



IST-ID Study

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

IST-ID Study

Background

- Community services for people with an intellectual disability (ID) have often been poorly planned both within the U.K and globally.
- There is a significant variability in the commissioning of services to provide adequate support to people with ID and in how services implement policy guidelines.
- A national mandatory commissioning framework has now been suggested.

Service models

- A report from the Royal College of Psychiatrists (2015) on *community based services for people with an intellectual disability and mental health problems* found that there is insufficient evidence to suggest a superior model in terms of service user outcome and effectiveness
- **Transforming Care** seeks to improve services for people with ID so that more people can be supported in their community and not in hospital. It was developed by the Department of Health as a national response to the abuse suffered by individuals with ID at Winterbourne Hospital
- **Building the Right Support** is a national plan which seeks to “*develop community services and close inpatient community facilities for people with a learning disability and/or Autism who display behaviour that challenges, including those with a mental health condition*” (Building the Right Support, 2015)

Intensive Support Teams: History

- Closure of many inpatient institutions in the 1980s led to community services focussing on managing challenging behaviour (CB) using a 'peripatetic support model' (Emerson et al., 1999)
- Early research of UK services utilising a peripatetic model suggested that this type of support was effective in reducing CB behaviour and improving quality of life for service users (Emerson et al., 1996; Lowe et al., 1996)
- A three-year outcome study in Australia reported pre- and post-intervention outcomes of intensive behaviour support (based on applied behaviour analysis). 75% of 134 interventions resulted in improvements in behaviour, authors concluded regionally-based specialist teams were effective at treating CB (Hudson et al., 1995)
- Review of community MH services for ID and CB, those combining outreach and specialised placements most beneficial in improving quality of life and ensuring social inclusion, but lack of good quality controlled trials (Hassiotis, 2002)

Intensive Support Teams: Policy

- Under Transforming Care, the **Model Service Specification Guide** has been developed to help “*support the implementation of the national service model for people with ID and/or autism who display behaviour that challenges*”
- Within this guide, NHS England propose that Intensive Support Teams (ISTs) should be part of all community ID services in England.

ISTs are specialist services for adults with ID and challenging behaviour which provide:

- Positive Behaviour Support (and other psychosocial approaches) to reduce the severity and frequency of behaviour that challenges
- Support to people during the transition period from assessment and treatment inpatient service to the community home/setting
- Support and training for other agencies supporting those individuals
- Crisis Response

Intensive Support Teams

Also known as....

- Intensive assessment and treatment service
- Enhanced care team
- Intensive support service
- Positive behaviour support team
- Intensive outreach service
- Rapid intervention team
- Psychological behaviour support team
- Enhanced support team
- Specialist support team
- Intensive support unit
- Peripatetic teams
- Assertive outreach teams
- Specialist behaviour teams

Intensive Support Teams: Research

- Recent research conducted by Davidson and colleagues (2015) sought to identify the current provision of peripatetic teams for adults and children with a learning disability and challenging behaviour within the UK.
- 20/46 teams responded to an online survey providing data regarding staffing, service use, service aims and philosophy and service user characteristics.
- Results obtained suggested a lack of peripatetic provision for children, questions regarding the use of evidence based practice and structural changes to services resulting in the demise of this type of service.
- Other studies have focused specifically on the provision of “*intensive support*” with positive behavioural outcomes being found for both stand-alone ISTs and an embedded model (Inchley-Mort, Rantell, Wahlich and Hassiotis; 2014 & Hassiostis et al., 2009)
- However to date there has been limited reporting on stakeholder experiences of ISTs (Inchley-Mort & Hassiotis, 2014; Robotham, King, Canagasabey, Inchley-Mort, & Hassiotis, 2011)

Learning Disability Benchmarking Report

April 2018

- **Provision**
‘Intensive response/support services are in place in 44% of organisations’
- **Service access**
‘Specific LD intensive intervention teams are less commonly available for emergency access to services’ (in comparison to other crisis /OOH teams etc), ‘being available an average of 68 hrs during the week, and 24 hrs over the weekend’



NICE Guidelines Learning disabilities and behaviour that challenges: service design and delivery (NG 93, 2018)

- Service planning
- Enable person-centred care
- Early intervention and support for families and carers
- Community – prevention, early intervention and response
- Housing
- Services for children and young people
- Short break services
- Making the right use of inpatient services
- Staff skills and values

Intensive Support Teams Study rationale

Challenging behaviour

- compromises a person's health and may be the precursor to abuse and restrictive practices in managing it.
- It mediates the quality of staff support and attitudes and is financially costly due to the need for intensive care often for out of area long term placements.

Intensive Support Teams

- Set up to address above issues
- Improve overall quality of life by maintaining individuals close to home
- Integrated within the care system.

Currently, we have no firm evidence about whether dedicated ISTs for challenging behaviour or alternative models achieve better outcomes for adults with challenging behaviours

Overall Study Objectives

1. Map and describe the provision of IST services in England.
2. Create a typology of IST service models.
3. Compare the effectiveness of different IST models for patient outcomes including challenging behaviour, mental health status, risk, satisfaction with care, quality of life, hospital admissions.
4. Estimate the costs of different IST models and investigate cost-effectiveness.
5. Understand how the ISTs impact on the lives of adults with ID and challenging behaviour, their families and the local services.

Phase 1: Screening and national survey

Aims

- To map the number and locations of IST's in England
- To describe the type of ISTs
- To develop a typology of ISTs
- Screening questionnaire → identify ISTs/community intellectual disability services (CIDS) that aim to prevent/manage crises for people with ID.

Screening

- 242 CIDS identified from 48 TCPs
- 236 CIDS completed screening questionnaire (by phone/hard copy).
- 6 CIDS did not respond

Responders

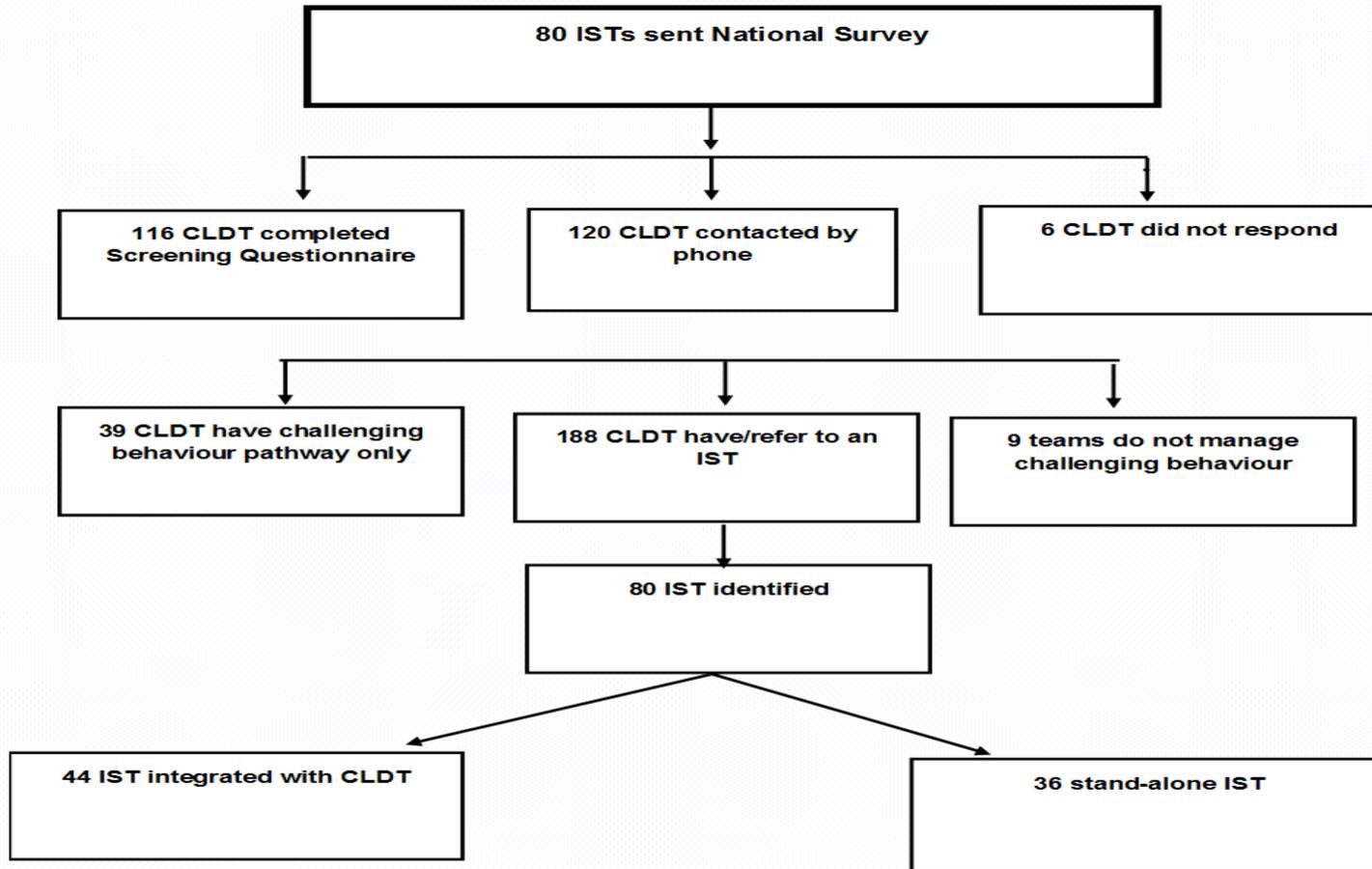
- 188 CIDS refer to an Intensive Support team
- 39 CIDS reported that they have a challenging behaviour pathway only and do not have/refer to an IST.
- 9 teams do not manage challenging behaviour (social care teams/health teams only)
- 86 Intensive Support Teams initially identified (48 integrated with CIDS and 38 stand-alone teams)
- Upon further clarification, 6 CIDS managers reported that they did not fulfil IST criteria.

Intensive Support Teams

- 📍 Worcestershire (Enhanced Care Team)
- 📍 Coventry and Warwickshire Intensive Su...
- 📍 Birmingham IST
- 📍 Wolverhampton (Behaviour Support Tea...
- 📍 South Derbyshire (Assessment and Trea...
- 📍 North Derbyshire IST
- 📍 South Nottinghamshire (Intensive Com...
- 📍 Ipswich Intensive Support Team
- 📍 Norfolk (Additional Support Team)
- 📍 Norfolk (Enhanced Assessment and Tre...
- 📍 Peterborough Intensive Support Team
- 📍 Cambridge (Huntingdon LDP)
- 📍 South Essex (Community LD Team)
- 📍 North Essex (Community LD Team)
- 📍 Bedfordshire IST
- 📍 Milton Keynes (Community Team for Ad...
- 📍 Hertfordshire (East/North Community A...
- 📍 Hertfordshire (West Community Assess...
- 📍 Northamptonshire (Intensive Support Te...
- 📍 Lincolnshire (Community Home Assess...
- 📍 Leicester (Outreach Team)
- 📍 Shropshire (Intensive Support Team Spe...
- 📍 South Staffordshire (Intensive Support T...
- 📍 North Nottinghamshire (Intensive Comm...
- 📍 North Staffordshire Intensive Support Te...
- 📍 Gloucester (Learning Disability Intensive ...)
- 📍 South Gloucester IST
- 📍 Bath (Complex Health Needs Service Le...
- 📍 Wiltshire IST
- 📍 Bristol (Bristol Intensive Response Nurs...
- 📍 North Somerset IST
- 📍 Somerset (Rapid Intervention Team)
- 📍 Cornwall IST
- 📍 North Devon (Intensive Assessment & Tr...
- 📍 South Devon (Intensive Assessment and...
- 📍 West Devon (Intensive Assessment and ...)
- 📍 Exeter (Intensive Assessment and Treat...
- 📍 West Kent (Psychological Behaviour Sup...
- 📍 East Kent (Psychological Behaviour Sup...
- 📍 Brighton and Hove (Positive Behaviour S...
- 📍 West Sussex (Enhanced Care Team)
- 📍 Surrey (Intensive Support Service)
- 📍 Oxfordshire IST
- 📍 Buckinghamshire (Learning Disability He...
- 📍 Berkshire IST
- 📍 Hampshire and Southampton IST
- 📍 Portsmouth IST
- 📍 Dorset IST
- 📍 East Cheshire IST
- 📍 Wirral IST
- 📍 West Cheshire IST
- 📍 Halton (Positive Behaviour Support Servi...
- 📍 Bolton IST
- 📍 Greater Manchester (Specialist Support ...)
- 📍 Lancashire (Specialist Support Team)
- 📍 Durham (Specialist Health Team)
- 📍 Stockton (Enhanced Support Service)
- 📍 Northumberland (Positive Behaviour Sup...
- 📍 Barnsley IST
- 📍 Calderdale IST
- 📍 Kirklees IST
- 📍 Wakefield IST
- 📍 Bradford IST
- 📍 Doncaster (Community Assessment and...
- 📍 North Lincolnshire IST
- 📍 North East Lincolnshire IST
- 📍 Sheffield (Assessment and Treatment S...
- 📍 East Riding (Continuum Team)
- 📍 Hull (Continuum Team)
- 📍 Brent (Therapy Team)
- 📍 Westminster (Flexible Response Service)
- 📍 Ealing (Ealing CLDT)
- 📍 Hounslow (Hounslow CLDT)
- 📍 Kensington and Chelsea (Behaviour Sup...
- 📍 Enfield (Integrated Learning Disabilities ...)
- 📍 Haringey (Assessment and Intervention ...)
- 📍 Hackney (Hackney Integrated Learning D...
- 📍 Tower Hamlets (Mental Health and Beha...
- 📍 Southwark (Enhanced Intervention Servi...
- 📍 Merton (Behaviour Support Team)



Screening Questionnaire



National Survey of identified ISTs

86 IST managers were sent link to Opinio Survey

- 80 ISTs
- 73 (91%) completed survey
- 2 (3%) missing data on staff FTEs
- Remaining 71 were entered into cluster analysis to determine IST typology
- 6 clarified status - not ISTs
- 4 (5%) teams declined participation in study
- 3 (4%) have not completed survey.

Analysis of survey responses

- Descriptive data will be collated for each survey question, and will be used to characterise ISTs and their geographical location.
- Cluster analysis will be used to develop a typology of IST, that is classify services on the basis of pre-specified variables into a number of different groups such that similar services are placed in the same group. This approach has been successfully implemented in previous studies, e.g. mental health crisis houses.
- A hierarchical approach will be used to determine how many clusters there are in the data.
- The study management group will review the models to confirm face validity and in case where no distinct clusters are identified, to propose alternatives.
- Once the cluster analysis is completed and the IST models are confirmed we shall proceed to stage 2.

Cluster analysis

Variable	How defined	Groupings
Caseload size	Team caseload divided by staff FTE to obtain average caseload per team member	Above or below median caseload size - to be confirmed
Setting	Embedded within CDLT or separate stand-alone	Embedded or stand-alone
Hours of operation	Mon-Fri 9-5 or any extended hours (e.g. evenings; weekends)	Normal working hours or extended
Use of outcome measures	Routine use of clinical measures to assess SU outcomes or none used	Outcomes used or not
Staff configuration	One profession only (e.g. nurses; psychologists) or more than one professional group (eg nurses & psychologists /nurses and social workers and psychologists)	Uniprofessional or multidisciplinary
Referral pathway	Accept self-referrals from clients known or unknown to the team and referrals from family/friends/carers of clients or accept referrals from professionals only	Accept self/carer referrals in addition to professionals or professionals only

Cluster profiles for two cluster groupings of IST services

	Cluster 1 N=25	Cluster 2 N=46
Self referral permitted	25 (100%)	16 (35%)
Large caseload	23 (92%)	15 (33%)
Outcome measures used	13 (52%)	41 (89%)
Standalone service	3 (12%)	21 (46%)
Multiprofessional staff team	21 (84%)	43 (93%)
Extended working hours	16 (64%)	31 (67%)

IST Map of England (2 Cluster Model)

- Bristol Intensive Response T...
- NE Lincolnshire IST (C1)
- Enhanced Care Service Brom...
- Intensive Assessment and T...
- Rapid Intervention Team Tau...
- IST Somerset (C1)
- Tees North CLDT (C1)
- Wakefield IST (C1)
- Brighton & Hove CLDT (C1)
- North Essex LD Service (C1)
- IATT South and Torbay (C1)
- Bath Complex Health Needs ...
- South Essex LD Service (C1)
- Cheshire and Wirral CLDT (C1)
- Wolverhampton CLDT (C1)
- AST IST Norfolk (C1)
- Continuum Team East Ridin...
- North Lincolnshire IST (C1)
- Milton Keynes CLDT (C1)
- Outreach Team Leicester (C1)
- Hackney Integrated Learning...
- Tower Hamlets Community L...
- Enfield Integrated Learning ...
- Ealing CTPLD (C1)
- Hounslow CLDT (C1)
- Dorset IST (C2)
- IATT West (C2)
- ICATT South Nottingham (C2)
- Cornwall IST (C2)
- ICATT North Nottingham (C2)
- Ash Green Specialist Learnin...
- Wiltshire IST (C2)
- Enhanced Care Team West S...
- Kirklees IST (C2)
- Hampshire and Southampto...
- Berkshire IST (C2)
- LD Intensive Support Service...
- Astley Court Norwich (C2)
- Northamptonshire IST (C1)
- IATT Exeter (C2)
- PBST West Kent (C2)
- Peterborough IST (C2)
- Sheffield IST (C2)
- Durham & Darlington Special...
- PBSS Halton (C2)
- Bedfordshire IST (C2)
- Northumberland CLDT (C2)
- ISS Surrey (C2)
- Ipswich IST (C2)
- PBST East Kent (C2)
- Haringey LDP (C2)
- Southwark Enhanced Interve...
- Buckinghamshire LD Health ...
- ATSS Derby (C2)
- Calderdale IST (C2)
- Bradford IST (C2)
- Shropshire IST (C2)
- Continuum Team Hull (C2)
- Cheshire IST (C2)
- RDASH Doncaster (C2)
- Oxfordshire IST (C2)
- Coventry IST (C2)
- Stroke-on-Trent Community ...
- Cheshire West CLDT (C2)
- Staffordshire IST (C2)
- IST BCHC Birmingham (C2)
- South Gloucester CLDT (C2)
- CHAT Lincolnshire (C2)
- Greater Manchester Speciali...
- Portsmouth IST (C2)
- Kensington and Chelsea CLD...



Cluster profiles for two cluster groupings of IST services

Cluster Variables Characteristics		
Service Hours		
Mon-Fri only 7-8 hours	9 (36%)	15 (33%)
Mon-Fri only 8+ hours	9 (36%)	8 (17%)
Mon-Fri 7-8+ hours and weekends	5 (20%)	13 (28%)
Mon-Fri 24 hours and weekends	2 (8%)	10 (22%)
Staffing (FTE) – median (IQR)	5.6 (3.6 to 9.6)	10.2 (6.8 to 15.0)
Service Users Characteristics		
All levels (mild / moderate / severe / profound)	18 (72%)	38 (83%)
All except profound	2 (8%)	4 (9%)
All except mild	4 (16%)	2 (4%)
Other combination	1 (4%)	2 (4%)
Clients with a neurodevelopmental disorder (%) – mean (SD)	62.1 (21.5)	51.1 (22.5)
Intensity of Support		
Less than once a week	1 (4%)	2 (4%)
Once a week	8 (33%)	9 (20%)
Twice a week	5 (21%)	6 (13%)
Three or more times a week	6 (25%)	14 (30%)
Other	4 (17%)	15 (33%)
Duration of contact with clients		
1-3 months	0	7 (15%)
3-6 months	7 (29%)	20 (33%)
6-12 months	13 (54%)	20 (43%)
12 months plus	4 (17%)	4 (9%)

Other Service Characteristics

	n/N	%
IST Location		
North England	19/73	26%
Midlands & East	22/73	30%
South England	23/73	32%
London	9/73	12%
Staffing		
Learning Disability Nurses	62/73	85%
Clinical Psychologists	47/73	64%
Psychiatrists	31/73	42%
Occupational Therapists	33/73	45%
Speech and Language Therapists	38/73	52%
Social workers	59/73	81%
Trainee staff (i.e. student nurses and trainee associate practitioners)	38/73	52%
Interventions and Assessments		
IST uses Positive Behaviour Support (PBS)	72/73	99%
Psychoeducational interventions with service-users' family/paid carers	68/73	93%
IST operates a waiting list	7/73	10%

Service Area	n/N	%
Eligibility Criteria		
IST will accept people age 18+	58/73	79%
There is no upper age limit to access IST	71/73	97%
IST will accept service users in contact with the Criminal Justice system	65/73	89%
IST will accept service users experiencing mental health problems	71/73	97%
IST will accept service users with intellectual disabilities and challenging behaviour who are not in crisis but need support	64/73	88%
Staff Mix		
Learning Disability Nurses	62/73	85%
Clinical Psychologists	47/73	64%
Psychiatrists	31/73	42%
Occupational Therapists	33/73	45%
Speech and Language Therapists	38/73	52%
Social workers	59/73	81%
Trainee Staff (e.g. student nurses, trainee associate practitioner)	38/73	52%
Interventions used in IST		
Positive Behaviour Support (PBS)	72/73	99%
Psychoeducational interventions with service-users' family/paid carers	68/73	93%
Other evidence based psychosocial therapies (e.g. anger management, mindfulness, counselling, CBT)	68/73	93%
Staff training		
IST perceives a need for additional training and skills (e.g. additional professional roles, or additional skills such as PROACT-SCIP training?)	50/73	68%
Other		
IST operates a waiting list	7/73	10%
IST operates a duty/crisis line	38/73	52%

The National Survey

- Analysis of open-ended survey questions produced the following findings:
- **Model or philosophy of care adopted by ISTs**
- **Challenges faced by services**
- **Priorities for improving ISTs**

Person Centred Models of Care

- A number of ISTs reported that they adopt positive behaviour support model of care in helping to understand and treat the psychological, social and physical reasons for behaviour that challenges:
- *“We use a PBS approach - primary, secondary & robust risk management (Team Manager, IST South Yorkshire)”*
- Intensive Services perceive themselves as aiming to deliver high quality responsive care, using a person-centred approach to supporting people with a learning disability and behaviour that challenges.

Perceived Challenges Faced by ISTs

- A lack of resources, differing expectations from service providers and inflexible working hours were identified as the main challenges faced by ISTs nationally.
- Many teams described a high turnover of staff and the absence of a full multidisciplinary team as significant barriers in responding appropriately to crises and delivering intensive specialised support.
- *“Clinical demands high -team have not been fully resourced since its start date. Retention of staff and recruitment problematic. Long periods without team manager in place. Difficult to function as an 'Intensive' support team and meet referral needs and manage risks and trust targets/expectations” (Team Manager, IST West Yorkshire)*

Priorities for Improving ISTs

- Longer working hours and implementing a more flexible approach to providing intensive support outside of a 9-5pm remit were identified as being significant priorities for improving service delivery.
- *Only offering Mon to Fri 9-5 is a real challenge at times, especially when an individual is going into crisis and you are leaving staff or families for a couple of days with no direct contact support over weekends (Team Manager, South West England)*
- In addition, developing more consistent relationships with associated agencies in order to improve communication and referral procedures were also described as key areas to develop.

Stage 2: Clinical and cost evaluation of intensive support teams

- **Investigation of IST models**
 - 16 ISTs based on 2 models (8 ISTs per model)
- **Participants and sample size**
 - 192 Adults with mild to profound ID (mild to profound)
 - Potential participants will be identified by each IST staff either at first assessment or from the IST services caseloads.
 - 9 months follow-up

Measures

Primary Outcome

Challenging Behaviour Aberrant Behaviour Checklist Community Version
(ABC-C)

Mental status:
Psychopathology
Assessment for
Adults with
Developmental
Disabilities
(PASADD)

Risk: Threshold
Assessment Grid
(TAG)

Quality of Life:
(QoL-Q)

Health related
quality of life: EQ-
5D (5 level)

Service use:
Client Service
Receipt Inventory
(CSRI)

Other Measures:

- Sociodemographic characteristics
- Clinician recorded Autism and ADHD diagnosis
- Level of functioning (Short Form Adaptive Behaviour Scale)
- Admissions to hospital during follow up period
- Change in accommodation and reasons for it, e.g. placement breakdown.
- Previous treatments received, by whom and outcome (at baseline)

Qualitative exploration of stakeholders' views

Qualitative work (semi-structured interviews/focus groups)

- How IST care is experienced by service users and family carers
- Benefits, limitations and functioning of each IST model.
- Differences between IST models service delivery,
- Facilitators and barriers to achieving IST objectives

Participants

- Service users
- Carers
- The managers of all selected IST services
- IST practitioners and practitioners from services that frequently refer to ISTs (i.e. in-patient services, third sector organisations, Early Intervention Services, Community Mental Teams, Transition services)

IST-ID Members

- **Angela Hassiotis** (Chief Investigator) - Professor and Honorary Consultant Psychiatrist in Intellectual Disability, UCL and Camden & Islington NHS Foundation Trust (CIFT)
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- **Elisabeth Victoria Crossey** – Consultant Psychiatrist in Intellectual Disability, Lothian Board
- **Ken Courtenay** - Consultant Psychiatrist in Intellectual Disability, Barnet Enfield and Haringey Mental Health NHS Trust
- **Brynmor Lloyd-Evans** - Senior Lecturer in Mental Health and Social Care, UCL
- **Renee Romeo** – Senior Lecturer in Health Economics, King's College London
- **Vincent Kirchner** – Medical Director, CIFT
- **Ian Hall** - Consultant Psychiatrist in Intellectual Disability, East London NHS Foundation Trust
- **Nicola Morant** – Independent Qualitative Research Consultant
- **Rebecca Jones** – Medical Statistician, UCL
- **Peter Langdon** - Senior Lecturer in Clinical Psychology and Disability, University of Kent
- **Laurence Taggart** – Reader in Nursing in Intellectual Disability, University of Ulster
- Research Assistant – **Amy Walsh / Jessica Budgett**
- Project Manager – **Isobel Harrison** (covering **Victoria Ratti's** leave)