Intensive support teams for adults with intellectual disabilities displaying challenging behaviour: the IST-ID mixed-methods study

Angela Hassiotis,[1]* Athanasia Kouroupa,[1]
Leila Hamza,[1] Nicola Morant,[1] Ian Hall,[2]
Louise Marston,[3] Renee Romeo,[4] Nahel Yaziji,[4]
Rebecca Jones,[1] Ken Courtenay,[5] Peter Langdon,[6]
Laurence Taggart,[7] Vicky Crossey[8]
and Brynmor Lloyd-Evans[1]

[1]Division of Psychiatry, University College London, London, UK
[2]Hackney Integrated Learning Disability Service, East London NHS Foundation Trust, London, UK
[3]Department of Primary Care and Population Health, University College London, London, UK
[4]Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK
[5]Assessment and Intervention Team, Barnet, Enfield and Haringey Mental Health NHS Trust, London, UK
[6]Centre for Educational Development, Appraisal and Research, University of Warwick, Coventry, UK
[7]Institute of Nursing and Health Research, University of Ulster, Antrim, UK
[8]South West Community Learning Disability Team & Mental Health Intensive Support and Treatment Team, NHS Lothian, Edinburgh, UK

*Corresponding author a.hassiotis@ucl.ac.uk

Declared competing interests of authors: Angela Hassiotis is a member of the Health Technology Assessment (HTA) Commissioning Committee (2018–present); occasionally receives honoraria for lectures to national and international higher education and professional organisations; and is a member of the RESPOND board (2018–present). RESPOND (London, UK) is a national charity treating people with intellectual disabilities who may also have offending histories (URL: https://respond.org.uk/, accessed 2 March 2022). The board position is unpaid. Peter Langdon is a Trustee of Asperger East Anglia and reports funding for expenses that occurred while attending meetings associated with this project.

Published November 2022
DOI: 10.3310/CHDC1642

Scientific summary

The IST-ID mixed-methods study

Health and Social Care Delivery Research 2022; Vol. 10: No. 33
DOI: 10.3310/CHDC1642

NIHR Journals Library www.journalslibrary.nihr.ac.uk

Scientific summary

Background

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

For many years, specialist teams called intensive support teams (ISTs) have been considered to be the right service 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 that is 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 the literature; ISTs, and their role in crisis management for adults with intellectual disabilities who display challenging behaviour, have not been comprehensively characterised. Currently, there is little evidence to recommend a preferred IST model. NHS commissioners require clear information about what works so that they can fund appropriate services, and policy initiatives demand a proper evaluation 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 of paramount importance to provide evidence of whether or not IST roll-out is effective in reducing challenging behaviour and improve stakeholder satisfaction with care.

Objectives

Phase 1

We aimed to:

- describe the provision of IST care across England
- create a typology of IST models based on common characteristics currently operating in England.

Phase 2

We aimed to:

- compare the clinical effectiveness of different IST models that best support improved outcomes for challenging behaviour
- investigate the cost-effectiveness of different IST models
- 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 1

Intensive support teams in England were identified through a screening survey that was distributed to all specialist community intellectual disability services (CIDSs). Services were identified through clinical commissioning groups, online searches, previous research and the 48 Transforming Care Partnerships,

Copyright © 2022 Hassiotis *et al.* This work was produced by Hassiotis *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health and Social Care. This is an Open Access publication distributed under the terms of the Creative Commons Attribution CC BY 4.0 licence, which permits unrestricted use, distribution, reproduction and adaption in any medium and for any purpose provided that it is properly attributed. See: https://creativecommons.org/licenses/by/4.0/. For attribution the title, original author(s), the publication source – NIHR Journals Library, and the DOI of the publication must be cited.

including all CIDSs. IST managers completed a separate comprehensive survey mapping the current IST provision and geographical distribution in England.

Phase 2

A total of 21 randomly selected ISTs in England from those identified in phase 1 were recruited to a mixed-methods cohort study. Ten enhanced and 11 independent ISTs in rural and urban areas of England were included in the study. The target population was adults with mild to profound intellectual disabilities 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 they agreed to achieve recruitment targets based on estimates from the local capacity and capability assessment. In total, 226 participants who were identified by IST staff, either at the first clinical assessment or from the existing IST service caseloads, were recruited to the study. The IST staff gave potential participants and/or their family carers and paid carers information about the study, and the contact details of those who expressed an interest in the study were shared with the research team. Individual-level data were collected at baseline and at 9 months.

The primary outcome measure was a change in challenging behaviour as measured by the Aberrant Behaviour Checklist-Community, version 2 (ABC-C). The secondary outcome measures included mental health status, clinical risk, quality of life and service use. Information was also collected on sociodemographic characteristics, additional health comorbidities, change in accommodation and reasons for it, level of functioning, and the number and length of admissions to a psychiatric hospital. In addition, the impact of ISTs was explored through 50 semistructured interviews with family carers, paid carers or adults with intellectual disabilities, and focus groups with IST managers and professionals. 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. size of caseload and number of referrals over the previous 12 months, length of time from referral to assessment and/or delivery of care plan, collaboration with other services) for the 21 participating ISTs, a desk-based review of operational policies (ISTs, $n = 19$), and an online survey investigating health-care professionals' views from CIDSs on the service pathway (e.g. number of referrals, reasons for referrals, support offered).

Results

Phase 1

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

Phase 2

Clinical effectiveness and cost-effectiveness outcomes

The study enrolled 226 participants (enhanced model: ISTs, $n = 11$; participants, $n = 115$; independent model: ISTs, $n = 10$; participants, $n = 111$). Overall, there was a reduction in challenging behaviour at 9 months in both IST models: the mean (standard deviation) difference was 63 (33) at baseline and 56 (34) at the 9-month follow-up. At follow-up, the observed ABC-C score reduced by 21% for the independent model and 13% for the enhanced model, but these differences were not statistically significant [β 3.08, 95% confidence interval (CI) –7.32 to 13.48; $p = 0.561$]. There were also no statistically significant differences in the secondary outcomes [Psychiatric Assessment Schedule for

Adults with Developmental Disabilities Clinical Interview organic condition (odds ratio 1.09, 95% CI 0.39 to 3.02), affective or neurotic disorder (odds ratio 0.91, 95% CI 0.32 to 2.59), or psychotic disorder score (odds ratio 1.08, 95% CI 0.21 to 5.50); risk score (β 1.12, 95% CI –0.44 to 2.68); or Quality of Life Questionnaire score (β –2.63, 95% CI –5.65 to 0.40)].

From an NHS perspective, the mean total health and social care cost over 9 months' follow-up was £15,302.66 in the enhanced model and £15,324.18 in the independent model. The mean health and social care cost difference was not statistically significant (£3409.95, 95% CI –£9957.92 to £4039.89). From a societal perspective, the mean total cost over 9 months' follow-up was £26,117.84 in the enhanced model and £24,259.33 in the independent model. The mean difference in societal costs between the enhanced and independent models was not statistically significant (–£4712.30, 95% CI –£11,124.85 to £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, 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 disability lived in a different locality. Adults with intellectual disabilities reported that they would prefer to have more opportunities for direct contact with the IST, rather than relying on carers to speak on their behalf.

Intensive support team professionals emphasised that collaboration with other services was a main ingredient of success, and the training offered to family and care home (paid) carers was also seen as a core function. However, they referred to several challenges, including recruitment and retention of staff, increased expectations, the fact that the eligibility criteria were unclear regarding adults with intellectual disabilities whose mental health should be prioritised over their challenging behaviour, and funding constraints.

Suggestions put forward by stakeholders were as follows: (1) increase awareness of care home managers and staff so that they are able to identify triggers of challenging behaviour; (2) promote 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) improve ISTs' communication and be more user friendly.

Service-level processes and outcomes

The average caseload and number of referrals in ISTs in the enhanced model were larger ($n = 51$ and $n = 101$, respectively) than those of ISTs in the independent model ($n = 30$ and $n = 80$, respectively). However, managers indicated high levels of engagement of patients in the IST caseload for both models. In addition, the speed of response in independent ISTs was greater (5 days, compared with 18 days in the enhanced model), as was the delivery of a management plan following assessment (33 days, compared with 51 days in the enhanced model).

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

- support adults with intellectual disabilities in placement breakdown
- reduce the number of hospital admissions
- deliver interventions for challenging behaviours
- ensure community integration to benefit the well-being and quality of life of the individual.

Copyright © 2022 Hassiotis *et al.* This work was produced by Hassiotis *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health and Social Care. This is an Open Access publication distributed under the terms of the Creative Commons Attribution CC BY 4.0 licence, which permits unrestricted use, distribution, reproduction and adaption in any medium and for any purpose provided that it is properly attributed. See: https://creativecommons.org/licenses/by/4.0/. For attribution the title, original author(s), the publication source – NIHR Journals Library, and the DOI of the publication must be cited.

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

Last, health-care professionals ($n = 31$) from CIDSs who referred adults with intellectual disabilities to the IST reported that the most common reasons for referral were the management of challenging behaviour and decline in mental health. The referrers stated that ISTs offered a range of input, including psychoeducation for family and paid carers, development of PBS plans, home visits and signposting adults with intellectual disabilities and carers to other relevant services. Referrers also raised concerns regarding the funding of ISTs, delays in response during a crisis, and the 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; 71 of these ISTs provided data. Two models – enhanced and independent provision – were operational in England. Although there was some variation in how ISTs were configured, there were no statistically significant differences between the models in their clinical outcomes. There is still lack of clarity about the role of ISTs, which appear to be exclusively a treatment service, with a slow turnover of referrals. The experiences of multiple stakeholders were predominantly positive, but indistinguishable between the models. Service users were engaged with the IST for a mean duration of 6 months. Operational policies clearly described the role of ISTs, but a lack of clarity of their role was an ongoing theme, highlighting the need to further specify their characteristics and expectations in terms of key performance indicators.

The independent model appears to be associated with gains in response time and could be the preferred model, given that it is not significantly more expensive than the alternative. Future studies could include a randomised controlled evaluation of ISTs and standard care, use of other qualitative methods such as ethnography and real time observations to pinpoint the therapeutic elements of the clinical encounter, and consideration of what should be the core elements of the IST role.

Recommendations for practice

- Local circumstances may dictate model choice, but some decisions on important domains, such as response time to crisis and admission duration, need to be taken into account.
- ISTs need to create an operational framework with descriptors of fidelity and to clarify their role in the crisis pathway for people with intellectual disabilities who display challenging behaviour.

Study registration

This study is registered as ClinicalTrials.gov NCT03586375, Integrated Research Application System (IRAS) 239820 and National Institute for Health and Care Research (NIHR) Central Portfolio Management System (CPMS) 38554.

Funding

This project was funded by the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme and will be published in full in *Health and Social Care Delivery Research*; Vol. 10, No. 33. See the NIHR Journals Library website for further project information.

Health and Social Care Delivery Research

ISSN 2755-0060 (Print)

ISSN 2755-0079 (Online)

Health and Social Care Delivery Research (HSDR) was launched in 2013 and is indexed by Europe PMC, DOAJ, INAHTA, Ulrichsweb™ (ProQuest LLC, Ann Arbor, MI, USA) and NCBI Bookshelf.

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: journals.library@nihr.ac.uk

This journal was previously published as *Health Services and Delivery Research* (Volumes 1–9); ISSN 2050-4349 (print), ISSN 2050-4357 (online)

The full HSDR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/hsdr.

Criteria for inclusion in the *Health and Social Care Delivery Research* journal

Reports are published in *Health and Social Care Delivery Research* (HSDR) if (1) they have resulted from work for the HSDR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

HSDR programme

The HSDR programme funds research to produce evidence to impact on the quality, accessibility and organisation of health and social care services. This includes evaluations of how the NHS and social care might improve delivery of services.

For more information about the HSDR programme please visit the website at https://www.nihr.ac.uk/explore-nihr/funding-programmes/health-and-social-care-delivery-research.htm

This report

The research reported in this issue of the journal was funded by the HSDR programme or one of its preceding programmes as project number 16/01/24. The contractual start date was in September 2017. The final report began editorial review in August 2021 and was accepted for publication in February 2022. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HSDR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health and Care Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the HSDR programme or the Department of Health and Social Care. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, the HSDR programme or the Department of Health and Social Care.

Copyright © 2022 Hassiotis *et al.* This work was produced by Hassiotis *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health and Social Care. This is an Open Access publication distributed under the terms of the Creative Commons Attribution CC BY 4.0 licence, which permits unrestricted use, distribution, reproduction and adaption in any medium and for any purpose provided that it is properly attributed. See: https://creativecommons.org/licenses/by/4.0/. For attribution the title, original author(s), the publication source – NIHR Journals Library, and the DOI of the publication must be cited.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Prepress Projects Ltd, Perth, Scotland (www.prepress-projects.co.uk).

NIHR Journals Library Editor-in-Chief

Dr Cat Chatfield Director of Health Services Research UK

NIHR Journals Library Editors

Professor John Powell Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), UK, and Professor of Digital Health Care, Nuffield Department of Primary Care Health Sciences, University of Oxford, UK

Professor Andrée Le May Chair of NIHR Journals Library Editorial Group (HSDR, PGfAR, PHR journals) and Editor-in-Chief of HSDR, PGfAR, PHR journals

Professor Matthias Beck Professor of Management, Cork University Business School, Department of Management and Marketing, University College Cork, Ireland

Dr Tessa Crilly Director, Crystal Blue Consulting Ltd, UK

Dr Eugenia Cronin Consultant in Public Health, Delta Public Health Consulting Ltd, UK

Dr Peter Davidson Interim Chair of HTA and EME Editorial Board. Consultant Advisor, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Ms Tara Lamont Senior Adviser, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Dr Catriona McDaid Reader in Trials, Department of Health Sciences, University of York, UK

Professor William McGuire Professor of Child Health, Hull York Medical School, University of York, UK

Professor Geoffrey Meads Emeritus Professor of Wellbeing Research, University of Winchester, UK

Professor James Raftery Professor of Health Technology Assessment, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Dr Rob Riemsma Consultant Advisor, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Professor Helen Roberts Professor of Child Health Research, Child and Adolescent Mental Health, Palliative Care and Paediatrics Unit, Population Policy and Practice Programme, UCL Great Ormond Street Institute of Child Health, London, UK

Professor Jonathan Ross Professor of Sexual Health and HIV, University Hospital Birmingham, UK

Professor Helen Snooks Professor of Health Services Research, Institute of Life Science, College of Medicine, Swansea University, UK

Professor Ken Stein Professor of Public Health, University of Exeter Medical School, UK

Professor Jim Thornton Professor of Obstetrics and Gynaecology, Faculty of Medicine and Health Sciences, University of Nottingham, UK

Please visit the website for a list of editors: www.journalslibrary.nihr.ac.uk/about/editors

Editorial contact: journals.library@nihr.ac.uk