopted, this was always accompanied by an attempt to increase occupational activity and a sense of purpose, identity and/or belonging outside of the family home. Where individuals struggled with moral reasoning or empathy for affected family members (perhaps feeling victims themselves), the psychoeducation component tended to focus on the personal advantages and disadvantages of interacting differently with the world, whilst acknowledging it did not always treat them fairly. Self-esteem issues were identified in at least half of this group, and could not be ruled out in any of the cases. Around a fifth of cases resulted in some form of separation being sown between the alleged perpetrator and their victim(s), with this being a primary recommendation in nearly two thirds of cases due to severity of risks and/or perceived barriers to change.

3e. Attachment, trauma and/or personality disorder:

Around a fifth of accepted referrals described individuals with complex trauma and attachment histories, and/or for whom personality disorder had been diagnosed or considered. These referrals were split evenly between males and females – suggesting that females were overrepresented in this category – and ranged in age from amongst the youngest to oldest of all referrals. All individuals had received at least one additional diagnosis to autism. Actual or queried diagnoses included ID, Attention Deficit and Hyperactivity Disorder (ADHD), Paranoid Psychosis, Mood Disorder, Obsessive Compulsive Disorder (OCD), Pathological Demand Avoidance (PDA), Conduct Disorder, Oppositional Defiance Disorder (ODD), Post Traumatic Stress Disorder (PTSD), and sometimes more than one category of Personality Disorder. Illicit drugs and/or alcohol were factors in around half of cases.

Most referrals in this category reported some sort of engagement, eligibility and/or satisfaction issue with existing services. A minority felt they were being denied an AMH service; whilst another minority were declining and/or disengaged from the AMH services offered to them. The majority of this group could be described as leading relatively chaotic lifestyles, that included concerning levels of self-harm and/or putting themselves at risk through their behaviour. Cases also included low-level criminality and/or moving between temporary addresses in and outside of the region, usually impacting on therapeutic engagement. This group were considerably more likely to be in receipt of multi-agency and multi-professional support packages.

This category of referrals was marked more by vulnerability and risks to self. A minority were reported to be presenting a severe and forensic level of risk to others (e.g. staff and other service-users). Most had experienced physical and/or sexual abuse, and repeated cycles of rejection and abandonment. Around half had experienced multiple placement breakdowns and/or hospital admissions, whilst also finding themselves again at risk of both. At least two thirds of this group had inpatient histories, with the majority having accessed a longer term rehabilitation and/or secure care settings. Around a third of these individuals were referred from inpatient settings.

The ISTs were less likely to work directly with these individuals, perhaps explained by their pre-existing multi-agency and multi-professional support packages, and the ISTs not wanting to add complexity to complexity. A minority declined IST input when offered and/or attempted. These referrals were often accompanied by significant stress and occupational

burnout at the direct support level, and high levels of organisational anxiety at a wider system-level. Professional systems often included multiple services and regions, including (often duplicate) mental health clinicians and social work professionals of ranging seniority and specialisms, NHS and local authority commissioners, third sector providers, voluntary organisations, advocacy, legal roles, Police and other *Transforming Care* personnel (e.g. clinical advisors, experts by experience). Some multi-agency meetings recorded well over twenty attendees in addition the service-user and family members. IST input usually included offers of formulation support and training to providers around autism, communication, sensory differences, attachment, trauma, mental health and/or occupational wellbeing; as well as consultancy to multi-agency colleagues around aspects of the same.

The majority of referrals reflected some sort of eligibility dispute between different services, agencies and/or regions; with the IST referral often being part product of this. It is here where the ISTs observed a possible paradox where multiple psychiatric diagnoses (potentially indicating eligibility for multiple services) led more teams and services to feel under-trained and under-equipped in one or more of the service-users' support needs. Menzies-Lyth's (1988) model for observing how professional social systems function under stress and uncertainty provided a useful conceptual framework for identifying practices more consistent with social defences against organisational anxiety than person-centred care (e.g. Whittaker, 2011; Lees *et al.,* 2013). The ISTs would not have been immune to these occupational practices, and occasionally used this model to promote greater responsibility-taking, shared decision-making and a re-centering of the person.

4. Nature of 'behavioural support' needs amongst declined referrals:

A standout support request amongst declined referrals was to assist and/or replace AMH services in providing an autism-sensitive mental health service for an individual. This was often where the individual and/or members of their health or social care team were reporting a lack of autism knowledge and skills. The ISTs were often reminded that the autistic person was displaying risky distress behaviours that they and/or the MDT were struggling to understand and manage; but as this was a manifestation of a mental health need for which the person was already accessing AMH services, this fell outside of the ISTs' specific remit. Referrals were also declined if the person's distress behaviours appeared related to a mental health need for which they had not yet approached and/or accessed AMH services (e.g. low mood, paranoia, reports of voice-hearing).

Some individuals were declined due to not having a formal autism diagnosis; often having been referred to the IST for this purpose. These individuals were usually sign-posted to local diagnostic services. The ISTs received a number of additional referrals for autistic people struggling with a range of psychosocial stressors (e.g. housing, finances, relationships, substance use, vulnerability, lack of support package), with limited to no access to additional health and social care. Given the often social origins, and therefore solutions, to these types of difficulties, individuals were usually signposted to more appropriate local services.

Some referrals were declined due to levels of forensic risk. This was usually for individuals with recent histories with forensic services; and/or for whom current risks met forensic thresholds. A minority were for autistic individuals being discharged from community forensic services, who did not have an ID or mental health diagnosis that otherwise qualified them for existing services. Affected individuals could be experiencing multiple difficulties across a number of support domains – all combining into a picture of significant but stable case-complexity – but where each difficulty, taken individually, was 'sub-clinical' for eligibility to any one secondary healthcare service. Outcomes from declined referrals included forensic services delaying discharge, existing health provision flexing their eligibility criteria (e.g. AMH or ID services), and/or individuals being discharged from secondary mental health services with only social care and Primary Care oversight (as could happen with accepted referrals). It is here where absence of longer term case-management services for autistic adults with complex risks and vulnerabilities, but in the absence of an ID, mental health and/or active forensic need, appears to represent a service-gap under *Transforming Care.*

Limitations:

A key limitation would be the project's small sample size, making for even smaller subgroup populations from which to make generalisations. Findings should therefore be treated with caution, and perhaps more as working hypotheses for further research and service-development. It is regrettable that opportunities were not taken to map and discuss how different support themes overlapped and clustered (e.g. DVA and physical aggression), to given an indication of the types of difficulties that individuals and/or carers may experience concurrently, and/or where a small number of referrals generated a disproportionate number of themes.

It is relevant that most of the therapeutic modalities reported in this evaluation were already available within the ISTs' specialist interests and skillsets (e.g. trauma and attachment, CBT and similar). This opens the strong possibility of epistemological bias in formulating,

articulating and responding to referrals. That said, PBS also represents a specialist skillset and interest of the ISTs, which did not emerge as a model of preference for this service-user population.

An accepted shortfall of this service-evaluation was the lack of patient and public involvement. Some collaboration with experts by experience would certainly have enhanced the authenticity and credibility of the research, and shaped the study in a direction that more confidently serves its service-user population (Fletcher-Watson *et al.*, 2019). A genuinely participatory approach will certainly be a consideration for future service-evaluations.

Summary and recommendations:

This service development served a diverse set of individuals and wider stakeholders, presenting with a broad range of needs and support requests. Below are some key discussion points for informing future service-developments for autistic adults without ID.

The ISTs' experience and credentials in PBS were key factors in them being commissioned to pilot a 'behavioural support service' for this client population. This is endorsed by *Transforming Care* policy and guidance, that has adopted Gore *et al's* (2013) definition of PBS, that inextricably links it to *Applied Behaviour Analysis* (ABA) as its underpinning theory, evidence-base and technology for assessing and intervening in the behavioural lives of people with IDD (DOH, 2015; p35-36). Central to this definition is that behaviours of concern serve important 'functions' for individuals, and should therefore be assessed via a process of FBA, to inform function-based interventions (DOH, 2015; p35-36). Guidance does not preclude other evidence-based approaches or theories, but is clear that these should be "secondary" or "complementary" to ABA as the primary lens through which to understand and intervene in the behaviours of people with IDD. FBA is generally defined as a systematic method for discovering observable relations between specific environmental events and behaviours, where results are used to guide the design of interventions for decreasing problem behaviours and increasing appropriate behaviours (Cooper *et al.* 2014; p8, p511). Behaviour analysists tend therefore to distinguish between "mentalistic"" and "environmental" explanations for behaviour, where the former describes unobservable causal constructs (e.g. thoughts and feelings), and only the latter are conducive to FBA (Cooper *et al.* 2014; p32):

> "Behavior analysts rely primarily on *what* and *when* questions that focus on the environmental conditions that exist before, during, and after a behavioral episode, instead of *why* questions,

> which tend to evoke mentalistic explanations that are of little value in understanding the problem." (Cooper *et al.* 2014; p70)

The ISTs met no individuals over the course of the pilot who sought to have their emotional and/or behaviour problems assessed and conceptualised in this way. Where individuals had direct therapeutic relationships with the ISTs, their problems were almost always explored in ways that attempted to connect personal histories, stressors, thoughts, emotions, relationships, communication patterns and personal recovery goals as part of a collaborative formulation. These tended to reflect a more eclectic or integrative approach (Dallos *et al.*; 2006) that went beyond PBS's openness to secondary or complementary methods to ABA, but often forwent a behavioural lens entirely. Whilst more recent definitions of PBS recognise the value of data collection methods developed outside of the behavioural disciplines, such as creative ways of seeking insights and contributions from service-users themselves (Gore *et al.* 2022), it is FBA that remains the mainstay of IDD policy and guidance.

When working with family carers and paid staff, models of most relevance appeared again to include trauma, attachment, communication, and the personal risks and therapeutic implications of carer stress and burnout. Whilst recommendations were occasionally summarised as PBS strategies, they would not have passed standard tests for intervention fidelity due to their lack of applied behavioural underpinnings.

These findings echo those by Milton (2018), who identifies that whilst PBS and ABA-based approaches maybe popular amongst carers and professionals, this is often at odds with the views of autistic people themselves. Reviews by Collins *et al.* (2021) and Taylor (2021) also identify how PBS may be at risk of being over-promoted into areas and client populations where it lacks an evidence-base, at the expense of other tried and tested modalities that do not. A study recommendation for similar service developments may be to deprioritise PBS knowledge and skills – at least whilst it remains inextricable from ABA – in favour of psychotherapeutic models informed by second and third-wave CBT, and concepts of trauma and attachment, specifically tailored to autism.

The pilot has also highlighted a need for specialist skills and training in the assessment and management of significant sexual risks and vulnerabilities. This appears most applicable to individuals without an offence history, but who may share risk profiles with people accessing forensic services.

For individuals with the most complex needs, there seems a need to understand the importance and pitfalls of multi-agency working, including theories on the functioning of professional social systems. This is to enable the early identification of less helpful features of organisational anxiety, to streamline limited resources, and guide intervention in the interests of key service-user stakeholders. Specialist skills also include the ability to navigate the complex interface of evidence, clinical guidance, legal and policy frameworks for people with complex risks and needs.

The pilot identified a small population of individuals and families living in situations of severe DVA, where a person's autism is a clinical consideration in aggressive, coercive and/or controlling behaviour, and how this is framed. This highlighted the importance of knowledge and expertise in the safeguarding and epistemic needs and rights of all affected parties, in ensuring optimal outcomes in often difficult and conflicting circumstances.

Another key recommendation would be the development of longer-term case-management services for autistic adults whose multiple social, emotional, sensory, risk and/or vulnerability issues combine into a picture of significant case-complexity, but where no single difficulty meets a threshold for specialist services.

Key service-gaps identified by the pilot would include more neurodiversity training for AMH and social care colleagues, and growing the offer of specialist neurodevelopmental roles into AMH services to ensure that all autistic adults have access to autism-informed mental health services. This service need has begun to be addressed locally through the development of at least two, small, neurodevelopment services aimed at improving experiences and outcomes for autistic adults accessing inpatient and community AMH services. Ideally these would be therapeutic skillsets held by all mental health professionals, just as any mental healthcare professional should be able to practice in culturally-sensitive ways across multiple other protected characteristics.

References:

Black, L., Cullen, C. & Novaco, R. (1997). Anger assessment for people with mild learning disabilities in secure settings. In. Kroese. B., Dagnan, D. & Loumidis, K. (Eds). *Cognitive-behaviour therapy for people with learning disabilities*. Routledge: London.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101.

Brooker, C., Ricketts, T., Bennett, S., & Lemme, F. (2007). Admission decisions following contact with an emergency mental health assessment and intervention service. *Journal of Clinical Nursing*. 16(7): 1313-1322.

Browning, M., Gray, R., & Tomlins, R. (2016). A community forensic team for people with intellectual disabilities. *Journal of Forensic Practice*.18(4): 274-282.

Brugha, T. S., Spiers, N., Bankart, J., Cooper, S. A., McManus, S., Scott, F. J., ... & Tyrer, F. (2016). Epidemiology of autism in adults across age groups and ability levels. *The British Journal of Psychiatry*. 209(6): 498-503.

Bubb, S. (2014). Winterbourne View – a time for change. London: NHS England.

Butler, J., Leighton, D. & Galea, J. (2004). *The Assessment of Sexual Knowledge: A sexual knowledge and assessment tool for people with an intellectual disability*. Melbourne: Department of Human Services.

Clifford, A., & Kemp, F. G. (2020). A pragmatic mixed-methods review of changing "case-complexity" of referrals to an intensive support service. *Advances in Mental Health and Intellectual Disabilities*. 14(4): 111-124.

Collins, J., Barnoux, M., & Baker, P. (2021). Managing challenging behaviour using applied behavioural analysis and positive behavioural support in forensic settings: A systematic review. *International Journal of Positive Behavioural Support*. 11(1): 15-41.

Cooper, J. Heron, T. & Heward, W. (2014). *Applied Behaviour Analysis*. (2nd Ed.) Essex, Pearson Education Ltd.

Cooper, K., Smith, L. G., & Russell, A. (2017). Social identity, self-esteem, and mental health in autism. *European Journal of Social Psychology*. 47(7): 844-854.

Crane, L., Adams, F., Harper, G., Welch, J., & Pellicano, E. (2019). 'Something needs to change': mental health experiences of young autistic adults in England. *Autism*. 23(2): 477-493.

Dallos, R., Wright, W., Stedman, J. & Johnstone, L. (2006). Integrative formulations. In Johnston, L. & Dallpos, R. (Eds). *Formulation in psychology and psychotherapy*. Hove: Routledge.

Department of Health (2001). *Valuing People: a new strategy for learning disability for the 21st Century.* London: Department of Health.

Department of Health & Skills For Care (2015). *A positive and proactive workforce. A guide to workforce development for commissioners and employers seeking to minimise the use of restrictive practices in social care and health*. Leeds: Department of Health.

Doherty, M., Neilson, S., O'Sullivan, J., Carravallah, L., Johnson, M., Cullen, W. & Shaw, S. (2022). Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study. *BMJ open*. 12(2): e056904.

, E., & Baines, S. (2010). The estimated prevalence of autism among adults with learning disabilities in England. *Improving Health and Lives: Learning Disabilities Observatory, Durham*.

Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., ... & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism*. 23(4): 943-953.

Gore, N. J., McGill, P., Toogood, S., Allen, D., Hughes, J. C., Baker, P., ... & Denne, L. D. (2013). Definition and scope for positive behavioural support. *International Journal of Positive Behavioural Support*. 3(2): 14-23.

Gore, N. J., Sapiets, S. J., Denne, L. D., Hastings, R. P., Toogood, S., MacDonald, A., ... & Williams, D. (2022). Positive behavioural support in the UK: a state of the nation report. *International Journal of Positive Behavioural Support*. 12(1): 1-39.

Hart, S. D., & Boer, D. P. (2010). Structured professional judgment guidelines for sexual violence risk assessment: The Sexual Violence Risk-20 (SVR-20) and Risk for Sexual Violence Protocol (RSVP). In R. K. Otto & K. S. Douglas (Eds.). *Handbook of violence risk assessment* (pp. 269–294). London: Routledge/Taylor & Francis Group.

Hassiotis A, Kouroupa A, Hamza L, Morant N, Hall I, Marston L, et al. (2022). Intensive support teams for adults with intellectual disabilities displaying challenging behaviour: the IST-ID mixed-methods study*. Health & Social Care Delivery Research*. 10(33): 1-103.

Herman, J. (2015). *Trauma and recovery: the aftermath of violence – from domestic abuse to political terror*. New York: Basic Books.

Hughes, K., Lowey, H., Quigg, Z., & Bellis, M. A. (2016). Relationships between adverse childhood experiences and adult mental well-being: results from an English national household survey. *BMC Public Health*. 16(222): 1-11.

Jahoda, A., Stenfert-Kroese, B. & Pert, C. (2017). *Cognitive behaviour therapy for people with intellectual disabilities*. London: Palgrave Macmillan UK.

Joffe, H. Thematic Analysis. In Harper, D. & Thompson, A. (Eds). *Qualitative research methods in mental health and psychotherapy.* Chichester: John Wiley & Sons Ltd.

Juranek, J., Filipek, P. A., Berenji, G. R., Modahl, C., Osann, K., & Spence, M. A. (2006). Association between amygdala volume and anxiety level: magnetic resonance imaging (MRI) study in autistic children. *Journal of child neurology*. 21(12): 1051-1058.

Kütük, M. Ö., Tufan, A. E., Kılıçaslan, F., Güler, G., Çelik, F., Altıntaş, E., ... & Kütük, Ö. (2021). High depression symptoms and burnout levels among parents of children with autism spectrum disorders: a multi-center, cross-sectional, case–control study. *Journal of autism and developmental disorders*. 51: 4086–4099.

Lai, M. C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., ... & Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. *The Lancet Psychiatry*. 6(10): 819-829.

Lees, A., Meyer, E., & Rafferty, J. (2013). From Menzies Lyth to Munro: the problem of managerialism. *British Journal of Social Work*. 43(3): 542-558.

Local Government Association & NHS England (2014). *Ensuring quality services*. London: Local Government Association.

Maenner, M., Warren, Z., Williams, A., Amoakohene, E., Bakian, A., Bilder, D., Durkin, M., Fitzgerald, R., Furnier, S., Hughes, M., Ladd-Acosta, C., McArthur, D., Pas, E., Salinas, A., Vehorn, A., Williams, S., Esler, A., Grzybowski, A., Hall-Lande, J., Nguyen, R.., … Shaw, K. (2023). Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. *Morbidity and mortality weekly report. Surveillance summaries (Washington, D.C.: 2002)*. 72(2): 1–14.

Mosquera, D., Gonzalez, A., & Leeds, A. M. (2014). Early experience, structural dissociation, and emotional dysregulation in borderline personality disorder: the role of insecure and disorganized attachment. *Borderline personality disorder and emotion dysregulation*. 1(1): 1-8.

Newell, V., Phillips, L., Jones, C., Townsend, E., Richards, C., & Cassidy, S. (2023). A systematic review and meta-analysis of suicidality in autistic and possibly autistic people without co-occurring intellectual disability. *Molecular autism*. 14(1): 1-37.

NHS England (2016). *Mental Health Clustering Booklet*: https://tinyurl.com/36z2hskx [Accessed: 01/12/22].

NHS England & NHS Improvement (2019). *People with a learning disability, autism or both.* England: NHS England.

NICE (2018). *Learning disabilities and behaviour that challenges: a service design and delivery.* London: National Institute for Health and Care Excellence.

O'Callaghan, A & Murphy, G. (2002) *Capacity to Consent to Sexual Relationships in Adults with Intellectual Disability* Final report to the Nuffield Foundation.

Peng, W., Liu, Z., Liu, Q., Chu, J., Zheng, K., Wang, J., ... & Yi, J. (2021). Insecure attachment and maladaptive emotion regulation mediating the relationship between childhood trauma and borderline personality features. *Depression and Anxiety*. 38(1): 28-39.

Peterson, J. L., Earl, R. K., Fox, E. A., Ma, R., Haidar, G., Pepper, M., ... & Bernier, R. A. (2019). Trauma and autism spectrum disorder: review, proposed treatment adaptations and future directions. *Journal of child & adolescent trauma*. 12(4): 529-547.

Robinson, O. C. (2022). Conducting thematic analysis on brief texts: The structured tabular approach. *Qualitative Psychology*. 9(2): 194-208.

Royal College of Psychiatrists, British Psychological Society & Royal College of Speech and Language Therapists (2007). *Challenging behaviour: a unified approach.* Royal College of Psychiatrists: London.

Roy, A., Matthews, H., Author, P., Fowler, V. and Martin, D. (2002), “Health of the nation outcome scale for people with learning disabilities (HoNOS-LD). *British Journal of Psychiatry*. 180(1): 61-66.

Russell, G., Stapley, S., Newlove-Delgado, T., Salmon, A., White, R., Warren, F., ... & Ford, T. (2022). Time trends in autism diagnosis over 20 years: a UK population-based cohort study. *Journal of Child Psychology and Psychiatry*. 63(6): 674-682.

Sandhu, D., & Tomlins, R. (2017). Clinical needs and outcomes of adults with intellectual disabilities accessing an inpatient assessment and treatment service and the implication for development of community services. *Journal of Intellectual Disabilities*. 21(1): 5-19.

Self, R., Rigby, A., Leggett, C. & Paxton, R. (2008). Clinical Decision Support Tool: A rational needs-based approach to making clinical decisions. *Journal of Mental Health*: 17(1): 33-48.

Taylor, J. L. (2021). Positive behavioural support for people with intellectual disabilities in forensic settings: A case of the emperor’s new clothes. *International Journal of Positive Behavioural Support*. 11(1): 7-14.

The Health Foundation (2015). *Evaluation: what to Consider. Commonly Asked Questions about How to Approach Evaluation of Quality Improvement in Health Care*. London: The Health Foundation.

Tromans, S., Chester, V., Kiani, R., Alexander, R., & Brugha, T. (2018). The prevalence of autism spectrum disorders in adult psychiatric inpatients: a systematic review. *Clinical practice and epidemiology in mental health.* 14: 177-187.

Varela, J. (2014). Formulating and working therapeutically with the concept of intellectual disability in the cognitive analytic therapy model. In Lloyd, J. & Clayton, P. (Eds). *Cognitive Analytic Therapy for People with Intellectual Disabilities and their Carers*. London: Jessica Kingsley Publishers.

Whittaker, A. (2011). Social defences and organisational culture in a local authority child protection setting: Challenges for the Munro Review? *Journal of Social Work Practice*. 25(4): 481-495.

Wilson, C., Seaman, L., & Nettelbeck, T. (1996). Vulnerability to criminal exploitation: Influence of interpersonal competence differences among people with mental retardation. *Journal of Intellectual Disability Research*. 40(1): 8-16.

Wing, J. K., Beevor, A. S., Curtis, R. H., Park, S. G. B., Hadden, J., & Burns, A. (1998). Health of the Nation Outcome Scales (HoNOS): research and development. *The British Journal of Psychiatry*. 172(1): 11-18.