The IST-ID Study Quantitative Results

UCL PSYCHIATRY

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

Information:

ISTs are specialist services that were formed to support people with intellectual disabilities who display challenging behaviour in the community. A number of different terms are used to describe ISTs including "peripatetic teams", "assertive outreach teams", and "specialist behaviour teams".

We use the term intellectual (also called learning) disabilities (ID) in this booklet.

This is one of two online booklets showing the findings of the IST-ID study.

Follow the line to read content in order.

Background

Approximately **18%** of adults with intellectual disabilities living in the community display any challenging behaviour

Concerns that this leads to:

- unnecessary long-term prescription of psychotropic medication
- abuse
- increased rates of hospitalisation
- exclusion
- poorer health

Intensive support teams (IST-ID) The right service to help?

Perhaps, but more insight is needed to recommend a preferred model to NHS commissioners

- different types of IST-ID operation
- outcomes for their clients

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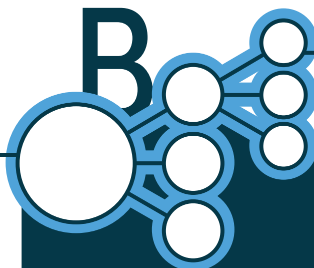
The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Objectives

A

To describe the provision of IST-ID care across England

B



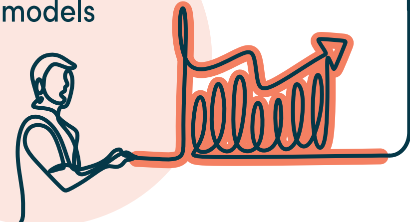
To create a typology of IST-ID models based on common characteristics currently operating in England

C

To compare the clinical effectiveness of different IST-ID models that best support improved outcomes for challenging behaviour

D

To investigate the cost-effectiveness of different IST-ID models



E

Human Impact

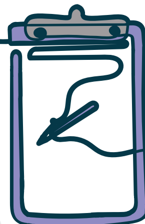
To understand the impact of IST-ID on the lives of adults with intellectual disabilities who display challenging behaviour, their families and/or paid carer and IST-ID managers and professionals.

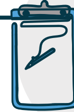
Methods

Stage 1

Identify IST-ID through a screening survey sent to all specialist community intellectual disability services.

Identified through Clinical Commissioning Groups (CCGs), online searches, previous research, and the 48 Transforming Care partnerships, including all community intellectual disability services.





IST-ID managers completed a separate comprehensive survey mapping the current IST-ID provision and geographical distribution in England

Stage 2

21

of these IST-ID's were recruited to a mixed-method cohort study

Criteria

Operational for +12 months

226

participants were recruited in the study

Individual-level data were collected at baseline and at 9 months

Agreed to achieve recruitment targets based on estimates via the local capacity and capability assessment

Committed to fund the service for the study duration

Measures

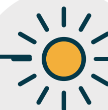
Primary

a change in challenging behaviour as measured by the Aberrant Behaviour Checklist-Community version 2 (ABC-C)

Secondary measures included:

mental health status

clinical risk



quality of life

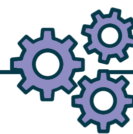
service use

Additional measures:

sociodemographic characteristics

additional health comorbidities

change in accommodation and reasons for it



level of functioning number

length of admissions to psychiatric hospital

50 semi-structured in-depth interviews with family or paid carers, adults with intellectual disability or focus groups with IST-ID managers professionals from either IST-ID model

You can find more about the stakeholder experience in our other online magazine.

Supplementary data

Patient throughput of **21** IST-ID

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.)

A desk-based review of operational policies (n=19)

Online survey investigating healthcare professionals views from Cognitive Impared and Dementia Service (CIDS) on the service pathway e.g., number of referrals, reasons for referrals, support offered.

Results

Objective A
To describe the provision

A

80 IST-ID identified across England that provides support to adults with intellectual disability who display challenging behaviour.

73 IST-ID (91%) returned an in-depth survey about their provision of care

To create a typology

B

Two IST-ID models were identified

Enhanced

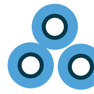
These included IST-ID integrated into the community intellectual disability services. Enhanced IST-ID are likely to:

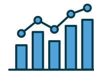
provide long-term support

accept self-referrals

have a large caseload

Independent


Comprised of stand-alone services


More likely to use measures to monitor progress

Both models described person-centred positive behaviour support as the main therapeutic intervention.

Objective C Clinical effectiveness

C

Overall, there was a reduction in challenging behaviour at 9 months

mean(SD) difference at baseline 63(33) mean(SD) difference at 9 months follow-up: 56(34) in both models

Primary

The observed ABC-C score at follow-up

21% **Independent** Challenging behaviour reduced by 21% at follow-up

13% **Enhanced** reduced by 13% *but this difference was not statistically significant (β: 3.08; 95% CI: -7.32, 13.48; p=0.561).*

Secondary

There were also no statistically significant differences in secondary outcomes

Both models had a similar impact on:

mental health status

reduction of risk

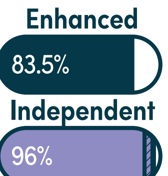
quality of life

Medications

All medications: Polypharmacy at a mean of 5 for both models

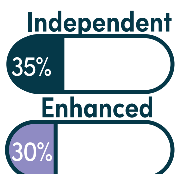
Psychotropics

% of participants on antipsychotics at baseline



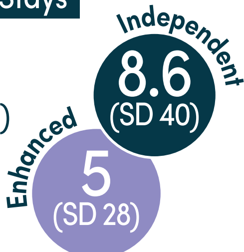
Small reductions (91%) at 9 months in the Independent model

% of participants who were prescribed psychotropics other than antipsychotics

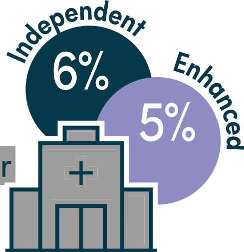


Inpatient Stays

Psychiatric inpatient: mean (=SD) bed days:



% of participants admitted at least once over the course of the study



Objective D
Cost effectiveness

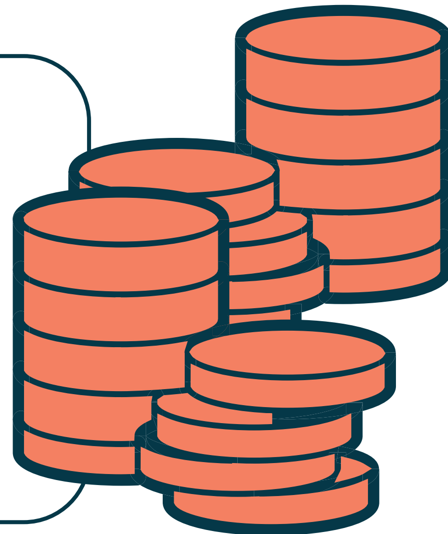
D

Mean total health and social care cost over 9 months follow-up was:

Independent
£15,324.18

Enhanced
£15,302.66

though not statistically significant (mean difference £3409.95; 95% CI [-£9957.92, £4039.89]).



Objective E
Human Impact

E

Health related quality of life based on carer report

QALYS

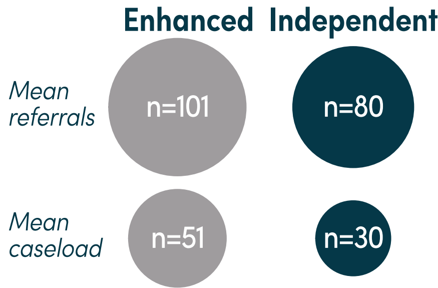
QALY (quality-adjusted life-year) is a generic measure of disease burden, is used in economic evaluation to assess the value of interventions

Independent 0.504

Enhanced 0.463

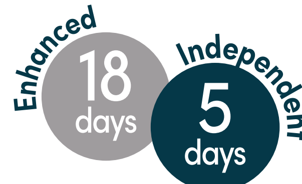
Service-level processes and outcomes

The caseload & number of referrals in IST-ID

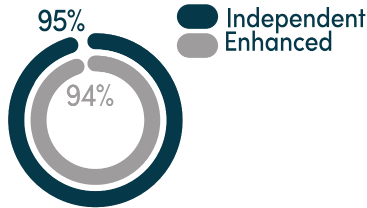


Time to respond to referrals

Service users were engaged with the IST-ID with a mean episode time duration of at least 6 months



Service users' engagement with the IST-ID, as reported by IST-ID managers, was high



Delivery of a management plan following assessment

Training of family or paid carers was reported as core function

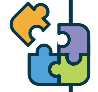
31 healthcare professionals from community Intellectual Disability Teams who referred adults with intellectual disability to the IST-ID said commonest reason for referral was the management of challenging behaviour and decline in mental health

For **19** IST-ID the remit was

Support adults with intellectual disabilities in placement breakdown

Reduce hospital admissions

Deliver interventions for challenging behaviours



Ensure community integration to benefit the well-being and quality of life of the individual

Operated outside of working hours (10 out of 19)

Part of the work the IST-ID delivered included:

Raising awareness about challenging behaviour

PBS plans

Home support

Signposting to other services

But: referrers also raised concerns around funding of IST-ID, delay in response during a crisis, need for a range of interventions and greater clarity of IST-ID role

Conclusions

IST-ID appear to be exclusively a treatment service rather than a rapid response to a crisis with slow turnover of referrals

Some variation between IST-ID models but similar improvements in clinical outcomes

Some aspects of the role of IST-ID could be devolved to social care professionals especially around care coordination

Operational policies clearly described the role of IST-ID but more clarity needed around their specific characteristics and expectations in terms of key performance indicators

The independent model appears to be associated with gains in referral response and admission times. Commissioners of services may choose a model that works best in their local circumstances.

PSYCHIATRY

Chief Investigator : Angela Hassiotis

Co-applicants: Ken Courtenay, Vicky Crossey, Ian Hall, Rebecca Jones, Peter Langdon, Bryn Lloyd-Evans, Nicola Morant, Renee Romeo and Laurence Taggart.

Researchers: Jessica Budgett, Leila Hamza, Isobel Harrison, Athanasia Kouroupa, Louise Marston, Victoria Ratti, Peiyao Tang and Amy Walsh.

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