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Stakeholder perspectives on intensive support teams for adults with intellectual disabilities who display behaviour that challenges in England

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Abstract

Background: Adults with intellectual disabilities often display behaviour that challenges that is a result of biological differences, psychological challenges, and lack of appropriate social support. Intensive Support Teams (IST) are recommended to support the care needs of this group and avoid hospitalisation. However, little attention has been paid to the perspectives of stakeholders who manage, work in, or use ISTs.

Method: Interviews and focus groups were conducted with 50 stakeholders (IST service managers and professionals, adults with intellectual disabilities, and family and paid carers) of ISTs. Services operated according to one of two service models previously identified in ISTs in England (enhanced or independent).

Results: Thematic analysis identified accessible and flexible support, individualised care, and the involvement of carers and other relevant agencies in management plans and reviews as features of good IST care highlighted by all stakeholder groups. IST managers and professionals described the key challenges of current IST provision as unclear referral criteria, limited interfaces with other local services, and perceived threats associated with funding and staff retention. Findings were similar between the two IST models.

Conclusions: ISTs are able to offer care and specialist support that is valued by families, service users and other care providers. However, they face several operational challenges that should be addressed if ISTs are to reach their potential along with community intellectual disability services in supporting adults with intellectual disabilities who display behaviour that challenges in the community.

KEYWORDS
challenging behaviour, community care, intellectual disabilities, intensive support, qualitative methods

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1 | INTRODUCTION

Intensive Support Teams (IST) were developed as specialist services to provide care for adults with intellectual disabilities who display behaviour that challenges and to prevent inpatient admissions following deinstitutionalisation in the United Kingdom (UK) (Balogh et al., 2016; Emerson et al., 1996; Hassiotis, 2002). ISTs are community-based multidisciplinary teams (e.g., psychology, nursing, psychiatry) aiming to offer high-quality specialist care. Among their role is to complement CIDS. It is likely that some ISTs may also provide in-reach support to adults with intellectual disabilities who required admission to an inpatient unit to facilitate discharge and improve contact with community intellectual disability services (CIDS) (Hassiotis et al., 2015). In some areas, ISTs also address mental health problems and behaviour that challenges in adults with intellectual disabilities (Hassiotis et al., 2015).

Similar initiatives were developed in the United States (Beasley et al., 2018; Kalb et al., 2019) and in Australia (Johnson, 2013). Different terms have been used to describe ISTs including 'peripatetic teams', 'assertive outreach teams', 'challenging behaviour teams', and 'specialist behaviour teams' (Davison et al., 2015; Guinn et al., 2016). In 2012, the Transforming Care: a national response to Winterbourne View Hospital (Department of Health, 2012) programme recommended ISTs as specialist, proactive and responsive services to enhance community provision for adults with intellectual disabilities who display behaviour that challenges or experience mental ill health. They usually deliver interventions such as Positive Behaviour Support (PBS), and may offer out of hours provision, and training for family and paid carers on the management of behaviours that challenge, including active support and enhanced participation in community activities (NHSE, 2015a, 2015b, 2017).

Research indicates that about 20% of adults with intellectual disabilities display behaviour that challenges (Bowring et al., 2019) with rates up to 52% in the community (e.g., supported living, residential settings, family home) (O'Dwyer et al., 2018). The presence of behaviour that challenges in adults with intellectual disabilities is often associated with a number of negative outcomes (i.e., overmedication, out of area placements, hospital admissions) that impact the wellbeing of the individual and their carers (Department of Health, 2012; Heaton & Whitaker, 2012; Lee & Kiemle, 2015; Lowe et al., 2007; NHS Digital, 2015; NHSE, 2020). Evidence suggests that behaviour that challenges in adults with intellectual disabilities should be acknowledged as a product of interacting biological, psychological and social factors (Brown & Beail, 2009; Duperouzel & Fish, 2010; Hastings et al., 2013; Jahoda et al., 2015), and services should target their efforts with this in mind to support people with intellectual disabilities and their carers within their community context. Therefore, the presence of behaviour that challenges in adults with intellectual disabilities should be acknowledged as a product of interacting biological, psychological and social factors, and service should target their efforts with this in mind to support people with intellectual disabilities and their carers within their community context.

In 2018, there were 80 ISTs in England to support adults with intellectual disabilities in the community (Hassiotis et al., 2020). Although national policy recommends ISTs for all areas, there has been little consideration of the opinions of stakeholders who use or provide services in the evaluation, design, or development of these services (NHSE, 2015b, 2015a, 2017). The small number of previous studies of stakeholder views have focussed on single services. For example, a qualitative study of the views of family members, paid carers and adults with intellectual disability following support from a single enhanced IST (Inchley-Mort & Hassiotis, 2014) reported high levels of satisfaction with the frequency of contact and availability of the team, greater understanding of behaviours that challenge, following input from the team and better handling of and reductions in the number of crises. Interviewees stated that they would value longer involvement of the IST, and more accessible materials for people with intellectual disabilities and their carers and complained about the amount of paperwork required to monitor progress and the lack of coherent guidance across services on managing behaviours that challenge across settings (e.g., inpatient units).

A recent national survey of ISTs in England identified two service models: enhanced and independent (Hassiotis et al., 2020). These have both distinct and overlapping characteristics (see Table 1 and Hassiotis et al., 2020 for further details of these two models). Whilst limited research indicates that independent ISTs can be cost neutral and clinically effective in reducing behaviour that challenges (Hassiotis et al., 2009), there is currently no substantial evidence on longer-term outcomes. This has led to scepticism about the value of IST provision, and suggestions that devoting a large number of resources to specialist services may detract from offering good quality care universally, especially as evidence suggests that alternatives (e.g., enhanced teams) may also be effective (Inchley-Mort et al., 2014). Furthermore, adults with intellectual disabilities and their carers may face disruption and discontinuity in care due to frequent changes in service provision, and may be dissatisfied with what they perceive as less 'expert' service provided by CIDS (Robotham et al., 2011). An evaluation of the redesign of one IST service found that placing two IST staff for 1 day per week within a CIDS for 6 months increased staff confidence and understanding of working with adults with intellectual disabilities who display behaviour that challenges (White et al., 2019). The role of the two IST staff (described as in-reach workers) during the evaluation period

TABLE 1 Characteristics of intensive support team models.

Enhanced provision	Independent provision
Embedded with CIDS[a]	Mainly separate from CIDS
Mainly self-referrals	Mainly professional referral
Larger caseload (typically 20+ service users)	Smaller caseload (typically around 15 service users)
Scarce use of outcome measures	Consistent use of outcome measures

[a]Community Intellectual Disabilities Service.

comprised of consultation, meetings with service users and/or staff and training of CIDS staff in PBS and behaviour that challenges. CIDS team members described IST support as beneficial in improving their understanding and use of service specific guidance for the management of behaviour that challenges and enhancing the visibility of the IST as an existing resource to support CIDS staff.

In this paper, we present the findings of a multisite multi-stakeholder investigation of perspectives and experiences of the two IST models in England. This study is focused on ISTs that operate principally to address behaviour that challenges rather than mental ill health in adults with intellectual disabilities. It is part of a multicentre evaluation study of the two models of IST care operating in England (Hassiotis et al., 2021, 2022).

2 | METHODS

In phase two of the larger study (Hassiotis et al., 2021), 21 ISTs were enrolled, of which seven case study sites were selected for the current qualitative study. These were selected to include both IST service models (enhanced and independent), and to capture other forms of service variability within each model, including location in rural or urban areas, caseload size, funding arrangements, and length of service existence (see Supplementary Material S1). The Consolidated Criteria for Reporting Qualitative Studies (COREQ; Tong et al., 2007), a 32-item checklist, guided the reporting of this study (Supplementary material S2).

2.1 | Participants

All participants were 18 years or older and had capacity to consent. IST managers and professionals were employed by the NHS in an IST at the time of the interview. Service users were receiving IST input at the time of the interview. Family or paid carers of service users receiving IST care were also invited to share their opinions. Purposive sampling aimed to achieve participant variation in age, work experience, gender, ethnicity, professional background, carer roles and relationship to the person with intellectual disability.

In total, 101 participants were approached. Fifty stakeholders took part in interviews/focus groups, 40 of whom including nine family carers, seven paid carers, six adults with intellectual disabilities, 14 IST managers and four IST professionals completed individual semi-structured interviews. The remaining 10 IST professionals participated in two focus groups. The details of the service users and carers are shown in Table 2.

Detailed characteristics of IST managers and professionals are shown in Table 3.

Due to recruitment difficulties during the early stages of the COVID-19 pandemic, we further recruited a small number of participants (three service users and one IST professional in three additional ISTs that shared similar characteristics with the original seven sites) (see Table 4).

2.2 | Ethics

The study received ethical permission from the London – Bromley Research Ethics Committee (REC) (reference number 18/LO/0890) which reviewed and approved all relevant research study procedures. Informed consent was obtained from all participants.

2.3 | Data collection

Recruitment of participants took place over a 12-month period between October 2019 and October 2020 and began with IST managers and professionals. The topic guides for each stakeholder group were developed based on the literature, the clinical experience of the project research group, and the expertise of service user and family carer advisory groups. They covered views on current IST practices; access to the IST; aspects of IST care perceived as important; challenges with IST care; and suggestions for improvement.

Semi-structured interviews (between 20 and 30 min) and focus groups (between 60 and 80 min) were facilitated by female trained researchers (e.g., master graduates and/or PhD students). Adults with intellectual disabilities, and family and paid carer were interviewed near the time of their discharge from the IST or at around the 9 month follow-up, whichever was sooner. As part of the data collection phase coincided with the first pandemic lockdown (March 2020 to October 2020), we adapted in-person consent and interviews to be held remotely in order to comply with government and institutional guidelines. Therefore, the researchers obtained verbal audio-recorded consent, and this was then transferred to a paper form. We offered a range of remote interview options to all participants including digital platforms (e.g., Zoom, MS teams) or telephone calls ensuring that we followed the research sponsor governance processes about confidentiality as was available at the time.

2.4 | Data analysis

Interviews and focus group discussions were audio-recorded and transcribed verbatim by an external sponsor approved agency. All identifiable information was removed at this phase. Data were analysed using thematic analysis (Braun & Clarke, 2006) conducted in NVivo software. The process included familiarisation with the data, generation of initial codes and themes, reviewing, defining, and naming themes, and compiling the report. Two researchers (AK and LH) familiarised themselves with the data independently, developed themes and subthemes and liaised several times with the qualitative expert (NM) and the chief investigator (AH) to resolve any discrepancies and discuss the final definitions of themes and subthemes. Findings from various stakeholder perspectives on ISTs were triangulated in order to obtain a comprehensive picture of the impact of ISTs in patient care. Thus, all the data were analysed together, comparing across both stakeholder groups and IST models throughout the analysis in order to understand both broadly common perceptions and experiences of

TABLE 2 Carer and adults with intellectual disabilities characteristics.

	Family carers, n = 9	Paid carers, n = 7	Adults with intellectual disabilities, n = 6
Gender			
Female	6	4	2
Male	3	3	4
Age (years)			
Median	65	37	28
IQR[a]	9 (61–70)	9 (34–43)	14 (26–40)
Ethnicity			
White British	7	6	6
Black African	1	1	-
Asian Indian	1	-	-
Number of years in current role			
Median	Not applicable	8	Not applicable
IQR		8.25 (4.75–13)	
Number of years' experience in ID[b]			
Median	Not applicable	9	Not applicable
IQR		6 (7–13)	
Relationship to service user			
Parent	7	Not applicable	Not applicable
Brother	1		
Aunt	1		
Comorbid mental health condition			
ASD[c]	Not applicable	Not applicable	1
ASD & Ehlers			1
Danlos Syndrome			
ASD & ADHD[d]			2
Cerebral palsy			1
IST model			
Enhanced model	4	3	5
Independent model	5	4	1

[a]Interquartile range.
[b]Intellectual disabilities.
[c]Autism spectrum disorder.
[d]Attention deficit hyperactivity disorder.

ISTs as well as of areas where stakeholder differences occurred. The analysis also involved close collaboration between the researcher, the qualitative lead, and other key members of the study team. The experts by experience advisory group provided views on our interpretation of the findings and facilitated the development of emerging (sub)themes and findings.

3 | RESULTS

The qualitative findings are presented in two sections. Section 3.1 draws on data from all stakeholder groups to synthesise common

views about what is valued about IST care, and what aspects of this are seen as lacking. Service accessibility and flexibility, individualised care, carer involvement and joint working were seen as central to good practice or beneficial aspects of IST care. Section 3.2 focuses on data from IST managers and professionals about the perceived role, functioning and organisation of ISTs. Their concerns included lack of clarity regarding the referral criteria, the interface of ISTs with other mental health services, and IST specific operational issues. In general, there were no differences in respondents' views according to whether they were commenting on ISTs identified as enhanced or independent. We therefore present pooled data from across all the study sites here. Where there were differences in stakeholder perspectives, we

TABLE 3 Demographic and professional characteristics of IST managers and professionals.

	IST managers, $n = 14$	IST professionals, $n = 14$
Gender		
Female	10	12
Male	4	2
Age (years)		
Median	41	28
IQR[a]	6 (40–46)	13 (27–40)
Ethnicity[b]		
White British	12	7
White Irish	0	2
Other White	1	-
Asian Indian	1	-
Number of years in service		
Median	5	3
IQR	9 (4–13)	2 (1–3)
Number of years with experience in ID[c]		
Median	20	5
IQR	19 (11–30)	5 (2–7)
Professional background		
Nursing	10	4
Psychology	3	5
SLT[d]	1	-
Social work/other	-	5
IST Model		
Enhanced model	7	6
Independent model	7	8

[a]Interquartile range.
[b]Data provided from nine participants.
[c]Intellectual disabilities.
[d]Speech and language therapist.

elaborate on those below, together with illustrative interview extracts.

3.1 | Good practice in IST care

3.1.1 | Service accessibility and flexibility

IST managers and professionals highlighted service accessibility and flexibility as important features of good IST care and core characteristics of their services, including working out-of-hours, if needed.

> 'I've been stood in gardens at ten, eleven o'clock at night…You don't finish there. So, there's flexibility'. (IST manager, enhanced provision)

In addition, they promoted and supported joint work with other NHS services, in particular when ISTs signposted adults with intellectual disabilities to a different service (e.g., community mental health teams) and praised staff professionalism and other staff attributes such as being approachable and friendly towards service users.

> 'We work so well…and we're all quite friendly, jolly adults that I think we're quite welcoming and adults tend to react well'. (IST professional, independent provision)

The perception of an accessible service was comforting to many service users and their family or paid carers. Adults with intellectual disabilities and carers reported that they valued IST staff responding to phone calls and conducting home visits in response to carers' or service users' distress. They also valued the IST keeping in touch by calling them regularly to monitor how they were coping during the COVID-19 pandemic. Carers described feeling confident in liaising with the IST professionals if they needed additional support.

> '…when we have needed something very urgent, the IST team have been really responsive, they've been brilliant'. (Adult with intellectual disability, enhanced provision)

Nonetheless, adults with intellectual disabilities found it difficult to articulate their wishes due to communication and/or cognitive difficulties (e.g., understanding the treatment plan). As a result, they relied on family or paid carers to help them communicate with IST healthcare professionals. One adult with intellectual disability described the process 'a bit confusing at times'.

> '…sometimes they have been difficult, because of my spoke (sic) and on the phone, so my parents have to come help me'. (Adult with intellectual disability, enhanced provision)

Although a minority, some family carers described liaising with the IST as challenging at the start of their involvement. Family carers either made unsuccessful attempts to connect with professionals or had not received updates for long periods of time. In particular, families of adults with intellectual disabilities in supported living or residential care reported that they were not fully informed of the IST involvement until they were invited to meetings.

> 'The regular meetings have stopped. The big problem is the communication, with everybody. So, we're constantly having to chase around, phoning adults, saying, what is happening and what are you doing about this? And it just feels like you can never get an answer. Nobody ever phones you back. They're not available, they never phone back'. (Family carer, enhanced provision)

TABLE 4 Setting.

Study site	IST model	Stakeholder groups			
		IST professionals (n = 14)	Family carers (n = 9)	Paid carers (n = 7)	Adults with intellectual disabilities (n = 6)
IST 1[a]	Enhanced		1		
IST 2[a]	Enhanced	4	1	1	
IST 3[a]	Enhanced	1	2	2	3
Additional IST 4	Enhanced				2
Additional IST 5	Enhanced	1			
IST A[a]	Independent	5	1		
IST B[a]	Independent	1	2	1	
IST C[a]	Independent	1	1	1	
IST D[a]	Independent	1	1	2	
Additional IST E	Independent				1

[a]Seven case study sites.

Similarly, one adult with intellectual disability described the difficulty in contacting the IST at the beginning of the allocation process.

> 'Lack of communication to start with as took long time to get appointment'. (Adult with intellectual disability, enhanced provision)

Finally, a few family carers thought that some aspects could be better accomplished or delivered by having easier access to social workers. They suggested social workers form part of the ISTs rather than liaising with duty social workers during an emergency. A social worker integrated into an IST would be able to access information rapidly via clinical records compared to family carers sharing personal information repeatedly across different professionals each time. IST managers and family carers emphasised that social workers could also support the identification of meaningful opportunities (e.g., employment) that promote integration in the local community.

> 'I mean having a social worker that I can talk to or ask something. Having easier contact with a social worker would have made things easier compared to a duty social worker. Because it's like the whole story all over again' (Family carer, independent provision)

3.1.2 | Individualised care

All stakeholders highlighted the importance of individualised care, that the treatment plan should be decided in consultation with family carers and service users, and that it should cover a range of physical/health, psychological, or social needs. IST managers and IST professionals provided examples of how they involve carers and adults with intellectual disability in care or review meetings including making any necessary reasonable adjustments.

> 'The letters that we send out, they're already, always written to the adults, where possible. We have the provision here, so if adults are anxious about coming into the room, they can sit on the sofas outside. We have the door open so they can hear what's being talked about. So that they can come and join the meeting if they want to'. (IST manager, enhanced provision)

Where possible, the adult with intellectual disability was consulted about his/her behaviour support plan, and what they would like to happen if they were in a mental health crisis.

> '...when I've got a problem or something happens, you know I can tell her...this is what I want to speak to you about and then obviously we can discuss what to do next, what's the next step...and then at least someone can come back and say yeah okay...we'll do that now, they'll do things for me'. (Adult with intellectual disability, enhanced provision)

IST professionals were seen as conduits for addressing a variety of physical health, psychological, and social needs. Respondents gave examples that included supporting requests for respite care, obtaining a wheelchair aid, and identifying ways that the service user could be more connected to their local community, such as accessing activities, education, or transport.

> 'It was the first time that she was going to school and that was with the help of them. They helped her with all the things. Take her, to drop her to activities and all the things'. (Family carer, enhanced provision)

However, some family carers reported that IST professionals did not always acknowledge and understand the challenges of living with

an adult with intellectual disability and consequently the full extent of the family carer's needs.

> 'I don't think they quite understand everything. I think sometimes, they haven't a clue what it's like to live with it [a person with intellectual disability]'. (Family carer, independent provision)

3.1.3 | Carer involvement and joint working

All stakeholders identified the active engagement of all relevant parties that are usually involved in the care of adults with intellectual disabilities as an important element of good IST care. IST managers and professionals agreed that the contribution of family or paid carers was important in formulating the management plan. Similarly, their involvement in multidisciplinary review meetings was regarded as positive in fostering reflection on an individual's needs and aiding clinical formulation. Updates on progress and incident reporting, collaborative work, and regular contact with paid carers around risk management were seen as particularly helpful in managing behaviour that challenges.

> 'Everybody is involved in decision making right from the beginning, from the point of referral...The families, carers, support workers and other professionals like social worker and anybody else that's involved in their care and that. So, we all make decisions together, and that's the real strength, I think, is the multidisciplinary formulation, assessment and, planning really, in terms of who's going to do what, why we're doing it, how, how long we're going to do that for'. (Focus group with IST manager and professionals, enhanced provision)

The majority of family and paid carers experienced the effort of IST staff to involve them in the care plan as positive. Most family and all paid carers reported being listened to and involved in the development of individual care plans and treatment decision-making.

> 'They did the care plan, came to us. First, they asked our opinion, and we went through that before. We discussed whenever they came after we debriefed each other. I think that overall, I can say they did support us very well'. (Paid carer, independent provision)

Family carers reported being concerned that their relative's behavioural or mental health crisis might affect the security of their placement. They were reassured by the IST's role in offering home-based support and training to care home staff even during a crisis and valued the intervention provided by the IST.

> 'I'm not on the phone to them [IST] all the time, but each time I call them when he's unwell, you know, they

did intervene on my behalf...Going to his place and speaking to staff there. So, I suppose they're quite effective'. (Family carer, enhanced provision)

In addition, paid carers and adults with intellectual disabilities thought that developing a management plan that considers the individual's day-to-day needs such as monitoring medication, accessing activities, or practising social skills benefits adults with intellectual disabilities by helping them feel happier and more able to enjoy life.

> 'When she [IST professional] came, I liked colouring... did some playing...I like arts and crafts...I'd like to do some playing'. (Adult with intellectual disabilities, independent provision)

3.2 | Professional perspectives on IST functioning

IST managers and professionals talked about their perspectives on the functioning of ISTs and their relationships with other health and social care services. A substantial proportion of these accounts focussed on perceptions of problematical aspects of current IST functioning.

3.2.1 | Lack of clarity regarding referral criteria

IST managers expressed frustration at what they observed as broad eligibility criteria for IST care. As a result, referrals could include adults with intellectual disabilities whose mental health needs are a priority (i.e., psychosis), or those with autism spectrum disorder without intellectual disabilities who have limited access to other community facilities.

> 'There is a significant black hole at the moment for adults who have autism but don't have a learning disability to fall into. Our trust will assess if they've received their diagnosis. They may not be eligible for our service but some of our PBS approach are highly relevant. So literally at the moment, we are recording those adults in our risk management system in order to evidence to the CCG, to the Clinical Commissioning Group very clearly what the identified need is'. (IST manager, enhanced provision)

On the other hand, some managers described how limiting IST referrals by strict criteria (e.g., prioritising only high-risk cases) could lead to exclusion of adults with intellectual disabilities with less challenging presentation who would equally benefit from additional support.

> 'There's a whole layer of adults who still might have significant difficulties because of their learning disabilities, but don't meet our really high threshold criteria.

They won't get a service because they're not at risk of placement breakdown'. (IST manager, enhanced provision)

Finally, IST managers stated that managing adults with intellectual disabilities during a mental health crisis is incompatible with IST care. They reported that IST care should be 'proactive' and 'possibly starting before the crisis arises'.

'We've got no bed management team to find beds at times when adults are in crisis. If we're left to get on and do our job, everything's fine, it's having to do all the other little bits...It took four days to actually find a bed. I spent six hours one day, ringing different services just to say have you got a bed anywhere'. (IST manager, enhanced provision)

3.2.2 | Interface of ISTs with other services

The majority of IST managers and professionals stressed the benefits of developing strong relationships with other teams and good liaison with internal and external agencies (e.g., primary care, CIDS, forensic teams, or the police) with the aim of all services providing equitable care to this population group.

'We work alongside primary care nurses and daily GPs if there are any issues. We also work alongside our CHC* colleagues. They are the ones that go and do the health assessments to see if adults meet the Continuing Healthcare Funding criteria. The fact that we are multidisciplinary definitely helps us'. (IST manager, enhanced provision)

CHC: Continuing Healthcare is a package of care funded by the NHS for adults with ongoing, complicated, and intense healthcare needs due to illness, disability or accident.

In addition, IST professionals highlighted the importance of (informal and formal) liaison among professionals, often referred to as 'corridor conversations', which were perceived as helpful in managing ongoing cases. Among the positive features of IST care they described was 'carer champions' networks, comprised of experienced family and/or paid carers who could offer one-to-one training to upskill other carers in recognising triggers of challenging behaviour before an incident occurs, with the aim to prevent a crisis, placement breakdown or hospital admission.

A few IST staff highlighted the challenge of working with accommodation providers for adults with intellectual disability where there was a high staff turnover, and the negative emotional impacts this could have on service users. As ISTs invest time in upskilling paid carers to better support service users and work with complex cases, this meant they needed to roll out training for new staff frequently.

'We don't have a huge abundance of skilled providers. We're often engaging with providers who are either overwhelmed because they're the only provider in that particular area or are under-skilled'. (IST manager, independent provision)

IST professionals also highlighted the need to establish better links with mainstream mental health services. They thought that having partnerships with community mental health teams would enhance opportunities to review cases early, decrease inappropriate referrals and consolidate the preventive role of IST.

'If you think someone might need to ring us but you're not sure don't wait to put a referral in. If there's an MDT*, invite us to it. So, we don't need a referral to come to an MDT. Invite us. We'll open them on the system for that day and close them again. Just invite us. We've also put in over the last year a duty social work system, so that there's someone around that can speak to you'. (IST manager, independent provision)

MDT: multidisciplinary team.

Managers and IST professionals described how ISTs often support adults with intellectual disabilities for long periods (e.g., 12 months), even after an intervention has concluded, due to other problems in the care pathway including long waiting lists for CIDS input, or difficulty in identifying alternative placements.

'We'll see it through from beginning to end which can, sometimes, be labour intensive because we might have done all the work but recognise that we need an alternative placement. And you could be six months looking for an alternative placement to then support them through the transition. So, depending on where they are and how adults are, we might close and then reopen them, or keep them open'. (IST manager, independent provision)

All stakeholders referenced the need to promote the visibility of IST with calls for better local information about services to support adults with intellectual disabilities who display behaviour that challenges including social care providers, the police, and other agencies. Such knowledge would be useful for the service users and their families but also to a wide range of professionals in relevant services.

'I don't think for one moment that the social worker who was involved with C at that time really knew of their existence or what they could provide. I think it's the agencies that are involved in supporting adults like C, perhaps themselves need to better informed, about what other agencies and organisations are capable of providing'. (Family carer, independent provision)

IST managers and family carers from both IST models highlighted that PBS plans need to be more accessible. For example, lengthy PBS plans could be substituted with brief Easy-Read documents which have higher utility. It is common that paid carers and/or care home managers lack time to review the full behavioural plan which often uses academic language and discourages support workers from fully engaging with it.

> 'Why do we produce 40-page PBSs* for adults who need an easy-read grab sheet' (IST manager, independent provision)

> *PBSs: Positive Behavioural Support plans.

3.2.3 | Operational issues: Funding and workforce issues

IST professionals described concerns that their services were under constant review by commissioners regarding annual performance indicators such as inpatient admission rates, use of outcome measures, numbers of referrals, and feedback from service users and carers. Some IST managers described feeling under pressure to justify the IST service to commissioners who expect the service to respond quickly to referrals, have large caseloads, and be available at all times.

> 'The teams have been a bit battered...Being 24/7 as well is quite a challenge for me because I really don't get to switch off, because ultimately even if I'm not on call, because I take my turn on call the same as anyone else in the team...But at 2:00 in the morning if someone doesn't know what to do, then they're on my phone. And then commissioners, my manager quite regularly at 7:00 in the morning they're on the phone... That is intense. You're kind of answerable to so many adults all the time'. (IST manager, independent provision)

Other concerns for IST managers related to lack of or limited funding, and the risk of IST services being decommissioned. IST managers from both models reported that fiscal constraints to social care caused distress and potentially contributed to exacerbating behaviour that challenges in service users whose care packages were reduced.

> 'The repercussions of austerity and the cuts that social care has experienced over a relatively long period of time have really impacted on adults with learning disabilities. Our social care colleagues are often involved in reviewing packages of care and reducing them. We have felt the repercussions of reduced packages of support, reduced amount of community enabling in the last two years'. (IST manager, enhanced provision)

Concerns about costs impacted decisions about IST personnel or resources for continuous professional development. IST professionals reported being overstretched and found the demands of supervising often junior clinical staff as resource intensive. In addition, IST managers highlighted the challenge of being unable to recruit and retain sufficiently qualified staff. This issue appeared to be felt mostly by ISTs in rural areas and may also be related to requirement such as on-call and staff shift patterns.

> 'We really struggle, which is why we can't recruit into nursing posts. Our registered professionals have quite a high turnover because of the on-call hours'. (IST manager, independent provision)

> 'You're not going to get lots of adults applying. The area is definitely a hindrance to recruitment. It's a vast area. It looks really small but it's not. From one end to the other you're talking a good hour and a half to go across'. (IST manager, enhanced provision)

Finally, IST staff thought that upskilling and supporting paid carers is an important element of their work. IST managers suggested funding should be invested in care homes to enhance the skills of paid carers and enable them to support a population with increasingly complex needs and multi-morbidity.

> 'I personally think that we have to provide the training to the top managers for it to be cascaded down to the bottom...if we were a wider team, we'd be able to go out and start doing some education within Social Care, within the managers of these services, and say, this is what your care team needs to do to give somebody a really good community present life'. (IST manager, independent provision)

4 | DISCUSSION

This is the first study in our knowledge to explore the views and experiences of multiple stakeholders of IST care in England. This qualitative study is part of a wider research programme that provided an overview of the current operation of ISTs and evaluated the clinical and cost effectiveness of two IST models in England (Hassiotis et al., 2021, 2022). Findings suggest that ISTs are often well received by family and paid carers and adults with intellectual disabilities. Nonetheless, IST managers and professionals reported domains of IST care that are problematic and require further attention to ensure better quality care for an underserved population.

Previous studies suggested that easy access to services, approachable professionals, practical guidance, and psychological support were important features for family carers of adults with severe intellectual disabilities (Hubert, 2011; Weise et al., 2018). Adults with intellectual disabilities and mental ill-health with/without behaviours

that challenge have described what to them 'makes a good worker' as: being interested in people with intellectual disabilities, building trusting relationships, maintaining professionalism at all times, communicating effectively, and acknowledging past traumatic experiences in people with experience of mental ill-health (Stenfert Kroese & Rose, 2011). Current legislation and policy encourage professionals to work closely with family and paid carers in ways that complement and enhance their role in caring for vulnerable adults (NHSE, 2015a; 2015b; People, 2001) and this was echoed in the interviews.

Adults with intellectual disabilities and co-occurring mental-ill health often find it difficult to access the appropriate service due to a complex service landscape, lack of clarity about the remit/scope of services, and service silos (Whittle et al., 2018). They often reported feeling 'neglected', 'small' or 'not even there' in their contacts with professionals (Weise et al., 2018). Two reviews examined the organisational factors that shape the work of professionals (e.g., psychiatrists, nurses, psychologists, therapists, social workers) in mainstream mental health services or specialist intellectual disability settings for adults with intellectual disabilities (Ee et al., 2021; Hemmings et al., 2014). Both studies concluded that the interface between ISTs and mainstream mental health services is problematic, as ISTs are behaviourally oriented with limited mental health expertise and resources (e.g., lack of staff and support from managers, heavy workloads, long hours, administrative work), whereas mainstream mental health services were focused on mental health and lacked knowledge of intellectual disability and behaviour that challenges. A common concern emphasised by professionals in mental health services was feeling 'unappreciated', 'exploited', and 'powerless'. In the current study, IST managers and professionals reported important obstacles related to the role of the IST within the local service provision and described problems in staff retention, workloads, access and flow of referrals, and funding. Managers' perceptions that IST services were under threat is consistent with data suggesting that investment in intellectual disabilities services has been reducing for the past 8 years (more so in London) (NHS Benchmarking Network, 2021), and savings from inpatient bed closures have not translated into community care investment. This report also supports IST managers' concerns about staffing issues, as CIDSs report a wide variation in staffing levels ranging from 3 to 35 full-time equivalent per 100,000 population.

Training family carers and service providers to consolidate their knowledge and understanding of adults with intellectual disabilities who display behaviour that challenges has been reported as a possible mitigating factor for poor staff retention in ISTs (Ryan et al., 2021). Embedding professionals with knowledge of intellectual disabilities or mental-ill health within existing structures (e.g., ISTs or CIDS) to offer specialist input has also been suggested (Ee, Kroese & Rose, 2021). These strategies may help overcome some of the challenges identified by IST managers and professionals in the current study regarding interfaces between intellectual disability and mainstream mental health services, and the need to upskill the carer workforce in supported accommodation and other parts of the social care system. In addition, the role of ISTs is to complement the work of CIDS and while ISTs may adopt a tiered preventive approach to better support

adults with intellectual disabilities across different systems (i.e., supported living, family home, school, day centres) (Gore et al., 2022), Our study findings did not reveal this. A tiered approach could offer the opportunity for skill acquisition in professionals to become universal so a wider service system could support adults with intellectual disabilities who display behaviour that challenges in the community (Gore et al., 2022). Further research is needed to trial and evaluate such strategies.

Finally, advocating for integrated health and social care ISTs was clearly echoed in the interviews by family carers of adults with intellectual disability. This initiative of integrating services (e.g., social workers to form part of ISTs) aims to address delays and gaps in the care of adults with intellectual disability particularly during a crisis. Current legislation in England encourages Integrated Care Systems where partnership organisations (e.g., NHS, local authorities and local partners) work together to plan and deliver health and care services and complement and enhance the quality of vulnerable adults' life from July 2022 (NHSE, 2022).

4.1 | Strengths and limitations

We engaged several different professional and expert by experience stakeholder groups and have accumulated extensive and rich perspectives on IST care. However, these findings are limited by the lower than anticipated number of interviews we were able to conduct and the addition of three sites. We were unable to access as many adults with mild intellectual disability and IST professionals compared to family and paid carers from our original seven 'case study' sites as we had anticipated; this difficulty became more pronounced during the lockdown and other restrictions due to the COVID-19 pandemic. The adults with mild/moderate intellectual disability we interviewed were primarily under the care of enhanced ISTs. This was a pragmatic decision related to the coronavirus pandemic and the pool of participants eligible for an interview at the time (e.g., near the time of their discharge from the IST or at around the 9 month follow-up). We acknowledge that this approach might have introduced a selection bias which undermines the internal validity of this study.

5 | CONCLUSION

Across England, there are at least 80 ISTs to support adults with intellectual disabilities who display behaviour that challenges in the community by aiming offer high-quality specialist care (Hassiotis et al., 2020). There is, however, a gap in the development of these services, with little evidence of experts by experience having been consulted, and unclear remits regarding whether ISTs should be offering long- or short-term engagement. The current study provides a picture of current IST functioning, based on multi-stakeholder views and experiences. It highlights the value of ISTs in providing specialist input for carers and other service providers, and individualised care that is valued by family carers and service users. It also synthesises

problematic features of IST functioning from the perspective of service managers and professionals. There is still scope for ISTs to realise the NHS Long Term Plan (Department of Health, 2019) in providing 'good quality health, care and treatment', and the current study provides pointers as to the organisational and service development pathways that may be needed. ISTs clients who display behaviour that challenges in combination with intellectual disability and mental illness can be extremely complex clinically, and carefully coordinated input across agencies may be needed. Performance targets and organisational improvement strategies should reflect the realities of this complexity. There are clear imperatives for further financial boosters for CIDS including ISTs in order to develop a holistic and high-quality care network for an underserved population group.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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REFERENCES

Balogh, R., McMorris, C. A., Lunsky, Y., Ouellette-Kuntz, H., Bourne, L., Colantonio, A., & Gonçalves-Bradley, D. C. (2016). Organising healthcare services for persons with an intellectual disability. *Cochrane Database of Systematic Reviews*, 4, 1–50.

Beasley, J. B., Kalb, L., & Klein, A. (2018). Improving mental health outcomes for individuals with intellectual disability through the Iowa START (I-START) program. *Journal of Mental Health Research in Intellectual Disabilities*, 11(4), 287–300.

Bowring, D. L., Painter, J., & Hastings, R. P. (2019). Prevalence of challenging behaviour in adults with intellectual disabilities, correlates, and association with mental health. *Current Developmental Disorders Reports*, 6(4), 173–181. https://doi.org/10.1007/s40474-019-00175-9

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

Brown, J., & Beail, N. (2009). Self-harm among people with intellectual disabilities living in secure service provision: A qualitative exploration. *Journal of Applied Research in Intellectual Disabilities*, 22(6), 503–513.

Davison, S., McGill, P., Baker, P., & Allen, D. (2015). A national UK survey of peripatetic support teams for children and adults with intellectual and developmental disabilities who display challenging behaviour. *International Journal of Positive Behavioural Support*, 5(1), 26–33.

Department of Health. (2012). Transforming care: A national response to Winterbourne View Hospital. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf

Department of Health. (2019). August 21. *The NHS Long Term Plan version 1.2*, 6-136 https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf

Duperouzel, H., & Fish, R. (2010). Hurting no-one Else's body but your own: People with intellectual disability who self injure in a forensic service. *Journal of Applied Research in Intellectual Disabilities*, 23(6), 606–615.

Ee, J., Stenfert Kroese, B., & Rose, J. (2021). Experiences of mental health professionals providing services to adults with intellectual disabilities and mental health problems: A systematic review and meta-synthesis of qualitative research studies. *Journal of Intellectual Disabilities*, 26(3), 758–781.

Emerson, E., Forrest, J., Cambridge, P., & Mansell, J. (1996). Community support teams for people with learning disabilities and challenging behaviours: Results of a national survey. *Journal of Mental Health*, 5(4), 395–406.

Gore, N. J., Sapiets, S. J., Denne, L. D., Hastings, R. P., Toogood, S., MacDonald, A., Baker, P., Allen, D., Apanasionok, M. M., Austin, D., Bowring, D. L., Bradshaw, J., Corbett, A., Cooper, V., Deveau, R., Hughes, J. C., Jones, E., Lynch, M., McGill, P., ... Williams, D. (2022). Positive behavioural support in the UK: A state of the nation report. *International Journal of Positive Behavioural Support*, 12(1), 4–39.

Guinn, A., Jaydeokar, S., McCarthy, J., Roy, A., & Hassiotis, A. (2016). A survey of consultant psychiatrists in intellectual disabilities based in England. *Advances in Mental Health and Intellectual Disabilities*, 10, 258–270.

Hassiotis, A. (2002). Community mental health services for individuals with intellectual disabilities. *Disease Management & Health Outcomes*, 10(7), 409–417.

Hassiotis, A., Guinn, A., Tanzarella, M., McCarty, J., & Roy, A. (2015). Community-based services for people with intellectual disability and mental health problems. Faculty report, Royal College of Psychiatrists in the UK, Faculty of Psychiatry of intellectual disability, may. https://www.rcpsych.ac.uk/docs/default-source/members/faculties/intellectual-disability/id-fr-id-06.pdf?sfvrsn=5a230b9c_2

Hassiotis, A., Kouroupa, A., Hamza, L., Morant, N., Hall, I., Marston, L., Romeo, R., Yaziji, N., Jones, R., Courtenay, K., Langdon, P., & Lloyd-Evans, B. (2022). Intensive support teams for adults with intellectual disabilities displaying challenging behaviour: The IST-ID mixed-methods study. *Health and Social Care Delivery Research*, 10(33), 1–106.

Hassiotis, A., Kouroupa, A., Jones, R., Morant, N., Courtenay, K., Hall, I., Crossey, V., Romeo, R., Taggart, L., Langdon, P., & Ratti, V. (2021). Clinical and cost evaluation of intensive support team (IST) models for adults with intellectual disabilities who display challenging behaviour: A comparative cohort study protocol. *BMJ Open*, 11(3), e043358.

Hassiotis, A., Robotham, D., Canagasabey, A., Romeo, R., Langridge, D., Blizard, R., Murad, S., & King, M. (2009). Randomized, single-blind, controlled trial of a specialist behavior therapy team for challenging behavior in adults with intellectual disabilities. *American Journal of Psychiatry*, 166(11), 1278–1285.

Hassiotis, A., Walsh, A., Budgett, J., Harrison, I., Jones, R., Morant, N., Courtenay, K., Crossey, E. V., Hall, I., Romeo, R., & Lloyd-Evans, B. (2020). Intensive support for adults with intellectual disabilities and behaviours that challenge: A survey of provision and service typologies in England. *BJPsych Open*, 6(2), e20.

Hastings, R. P., Allen, D., Baker, P., Gore, N. J., Hughes, J. C., McGill, P., Noone, S. J., & Toogood, S. (2013). A conceptual framework for understanding why challenging behaviours occur in people with developmental disabilities. *International Journal of Positive Behavioural Support*, 3(2), 5–13.

Heaton, S., & Whitaker, S. (2012). The attitudes of trained and untrained staff in coping with challenging behaviour in secure and community settings. *International Journal of Developmental Disabilities*, 58(1), 40–47.

Hemmings, C., Bouras, N., & Craig, T. (2014). How should community mental health of intellectual disabilities services evolve? *International Journal of Environmental Research and Public Health*, 11(9), 8624–8631.

Hubert, J. (2011). 'My heart is always where he is'. Perspectives of mothers of young people with severe intellectual disabilities and challenging behaviour living at home. *British Journal of Learning Disabilities*, 39(3), 216–224.

Inchley-Mort, S., & Hassiotis, A. (2014). Complex behaviour service: Content analysis of stakeholder opinions. *Advances in Mental Health and Intellectual Disabilities*, 8, 228–236.

Inchley-Mort, S., Rantell, K., Wahlich, C., & Hassiotis, A. (2014). Complex behaviour service: Enhanced model for challenging behaviour. *Advances in Mental Health and Intellectual Disabilities*, 8, 219–227.

Jahoda, A., Melville, C. A., Pert, C., Cooper, S. A., Lynn, H., Williams, C., & Davidson, C. (2015). A feasibility study of behavioural activation for depressive symptoms in adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 59(11), 1010–1021.

Johnson, S. (2013). Crisis resolution and home treatment teams: An evolving model. *Advances in Psychiatric Treatment*, 19(2), 115–123.

Kalb, L. G., Beasley, J., Caoili, A., & Klein, A. (2019). Improvement in mental health outcomes and caregiver service experiences associated with the START program. *American Journal on Intellectual and Developmental Disabilities*, 124(1), 25–34.

Lee, A., & Kiemle, G. (2015). 'It's one of the hardest jobs in the world': The experience and understanding of qualified nurses who work with individuals diagnosed with both learning disability and personality disorder. *Journal of Applied Research in Intellectual Disabilities*, 28(3), 238–248.

Lowe, K., Allen, D., Jones, E., Brophy, S., Moore, K., & James, W. (2007). Challenging behaviours: Prevalence and topographies. *Journal of Intellectual Disability Research*, 51(8), 625–636.

NHS Digital. (2015). Learning disability census report. https://files.digital.nhs.uk/publicationimport/pub19xxx/pub19428/ld-census-initial-sep15-rep.pdf

NHS England. (2015a). Building the right support: A national plan to develop community services and close inpatient facilities for people with a learning disabilities and/or autism who display behaviour that challenges, including those with a mental health condition. https://www.england.nhs.uk/wp-content/uploads/2015a/10/ld-nat-imp-plan-oct15.pdf

NHS England. (2015b). *Supporting people with a learning disabilities and/or autism who have a mental health condition or display behaviour that challenges*. NHS England https://www.england.nhs.uk/wp-content/uploads/2015b/07/ld-draft-serv-mod.pdf

NHS England. (2017). Care and treatment reviews (CTRs): Policy and guidance including policy and guidance on care, education, and treatment reviews (CETRs) for children and young people. http://www.scie-socialcareonline.org.uk/care-and-treatment-reviews-ctrs-policy-and-guidance-including-policy-and-guidance-on-care-education-and-treatment-reviews-cetrs-for-children-and-young-people/r/a110f00000KvrwJAAR

NHS England. (2020). Patient trends and change over time. www.england.nhs.uk/wp-content/uploads/2020/12/learning-disability-and-autism-patient-trends-and-changeover-time-sept-2020.pdf

NHS England. (2022). Health and care bill granted Royal Assent in milestone for healthcare recovery and reform. https://www.gov.uk/government/news/health-and-care-bill-granted-royal-assent-in-milestone-for-healthcare-recovery-and-reform

O'Dwyer, C., McCallion, P., Burke, É., Carroll, R., O'Dwyer, M., & McCarron, M. (2018). Prevalence and associated factors of problem behaviours among older adults with intellectual disabilities in Ireland. *Research in Developmental Disabilities*, 80(May), 192–204. https://doi.org/10.1016/j.ridd.2018.05.007

People, V. (2001). A new strategy for learning disabilities for the 21st century. A White paper presented to parliament by the secretary of state for health by command of her majesty. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf

Robotham, D., King, M., Canagasabey, A., Inchley-Mort, S., & Hassiotis, A. (2011). Social validity of randomised controlled trials in health services research and intellectual disabilities: A qualitative exploration of stakeholder views. *Trials*, 12(1), 1–10.

Ryan, C., Bergin, M., & Wells, J. S. (2021). Work-related stress and well-being of direct care workers in intellectual disability services: A scoping review of the literature. *International Journal of Developmental Disabilities*, 67(1), 1–22.

Stenfert Kroese, B., & Rose, J. L. (2011). *Mental health services for adults with learning disabilities*. The Judith Trust.

Stephen Watkins, NHS Benchmarking Network. (2021). Personal communication with Mr Peter Cartlidge, Divisional Director, Services for Ageing and Perinatal Mental Health (SAPMH).

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357.

Weise, J., Fisher, K. R., Whittle, E., & Trollor, J. N. (2018). What can the experiences of people with an intellectual disability tell us about the desirable attributes of a mental health professional? *Journal of Mental Health Research in Intellectual Disabilities*, 11(3), 183–202.

White, J., Symes, M., & Pearce, C. (2019). Redesigning a community-based challenging behaviour intensive support service. *Advances in Mental Health and Intellectual Disabilities*, 13, 123–132.

Whittle, E. L., Fisher, K. R., Reppermund, S., Lenroot, R., & Trollor, J. (2018). Barriers and enablers to accessing mental health services for people with intellectual disability: A scoping review. *Journal of Mental Health Research in Intellectual Disabilities*, 11(1), 69–102.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.