Clinical and cost evaluation of intensive support teams (IST) for adults with intellectual disabilities and challenging behaviour (The IST-ID study)

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Scientific summary

Background

Approximately 18% of adults with intellectual disabilities living in the community display any challenging behaviour including aggression, self-injury or other socially inappropriate behaviours. There are significant concerns that these adults will be subject to poorer clinical

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outcomes and excessive use of restrictive practices. Intensive support teams (IST) are specialist teams that have been advocated for many years as the right services to help adults with intellectual disabilities who display challenging behaviour remain in their local communities. **Based on stakeholder consensus, the national policy for adults with intellectual disabilities who display challenging behaviour recommends ISTs as a means of providing high-quality proactive care aimed at avoiding unnecessary inpatient admissions and/or reducing inpatient length of stay and supporting adults who are in a mental health crisis in the community.** To date, there has been a gap in comprehensively characterising ISTs and their role in crisis management for adults with intellectual disabilities who display challenging behaviour. Currently, there is little evidence to recommend a preferred IST model. NHS Commissioners require clear information about what works in order to fund appropriate services and policy initiatives demand a proper evaluation in order to ensure that they are effective and impactful. Therefore, a demonstration of the different types of IST operation and their associated outcomes for adults with intellectual disabilities is paramount to provide evidence as to whether IST roll out is effective in reducing challenging behaviour and improve stakeholder satisfaction with care.

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Objectives

Phase one

1) to describe the provision of IST care across England;

2) to create a typology of IST models based on common characteristics currently operating in England.

Phase two

1) to compare the clinical effectiveness of different IST models that best support improved outcomes for challenging behaviour;

2) to investigate the cost-effectiveness of different IST models;

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3) to understand the impact of ISTs on the lives of adults with intellectual disabilities who display challenging behaviour, their families and/or paid carers and IST managers and professionals.

Methods

Phase one

The ISTs in England were identified through a screening survey distributed to all specialist community intellectual disability services. Services were identified via clinical commissioning groups, online searches, previous research, and the 48 Transforming Care partnerships, including all community intellectual disability services. IST managers completed a separate comprehensive survey mapping the current IST provision and geographical distribution in England.

Phase two

A mixed-method cohort study recruited 21 randomly selected ISTs in England from those identified in phase one. Ten enhanced and 11 independent ISTs in rural and urbal areas of England were included in the study. The target population was adults with mild to profound intellectual disability who displayed challenging behaviour and were eligible to receive support from an IST service. IST services were included if they had been operational for at least 12 months, there was commitment to fund the service for the study duration and agreed to achieve recruitment targets based on estimates via the local capacity and capability assessment. In total, 226 participants were recruited in the study who were identified by IST staff either at the first clinical assessment or from the existing IST service caseloads. The IST staff gave potential participants and/or their family and paid carers information about the study and those who expressed an interest in it had their contact details shared with the research team. Individual-level data were collected at baseline and at 9 months.

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The primary outcome measure was a change in challenging behaviour as measured by the Aberrant Behaviour Checklist-Community version 2 (ABC-C). Secondary outcome measures included mental health status, clinical risk, quality of life, service use. Additional information was collected on sociodemographic characteristics, additional health comorbidities, change in accommodation and reasons for it, level of functioning, and number and length of admissions to psychiatric hospital. In addition, 50 semi-structured interviews with family or paid carers, adults with intellectual disability or focus groups with IST managers and professionals explored the impact of ISTs. The interviews were analysed using thematic analysis. Supplementary data were also retrieved from ISTs to broaden the evaluation of IST models including patient throughput (e.g., number of caseload and referrals over the past 12 months, length of time from referral to assessment and/or delivery of care plan, collaboration with other services etc.) for the participating 21 ISTs, a desk-based review of operational policies (n=19), and an online survey investigating healthcare professionals views from community intellectual disability services on the service pathway (e.g., number of referrals, reasons for referrals, support offered).

Results

Phase one

In total, 80 localities identified as having an IST that provides support to adults with intellectual disability who display challenging behaviour. Seventy-three ISTs (91%) returned an in-depth survey about their provision of care. Following cluster analysis of data from 71 ISTs, two IST models were identified. The enhanced model included ISTs integrated into the community intellectual disability services whilst the independent provision model comprised of stand-alone services. Enhanced ISTs are likely to provide long-term support, accept self-referrals and have a large caseload but are less likely to use measures to monitor progress compared to the independent IST model. Both models described person-centred positive behaviour support as the main intervention.

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Phase two

Clinical and cost-effectiveness outcomes

The study enrolled 226 participants (enhanced model, n=11 ISTs including 115 participants; independent model, n=10 ISTs including 111 participants). Overall, there was a reduction in challenging behaviour at 9 months in both IST models [mean(SD) difference at baseline 63(33); mean(SD) difference at 9 months follow-up: 56(34)]. The observed ABC-C score for the independent IST model reduced by 21% at follow-up and for the enhanced model by 13% but this difference was not statistically significant (β*:* 3.08; 95% CI: -7.32, 13.48; p=0.561). There were also no statistically significant differences in secondary outcomes [PASADD checklist – organic condition (OR: 1.09; 95% CI: 0.39 – 3.02), affective or neurotic disorder (OR: 0.91; 95% CI: 0.32 – 2.59), psychotic disorder (OR: 1.08; 95% CI: 0.21 – 5.50); Risk score (*β:* 1.12; 95% CI: -0.44 – 2.68); QoL-Q score (*β:* -2.63; 95% CI: -5.65 – 0.40)].

From an NHS perspective, the mean total health and social care cost over 9 months follow-up was £15302.66 in the enhanced and £15324.18 in the independent model. The mean health and social care cost difference was not statistically significant (£3409.95; 95% CI [-£9957.92, £4039.89]). From a societal perspective, the mean total cost over 9 months follow-up was £26117.84 in the enhanced model and £24259.33 in the independent model. The mean difference in societal costs between the enhanced and independent models was not statistically significant (-£4712.30;95% CI [-£11124.85, £2106.36]).

Qualitative findings

In total, 40 individual interviews and two focus groups (n=5 in each) were conducted including IST managers (n=14), IST professionals (n=14), family carers (n=9), paid carers (n=7) and adults with mild to moderate intellectual disabilities (n=6) from either IST model.

The majority of stakeholders reported positive experiences of their contact with ISTs. Family and paid carers and adults with intellectual disabilities valued having easy access to the ISTs,

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receiving person-centred care, and involving carers in the decision-making process related to the individual with intellectual disability. However, a minority of carers reported lack of communication being a stumbling block in their involvement especially when the person with intellectual disabilities lived in a different locality whereas adults with intellectual disabilities reported they would prefer to have more opportunities for direct contact with the IST rather than relying on carers to speak on their behalf.

IST professionals emphasised collaboration with other services was a main ingredient of success and training offered to family and care home (paid) carers was also seen as a core function. On the other hand, they referred to several challenges including recruitment and retention of staff, increased expectations, unclear eligibility criteria for referrals extending to those with intellectual disabilities whose mental health was a priority rather than challenging behaviour and funding constraints.

A number of suggestions were put forward by all stakeholders as follows: 1. Increasing awareness of care home managers and staff to identify triggers of challenging behaviour; 2. promoting the IST as a service more broadly with the view to develop opportunities for collaborative work with more community services (i.e., emergency departments, police, care homes); and 3. improving ISTs communication and being more user friendly.

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Service-level processes and outcomes

The caseload and number of referrals in ISTs in the enhanced model was higher (n=51 and n=50 respectively) compared to ISTs in the independent model (n=30 and n=35 respectively). However, service users' engagement with the IST, as reported by IST managers, was high for both models (94% and 95% respectively). In addition, the speed of response in independent ISTs was greater (5 days; enhanced model: 18 days) as well as the delivery of a management plan following assessment (33 days; enhanced model: 51 days).

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Examination of the operational policies of 19 ISTs (both models) revealed that the remit of the service was to:

1. Support adults with intellectual disabilities in placement breakdown;
2. Reduce hospital admissions;
3. Deliver interventions for challenging behaviours;
4. Ensure community integration to benefit the well-being and quality of life of the individual.

The policies referred to multidisciplinary teams including having access to a number of health professionals with about half (10 out of 19) also operating outside of working hours.

Finally, healthcare professionals (n=31) from community intellectual disability services who referred adults with intellectual disability to the IST reported that the commonest reason for referral was the management of challenging behaviour and decline in mental health. The referrers stated that ISTs offered a range of input including psychoeducation to family and paid carers, development of Positive Behaviour Support plans, home visits and signposting adults with intellectual disabilities and carers to other relevant services. Referrers also raised concerns around funding of ISTs, delay in response during a crisis, need for a range of interventions and greater clarity of the IST role.

Conclusion

Our study found that 80 ISTs were in operation in England in 2018 suggesting a more widespread roll out of the ISTs than previously identified of which 71 provided data. Two models – enhanced and independent procision – were operational in England. Although there is some variation in how ISTs were configured, there are no statistically significant differences between models in clinical outcomes. There is still lack of clarity about the role of IST, which appear to be exclusively a treatment a treatment service with slow turnover of referrals. The experience of multiple stakeholders was predominantly positive, but

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indistinguishable between models. Service users were engaged with the IST with a mean episode time duration of at least 6 months. Operational policies clearly described the role of ISTs but lack of clarity of their role was an ongoing theme highlighting the need to further specify their specific characteristics and expectations in terms of key performance indicators. The independent model appears to be associated with gains in response time and could potentially be a preferred model given that it is not significantly more expensive than the alternative. Future studies could include a randomised controlled evaluation of ISTs compared to standard care, use of other qualitative methods such as ethnography and real time observations to pinpoint the therapeutic elements of the clinical encounter and consider what should be the core elements of the IST role.

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Recommendations for practice

- Local circumstances may dictate model choice but some decision on important domains such as responses time to crisis and admission duration need to be taken into account.
- ISTs need to create an operational framework with descriptors of fidelity and clarify their role in the crisis pathway for people with intellectual disability who display challenging behaviour.
- At present, ISTs are second line support for adults with intellectual disability and in the main associated with specialist community intellectual disability care.

Study registration

ClinicalTrials.gov NCT03586375; IRAS 239820; National Institute for Health Research (NIHR) Central Portfolio Management System (CPMS) 38554

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