

The IST-ID Study Qualitative Results

Stakeholder experiences of intensive support teams:
what works and what can be improved

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.

The colours refer to the different participant groups, as shown below. Quotes and points are allocated to the relevant group using the relevant colour.

Follow the line to read content in order.

Participants

We identified two different IST-ID models: **enhanced provision** within the broader community intellectual disability services and **independent provision**, a standalone service.

We interviewed
50
people

14
managers

28
IST-ID
professionals

9
family
carers

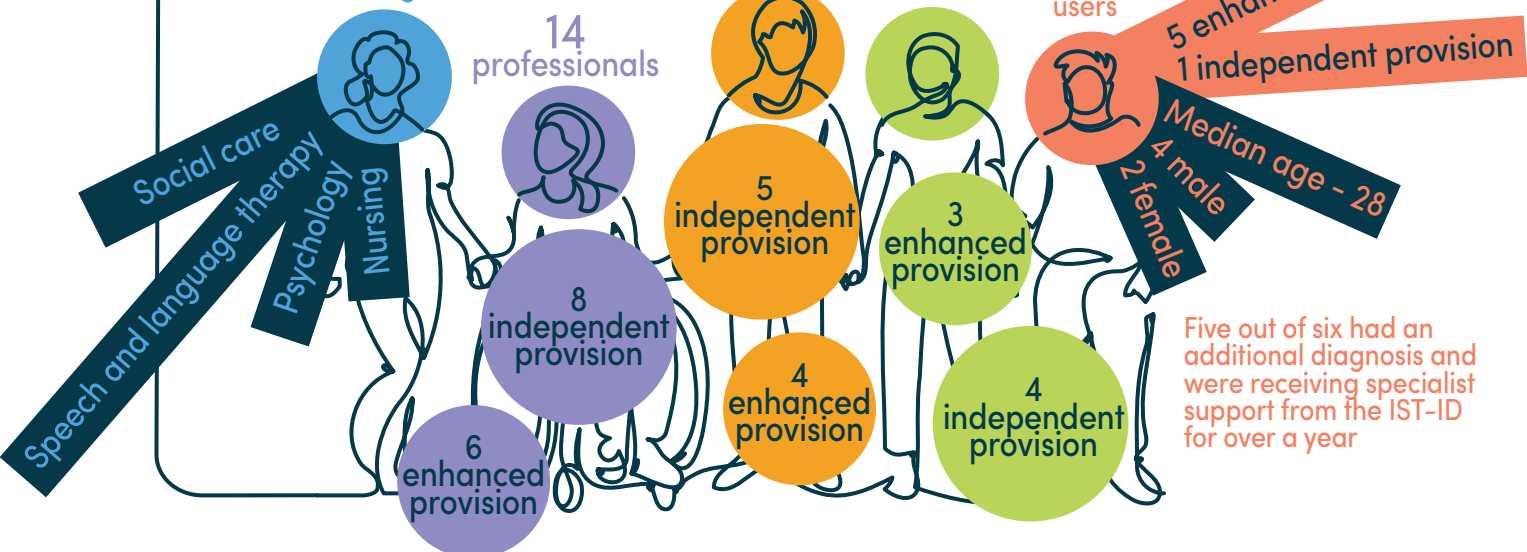
7
paid
carers

6
service
users

5 enhanced provision
1 independent provision

Median age - 28
4 male
2 female

Five out of six had an additional diagnosis and were receiving specialist support from the IST-ID for over a year



Value of the IST-ID

Value One: Service Accessibility and Flexibility

Late home visits and observations

I've been stood in gardens at ten, eleven o'clock at night... You don't finish there. So, there's flexibility.

We're all quite friendly, jolly adults that I think we're quite welcoming and adults tend to react well



IST-ID manager

enhanced provision

Promoted and supported joint work with other services during referrals

Friendly and approachable

IST-ID professional/ independent provision

...when we have needed something very urgent, the IATT team have been really responsive, they've been brilliant*

**Intensive Assessment and Treatment Team*

Confident asking for additional support as IST-ID staff know their needs over time

Regular check-ins during Covid-19 pandemic

Comforting as IST-ID staff responded to phone calls /visited when carers and adults with intellectual disabilities got worried or felt upset

Adult with intellectual disability

enhanced provision



Family carer

paid carer

Value Two: Person Centred Care

All stakeholders highlighted the importance of person-centred care

Involve carers and adults with intellectual disabilities in care or review meetings

They're asked what they would like to happen if they were in a mental health crisis

Adult with intellectual disability, enhanced provision

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.

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-ID manager enhanced provision



The letters that we send out, they're already, always written to the adults, where possible ...

Where possible, the person with intellectual disability was consulted about their behaviour support plan

IST-ID staff developed a Positive Behaviour Support (PBS) plan that took day to day needs into consideration to help adults with intellectual disabilities feel happier and able to enjoy life more

Service users, family carers and paid carers said :

IST-ID professionals supported requests for social or other services such as respite care, obtaining a wheelchair aid

Identified ways the service user could be more connected to their local community e.g., activities and education

Reassured by the IST-ID support and training of care home staff, especially during a crisis

I liked colouring ... did some playing ... like arts and crafts ... I like to do some playing.

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

Extra assistance was given with service users transportation, school activities or school courses

Value Three: Carer involvement

The active engagement of all relevant parties was identified as an important element of good IST-ID care across stakeholder groups

It was reported that the contribution of family or paid carers was important in meetings when developing a management plan

Family or paid carers promote broader thinking about individual's needs in meetings

Helpful to have contact/collaborative working with paid carers around risk assessment, updates on progress and incidents



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.

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

Most family and paid carers reported being listened to and being an integral part of the individual's care plan and treatment decision-making processes

They appreciated that the IST-ID offered practical suggestions to handle challenging behaviours

Carers reported that they coped better as a result of the IST-ID input, even when there were setbacks



Areas where IST-ID can do better

Make IST-ID easier to get hold of

Family carers and service users told us that they were not able to get through, waited for a long time for updates or were not told at all that a new service were involved until they were invited to a meeting



Lack of communication to start with as took long time to get appointment

enhanced provision

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.

Families reported that some IST-ID professionals did not always acknowledge the challenges of living with an adult with intellectual disability and the family'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.

Where is the social worker?



A social worker could support the identification of meaningful opportunities e.g., employment, activities for adults with mild intellectual disability to integrate them into the community



I just sometimes feel frustrated when there's nobody there for him. Because years ago, there was something every day. The services, the activities. I mean, he's gone at odd times to the allotment. But he won't go a lot. I can't believe the things he used to do and there's just nothing for them, is there?

A social worker would have quicker access to information about the service user and his/her family so that they could save having to repeatedly share their stories across professions



Think beyond behavioural approaches



IST-ID managers said that more therapeutic options should be available, e.g., family therapy, anger management, CBT, EMDR.



Roles and Organisation of IST-ID

Who is the IST-ID client?

Managers are frustrated by broad eligibility for IST-ID care – filling a gap in care provision

This leads to focus on priority needs, e.g., psychosis, or adults without access to other facilities e.g., autism spectrum disorder without intellectual disability.



“There is a significant black hole at the moment for adults who have autism but don't have a learning disability to fall into ... They may not be eligible for our service but some of our PBS approaches are highly relevant.”

So literally at the moment, we are recording those adults in our risk management system in order to evidence to the clinical commissioning group very clearly what the identified need is.”



Services often have to prioritise e.g., high risk over low risk cases

“There's a whole layer of adults who still might have significant difficulties because of their learning disability, but don't meet our really high threshold criteria. They won't get a service because they're not at risk of placement breakdown”

How IST-ID operate

Interface of IST-ID with other services

IST-ID provide long periods of care due to waiting lists in Community Intellectual Disability Service (CIDS), identifying alternative placements or home care provision

Relationships with other teams and external agencies help response time



There's value in collaborating with CIDS staff to complete joint assessments

IST-ID manager independent provision



“We'll see it through from beginning to end which can ... you could be six months looking for an alternative placement to then support them through the transition”

“We work alongside primary care nurses and daily GPs if there are any issues. We also work alongside our CHC* colleagues.”

*Continuing Health Care

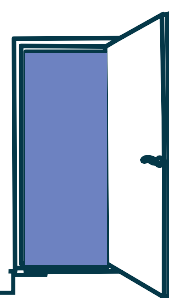


Working with commissioners to define success via admission rates and clinical records

IST-ID Professional enhanced provision



“We try to collect service user feedback where that's possible... We do also use outcome measures as well that will help us evidence change.”



Formal and informal 'corridor conversations' help staff liaison

Barriers to IST-ID Care

Service funding



IST-ID manager enhanced provision

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.

Both models saw this caused distress to adults with intellectual disability and potentially exacerbated their challenging behaviour

Staff recruitment and retention

Cost concerns have impacted staffing decisions

Challenge to find qualified staff especially 24/7 IST-ID in rural locations struggle to attract qualified professionals



IST-ID manager independent provision

Our registered professionals have quite a high turnover because of the on-call hours

Maintaining professional standards

Lack of resources for training to upskill IST-ID professionals / offer continuous professional development

Constantly training at accommodation provider staff due to high turnover



IST-ID manager enhanced 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.

Intensive support / daily contact whilst also maintaining staff safety without sufficient resource

Workload

Small or part time IST-ID struggle with caseload and time management during busy periods e.g., Christmas

External Pressures

Additional pressure to justify service to commissioners by responding quickly, long caseloads and 24/7 availability



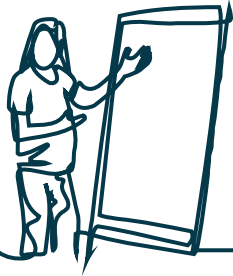
IST-ID manager independent provision

Being 24/7 as well is quite a challenge for me because I really don't get to switch off, - 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.

Suggestions for Improvement

Wider training

IST staff agreed that upskilling and supporting paid carers and providers is an important element of their work



Needed in order to enable carers and providers to deliver better care to people with multiple and complex needs

We've got a lot of providers popping up all over the place at the moment that have all lovely brochures telling us all the amazing things they can do. And then people move in and, and it doesn't quite work out that way and we find that we have to come in and pick up the pieces.

IST-ID manager independent provision

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, right, this is what your care team needs to do to enable ... to give somebody a really good community present life, you know, and we're not.

Visibility of IST-ID and collaborative approach

Promote the service and define its role



Inform each locality about specific IST-ID services available

Family carer, independent provision

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

Better links with mental health services

- Cases could be reviewed earlier
- Support peer supervision
- Decrease inappropriate referrals
- Consolidate role of IST-ID

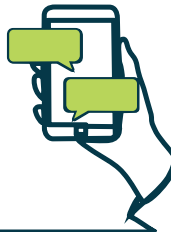
IST-ID manager independent provision

If you think someone might need to ring us but you're not sure, um, don't wait to put a referral in. If there's an MDT, invite us to it.*

*MDT: multidisciplinary team

User friendly IST-ID

Think about busy care staff who need information at their fingertips



IST-ID manager independent provision

Why do we produce 40-page PBSSs for adults who need an easy-read grab sheet, positive behavioural support

Remove jargon which is a barrier to engagement



PSYCHIATRY

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