FULL PROTOCOL TITLE OF THE STUDY

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

SHORT STUDY TITLE / ACCRONYM

The IST-ID study

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Supported by

NIHR HSDR 16/01/24

Sponsored by

University College London (UCL)

Document version number and date:

Version 1. 27/06/2017

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Summary of Research

Approximately 17% of adults with intellectual disabilities (ID also called learning disabilities in the UK; constitute about 1% of the population; 2) living in the community present with serious challenging behaviour including aggression self-injury or other socially inappropriate behaviours (3). As many as 100,000 children and adults are estimated to be at risk of admission to inpatient care due to the presence of such behaviours if they are not successfully managed in the community (4). There are ongoing concerns that these individuals are subject to increased rates of hospitalisation, unnecessary long term use of psychotropic medication, poorer health, abuse and exclusion (5). Intensive Support Teams (IST) are recommended to provide high quality proactive and responsive care aimed at avoiding unnecessary admissions or reducing inpatient length of stay and supporting people in the community (6, 7). However, there is little evidence to recommend a preferred IST model and there has not been any comprehensive attempt to describe IST outcomes. NHS Commissioners require clear information about what works in order to fund appropriate services. NG11 (8) reports the state of evidence thus: "*It is widely recognised that locally accessible care settings could be beneficial and could reduce costs but there is no strong empirical evidence to support this*".

Objectives: 1. To create a typology of IST currently operating in England; 2. To generate evidence on the effectiveness of different IST models which best support improved outcomes for adults with challenging behaviour; 3. To estimate the costs of different IST models and investigate cost effectiveness; 4. To understand how ISTs impact on the lives of adults with ID and challenging behaviour, their families and the local services; 5. To generate evidence to inform and support decision making on commissioning IST for adults with ID and challenging behaviour.

Methods: the proposed study has two phases: phase 1 (9 months) includes a national survey (England) of ISTs. Service managers of community ID teams (CIDT) will be approached to first identify whether they have such a service locally and then a piloted and refined survey will be carried out. Outputs will include mapping the distribution of ISTs, developing of IST models and a description of the key characteristics of these models. Phase 2 (27months) includes a mixed methods evaluation of up to 4 IST models. We will collect both patient level outcomes, e.g challenging behaviour, risk, hospitalisations, service use etc, at two assessment points (baseline and 9 months) and service level outcomes (referrer satisfaction, reach, referral numbers) over 9 months. Statistical analysis will compare outcomes across ISTs and identify which are most associated with positive outcomes (e.g. improvement in challenging behaviour). The costs of delivering the different models will be calculated and compared across all models. We shall collect qualitative data to understand the experiences and views of key stakeholders and the impact of the different models. We shall follow with a project report and a wide range of dissemination activities, e.g. publications, contacts with NHS England and policy makers, commissioners (CCGs), clinicians etc.

Main benefits: In line with NHS England (NHSE) guidance in managing people with ID locally and effectively, the proposed work will provide commissioners and clinicians with the evidence they need to deliver high quality care to an under-served population group. The project maps onto principles 7 and 8 of the plan outlined in *Building the Right Support* which describes the objectives of community ID services in England (9).

Plain English Summary

About 17% of people with ID living in the community have challenging behaviour such as aggression to others or property, self-injury or hyperactivity. There are concerns that adults with ID and challenging behaviour over-use medication, spend large periods of time in hospital, and miss out on living in the community. Hospital care is expensive, and costs are increasing. NHS England has produced draft guidance about Intensive Support Teams (ISTs) proposing that they should be part of all community ID services in England. However, there is currently very little evidence about how effective ISTs are. The people who pay for Health and Social Care services (commissioners) would like more information, and this project aims to provide this.

We propose to do a project over 36 months. It will be in two parts. First we will find out about how many, and what type of ISTs exist in England, by asking service managers about their service, their staff, and the work they do. With this information, we will identify different models of ISTs (probably up to 4). Then we will look at three services in each model to compare how they work with people with ID and other local services. We will collect data twice over 9 months to see which model(s) work best. We will also carry out interviews with people who use ISTs, family and paid carers, and referrers to ISTs to find out about their experiences of these services, and how happy they are with them. Analysing and putting this data together will tell us about how effective each of the models are at reducing challenging behaviours, how much they cost, and which one service users, their families and people who work in other connected services prefer most.

We will tell people about our results at conferences and in academic and services journals. We will ask our group of involved service-users and family carers to guide us, and help us tell other people about the results. We have a team of clinicians and academics who are experts in all aspects of the research, e.g. statistics, ID, service evaluations, and in running ISTs. We will follow research rules and recommendations to make sure we carry out safe, ethical and rigorous research.

Background and rationale

1. *What is the problem being addressed*

The quality of community support for people with ID and challenging behaviour across the life span has been of concern to family carers, clinicians, researchers, and commissioners for many years. In this application we focus specifically on the support offered to adults with ID and challenging behaviour. Approximately 17% of adults with ID living in the community will present, at some point in their lives, with new onset or relapse in challenging behaviour, e.g. aggression, hyperactivity, self injury (5,8,10). These behaviours are long term and associated with younger age, comorbid disorders, e.g. autism or communication and sensory impairments (11,12). Recent extrapolation from data collected by the Department of Health indicate that 100,000 adults with ID are at risk of being admitted to assessment and treatment units, often hundreds of miles away from home, because of challenging behaviour (4, p8). Such admissions are associated with poorer health outcomes, increased prevalence of abuse and of difficulties in resettlement back into the localities of origin, as the longer the patient is out of area the more likely he or she is to remain there (13). Failure to manage challenging behaviour before it reaches crisis point causes significant distress and burden to families and consequent breakdown of placements. The ID inpatient census indicates a disparity of inpatient admissions between the north and south of England confirming concerns about how care for this population group is delivered by CIDS across the country (14).

Successive reports in the UK, from as early as 1993 have been advocating ISTs for the effective management of challenging behaviour in the community and to prevent inpatient admissions (6,7,15). ISTs are specialist services for adults, occasionally across the lifespan, with ID and challenging behaviour, aiming to treat such behaviours by applying positive behaviour support and other psychosocial interventions, thus promoting recovery and leading to reduction in severity and frequency of further episodes.

A number of different terms are used to describe ISTs including “peripatetic teams”, “assertive outreach teams”, and “specialist behaviour teams”. Some include the management of mental health crises within their remit and others may also offer support or augment autism specific work (16). Whilst there may be a rationale for stand-alone ISTs, this is not underpinned by evidence on long term outcomes and the available studies are subject to bias (see section on research evidence). This has led to scepticism that ISTs simply offer good care and that devoting large amount of resources to specialist services will detract from offering good quality care universally especially as emerging evidence suggests that alternatives, e.g. embedded teams, may also be effective (17). Given the short term follow ups reported in published literature, it is possible that gains made during engagement with the IST are not maintained after discharge or after transfer to other services. Furthermore, patients and their carers may face disruption and discontinuity in care due to frequent changes in service provision and may be dissatisfied with what they perceive as less “expert” service provided by CIDS (18). There may be benefits from other model configurations including improved staff skill mix; better management of resources; continuity of care for those requiring longer term follow up; high fidelity if all workers work to the same protocol; investment from management in a particular model if seen as novel or innovative.

The IST model aspires to key functions including: input to enable people to access mainstream health and social care services and to work with mainstream services to develop their ability to deliver individualised reasonable adjustments, support to Commissioners in service development and quality monitoring, and the delivery of direct assessment and therapies (19). However, it does not distinguish between mental health or challenging behaviour functions, nor does it give any guidance on duration of engagement with the person. Therefore, there is confusion about whether the ISTs should resemble mental health Crisis Resolution and Home Treatment Teams or Assertive Case Treatment teams. Clarification on these points is very important as it has direct consequences on how patients can be supported in the short and longer term. Anecdotally, two of the NHS Consultant Psychiatrist co-applicants who both run ISTs, work within different models. Summary details of the services are shown below:

KC’s team (20) serves an inner city population of 267,541 with diverse communities and a caseload of 652 complex cases. The aims of the IST are: to support adults with ID and challenging behaviour; to support people in the community; to use in-patient care appropriately; to provide reflective and person-centred care. These objectives are achieved by employing a part time clinical psychologist, a nurse, a psychiatrist, 2 full time assistant psychologists and other professions (Speech and Language Therapy, Occupational Therapy, Social Work) as needed. Cases suffer with multimorbidity, e.g. ID, autism, or other neurodevelopmental conditions, most are on psychotropic medication, in contact with the Criminal Justice System or have been subject to frequent hospitalisations and placement breakdown. The team reports that only 9% of their cohort were admitted to hospital, 73% of people supported remained in own accommodation and almost half required enhanced support to do so.

VC’s team (21) serves a population of 250,000 in an urban centre. The aims of the Mental Health IST are: to prevent admission to hospital, to facilitate admission and ongoing liaison with adult mental health services and coordinate discharge. The Challenging Behaviour Team is a separate team, what is locally called an Intermediate Tiered Service. Aspects of the work involve management of people with ID in crisis, in-reach to community ID teams and training on challenging behaviour to family and paid carers. Staffing is multidisciplinary including nursing (full time) and psychiatry (part-time) whilst other professions, e.g. psychology, speech and language therapy may also provide input. Service users are positive about the team and the support they receive following discharge from hospital.

Both IST examples are available within normal working hours and have caseloads of up to 45 service users. Whilst the majority of patients maybe discharged within six to nine months, a minority remain on the caseloads at least a year.

Overall, we currently have no firm evidence about whether dedicated ISTs for challenging behaviour or alternative models achieve better outcomes for adults with challenging behaviours, many of whom have long standing difficulties. NHSE has prioritised ISTs and challenging behaviour services backing this England-wide policy initiative with millions of pounds. This planned expenditure demands a proper evaluation and a clear demonstration of whether a specific model of IST is optimal for treating and managing challenging behaviour in local communities. We believe that if all areas in England are to be tasked with implementing ISTs and if commissioners are to see them as worthy of long term investments, then an inquiry into their characteristics and ability to deliver positive outcomes is an important and pressing clinical question.

2. Why is the research important in terms of improving the health of the public and/or to patients and the NHS?

Challenging behaviour compromises a person's health and may be the precursor to abuse and/or and restrictive practices by staff looking after those individuals. It mediates the quality of staff support and attitudes (22) and is exceedingly costly due to the need for more intensive support and often leading to long term out of area placements (23,24). ISTs are expected to address these issues effectively in the local communities and to improve overall quality of life by supporting them to remain closer to home and integrated within the social networks. However, there has not been a systematic evaluation of IST in terms of characterisation, patient outcomes and relationships with other services within the areas in which they operate. The relative lack of data on their functionality and utility as well as costs may have hindered the rolling out of such teams in contrast to the generic mental health services whereby the creation of Crisis Resolution and Home Treatment Teams (CRHT) is widely implemented.

Recently, in response to the TCP recommendations, NHSE has funded six services in England (fast-track) (9) to act as pilot sites in reducing admissions and re-invest savings in enhancing their community services. The timescale for achieving this objective is much longer term than originally envisaged (personal communication to AH) and the model remains in draft form. Given the diversity of the services as shown in the previous section and the care environments, it is doubtful whether a model will emerge from this investment which will provide sufficient detail of clinical and cost outcomes without further systematic evaluation at least in England. In the course of the proposed project, we shall liaise with the fast-track group of services and request access to operational procedures and other data as they are relevant to our research aims and objectives.

A main output of the project will be to produce evidence for commissioners based on comparisons of clinical outcomes and costs between IST models. This is particularly valuable information given the scarcity of such data. Comprehensive searches for studies containing economic outcomes of service models undertaken during the development of NG11, found three studies reporting costs of local services. Two of those (25,26) described services for young people in transition with ASD or ID which are not directly comparable to the adults with ID and challenging behaviour requiring intensive support. A third paper reported a small scale evaluation of a service which applied positive behaviour support (PBS) in managing challenging behaviour in five adults with ID in a single inner city area;

only 3 provided usable data (27). We conclude that due to the absence of large representative samples and the lack of a control group indicate that information on costs of service delivery linked to IST models is woefully inadequate.

The GDG were of the opinion that formalising care pathways for people with learning disability and behaviour that challenges, including transition between and within services, would enable more effective delivery of care and better outcomes for service users, reducing, at the same time, the high variation in care costs resulting from provision of ineffective and poorly coordinated care. It recommended that further research is warranted to examine what are the ingredients of good close to home care which maintains community placements (10).

As a research group we have the necessary clinical and methodological expertise and networks to carry out the study and to contribute significantly to the understanding of patient and service level aspects that may hinder or facilitate the implementation of good care for adults with ID.

> *3. Please provide evidence explaining why this research is needed now (how does the existing literature support this proposal)*

A number of studies have investigated the impact of ISTs delivering behavioural interventions for challenging behaviour in the community. Early studies describe either demonstration projects following the closure of institutions (28,29) or region wide implementation of stand-alone services (30) which though report positive outcomes for service users lack control groups. Three small randomised controlled trials (RCTs) examined 1) a stand-alone specialist support service delivering Applied Behaviour Analysis in one area in England (31, 2) a stand-alone team delivering assertive outreach in inner London (33) and 3) an active case management model (33). Comparator treatment was usual care in all three studies. Hassiotis et al and Coelho et al reported significant findings for the stand alone model but Martin failed to find any difference. The studies were deemed to be subject to bias and the findings must be interpreted with caution. Further, Hassiotis et al (2014; 17), showed that positive behavioural outcomes may be achieved by an embedded IST model where a proportion of CIDS staff train in managing challenging behaviour, meet together regularly to discuss referrals, for specialist supervision and peer support. Literature from other population groups, e.g. dementia care (34) suggests that home treatment teams seemed to be effectively managing crises and reducing admissions. Wheeler et al (2015; 35) showed that stakeholders have a number of expectations from crisis resolution teams and this is likely to be the case for ISTs in the field of ID. So far, there has been limited reporting on stakeholder experiences of ISTs (18,36) which shows that service users and paid and family carers find the involvement of IST staff and frequency of contact helpful and acceptable.

We, therefore, must develop the evidence to guide the rolling out of a potentially beneficial policy initiative especially where it may diverge from services which are already provided as part of the CIDSs. This imperative is supported by the TCP (9) which states *although a good deal of work has been done to describe what community-based services for people with learning disabilities and/or autism should look like, we have heard from many commissioners a desire for this to be drawn together more clearly into service models and quality standards*.

A recent, limited in scope, survey of CIDS in England indicated that 20 of the respondent CIDS (=53) have ISTs devoted mainly to managing people with challenging behaviour but also with autism or mental illhealth in a variety of configurations (16). Therefore, we are confident that more ISTs will be identified based on over 150 existing CIDS and that we shall be able to carry out a typology of IST models.

Aims and objectives

The overall aim is to examine the characteristics of different models of ISTs and investigate service user and service level outcomes.

Our objectives are to:

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.

Our key research questions are:

1. What models of IST are currently in operation?

2. Which ones perform better in achieving positive outcomes for service users?

3. What are the costs and cost effectiveness of the different IST models and how do they compare?

4. How does the local service context support of hinder these processes?

5. What are service users' and family carers' experiences of IST and do they differ between models?

6. What are the views of service providers on the strengths and limitations of different IST models and the processes that support or hinder their functioning?

Research plan/Methods

We propose a two stage mixed methods design, starting with 1. a national survey of IST leading to mapping of current provision and its geographical distribution and followed by 2. the clinical and cost evaluation and comparison of up to four different IST models. The project will thus allow us to examine IST model effectiveness at service user and organisational levels.

Prior to the study commencing, we will obtain ethical approval and complete all regulatory processes.

Government via NHS England families and adults with ID demand better services and consequently better outcomes for people with ID and challenging behaviour. ISTs are seen as central in delivering those objectives and the proposal aims to provide the evidence needed to support commissioning and clinical and strategic decision making in order to improve care where people live. To our knowledge, there is no existing evidence on this topic.

Prior to the study commencing, we will obtain ethical approval and complete all regulatory processes.

STAGE 1 (9 months)

1.1 Aims

- To establish the prevalence of and map ISTs in England
- To describe the typology of ISTs in England
- To develop a typology of ISTs

We shall develop brief screening questions to identify ISTs with reference to national recommendations, but adopting an inclusive approach to ensure we include all community services which are additional to general CIDS and aim to address challenging behaviour and prevent/manage crises for people with ID. Given that some information will be emerging towards the completion of stage 1, we shall be flexible in terms of the specific design of stage 2 to allow for potential revisions in recognition of the different IST models in operation regarding staffing and scope of work. A study which includes both stages is more beneficial given that previous studies which were carried out in single stages did not capture current practice nor did they establish and maintain research, policy and clinical networks engaged with the study. Therefore, their findings were limited to descriptive information compromising the efficiency and final outputs of the work (7).

1.2 Screening and survey

We shall carry out a brief telephone interview with CIDS to ascertain provision of any type of IST based on the criteria above recorded on a proforma. Those will be reviewed independently by three members of the study management team (AH, KC, IH) to judge whether they fulfil the IST inclusion criteria. Any discrepancies will be resolved by discussion among the 3 reviewers and final decisions will be made by the Study Management Group (SMG) where the discussion of the team characteristics will take place.

We shall obtain contact details of the team manager/senior clinician for the survey which we shall administer via telephone interviews using an online survey tool (Opinio). We shall use previous research, web search, recent reports (such as those published by the Public Health Observatory Learning Disabilities) and our extensive clinical contacts to identify all CIDS and ISTs in existence.

The survey guide will include both fixed response and free text questions. The draft survey will be administered to the SMG to test whether individual items are clearly understood and the ease of completing it. The feedback will be used to make revisions and the revised survey will be used with a small eligible sample of practitioners and if required, any further revisions will be made prior to the main data collection. The team managers of the ISTs will be approached in order to complete the survey. We shall employ a number of strategies to achieve a completion rate of more than 60% in order to avoid selection bias. Those include at least three attempts to approach respondents. We shall then compare respondents and non respondents to consider whether any further approaches are needed (37).

We shall collect data on: aims of IST, staff composition, eligibility criteria, referrals pathways, existence of waiting lists and caseload number, duration of engagement with patient, in/outreach to other services, detail on the assessment process (structured or not, use of outcome measures, review and discharge), content of care and interventions offered, funding involvement in transition, wider context of IST service liaison.

Data from all services identified as ISTs will be taken forward for analyses. A basic **content analysis** of free text comments will add depth, contextual understanding and/or additional information to the fixed-response formats responses.

1.3. Statistical analysis

Descriptive data will be collated for each survey question, and will be used to characterise ISTs and their geographical location. We shall use cluster analysis 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 (38)

Based on available information from published research and clinical judgment we consider the following domains as potentially important to identify the different clusters:

Caseload: smaller vs higher

Setting: collocated/embedded vs separate/tertiary/tiered

Hours of operation: working vs extended hours

Staff: uni-professional vs multidisciplinary; core vs extended input; skill mix

Referral pathway: professionals vs self referral

Use of outcome measures vs none

Wider context: additional supports vs none; integrated with social care vs not; joint commissioning vs not

A hierarchical approach will be used to determine how many clusters there are in the data. The number of clusters will be selected by examining the Dendrogram as well as using clinical judgement. Other methods such as elbow, silhouette, gap statistic methods will be used to help determine the optimal number of clusters. The cluster centres obtained from this will be used as initial cluster centres in a k-means cluster analysis.

The study management group will review the models to confirm face validity and in case where no distinct clusters are identified, to propose alternatives. Finally, we shall present the resulting groups to the independent Study Steering Committee to consider potential revisions and arrive at a final typology. If needed, we shall augment the study management group and the study steering committee with additional experts and service users and carers for that particular task.

Once the cluster analysis is completed and the IST models are confirmed we shall proceed to stage 2.

STAGE 2 (27 months)

2.1. Aims

- Compare the IST models for service user and IST level outcomes
- Identify IST characteristics associated with positive outcomes (e.g. reduction in inpatient stays or overall admissions) and the factors which affect the process (e.g. diagnoses and comorbidities, service context etc)
- Model the relative costs and compare them across the different IST models
- Explore the experience of stakeholders in contact/interface with ISTs including service users, family carers, referrers, commissioners, third sector

2.2. Investigation of IST models

For this stage we shall include up to 12 ISTs based on a maximum of 4 models (3 ISTs per model) in order to increase the generalisability of the findings. A model will be selected if it is not specific to a particular local configuration, it has been operational for at least 12 months, there is commitment to fund it for the study duration and it can achieve the sample size estimates. Stratified sampling will ensure representation of different size teams/caseloads, rural/urban services, where possible.

2.3. Setting and sample size

Participants aged 18 years and over across the ID range (mild to profound) will be recruited from the ISTs selected for stage 2. Level of ID will be recorded as that stated by services at the point of accepting eligibility of the service user to receive specialist ID services. Potential participants will be identified by each IST staff either at first assessment or from the IST services caseloads.

We have chosen as our primary outcome the reduction in challenging behaviour measured by the Aberrant Behaviour Checklist-Community version (ABC-C; 39). A sample of 102 per IST model is required to detect a low to moderate (standardised) effect size of 0.45 for the primary outcome total ABC score at 9 months at the 5% significance level with 80% power, assuming an intra-class correlation of 0.01. In order to achieve this sample size we will recruit 34 patients from 3 ISTs for each model, totalling 100 patients per model (n=408). Current data provided by VC and KC indicate that the combined new referrals total to their respective ISTs is approximately 60 a year with another 60 service users on ongoing treatment. Also average caseloads are estimated at approximately 40-45 patients. Therefore, we estimate that we shall be able to recruit our suggested sample size within the 18 month recruitment timeframe.

2.4. Outcome measures

Primary outcome

Challenging behaviour Aberrant Behaviour Checklist-Community version (ABC-C; 39). This is an established and internationally used carer administered measure of challenging behaviour. It is adopted as primary outcome given that reduction in challenging behaviour is the main remit of ISTs.

Secondary outcomes

Mental status: Carer reported Psychopathology Assessment for Adults with Developmental Disabilities checklist (PASADD Checklist; 40) is useful for screening for mental disorder but not diagnostic. However, it will provide sufficient information on potential mental health comorbidity which is often under-ascertained in adults with ID.

Risk: Threshold Assessment Grid (TAG; 41) measures clinical risk and previous research has found associations between perceived risk and hospital admission (42)

Quality of Life (QoL, 43). Management of challenging behaviour ultimately leads to improvement in individual quality of life and this is considered an important outcome. This is a widely used measure with good psychometric properties which has been developed specifically for people with ID and can be proxy completed.

Health related quality of life: EQ-5D (5 level, 44) is a standard measure for health economic evaluations and it is used to generate quality adjusted life years as a result of IST input.

Service use: Client Service Receipt Inventory (CSRI; 45) (adapted for the study, 3 month retrospective service use at each assessment point). The CSRI is a widely used service use questionnaire and has been validated for use in mental health and ID services research. It will be adapted specifically for the study to reflect the specific type of data to be collected.

Other:

Sociodemographic characteristics

Clinician recorded Autism and ADHD diagnosis

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)

All outcomes, will be measured at baseline and 9 months which reflects the time period expected to be required for IST involvement to have led to resolution of the behavioural issues including implementation of behavioural plans and working towards discharge. Service-level data will be collected over 9 months.

2.5. Service level processes and outcomes

Collection of data on number of people referred and proportion who engage with IST; time to 1st assessment and delivery of management plan; other IST scope, e.g. days of training given and other engagement with local services, e.g. joint assessments with crisis teams; population reach. The latter is important as it can provide an estimate for ISTs' caseloads. The prevailing view is that small caseloads up to 15 individuals are desirable. However, previous research in Intensive Case Management did not find substantial differences between smaller vs larger caseloads (46). Therefore, it is essential to understand how caseloads and staff numbers may be interacting to provide care to those in need based on national prevalence rates of ID and challenging behaviour.

We shall map our service data onto the monthly reports from the Mental Health and Learning Disabilities Data Set (MHLDDS) over the study period which provides information on hospital admissions aggregated by IST model. This will provide a proxy measure of IST model impact on admissions.

Finally, we shall construct a short questionnaire to capture satisfaction with referral process and training/advice/in-reach provided where applicable (47). This will be distributed to managers of services in contact with the IST within the 12 months preceding the study and listed by the participating IST units.

2.5 Analysis plan

The primary outcome is mean total ABC and subdomain scores at 9 months. A mixed model will be used to compare the mean total ABC and subdomain scores for each IST Model. This will include a fixed effect for Model and for ABC score at first assessment, as well as a random effect for IST to take into account clustering within each IST. Mean differences and 95% CI will be presented. The assumptions of the model will be tested. If these are not met, a suitable transformation or non-parametric test will be considered.

Some patients have their first assessment later than others. To ensure the effect sizes are not reduced as a result of this, we will perform a sensitivity analysis adding a fixed effect for time of first assessment. Mean differences and 95% CI will be presented if these are different from the primary analysis.

Variables such as duration of treatment/engagement with IST will be summarised for each model using means (standard deviation) or frequency (%) as appropriate. Variables which vary between models will be adjusted for in a secondary analysis but including the variable as a fixed effect in the primary model.

The primary analysis will be repeated for the continuous secondary measures. Binary outcomes will be analysed using a random effect logistic regression.

2.6 Economic evaluation

We shall derive and report the costs of each IST service model over 9 months. To estimate the cost of each IST service model, we shall use an established building block approach to service costing (48). Informed by this approach, we shall obtain a description of each IST model, disaggregated by different elements as each IST model is likely to have different parts, and for those we shall include grade and hours of staff in different professions, number of clients or size of the caseload, including elements funded by other department budgets, in the calculation. Combining the data on the description and cost information will facilitate the calculation of the total cost of each IST model.

We shall calculate and report a comprehensive total cost of services and support provided external to the IST model and an IST–specific cost per study participant using a modification of the approach above. To calculate the IST-specific cost per study participant, organisational and staffing inputs for each study participants will be combined with the unit cost for each professional with whom the study participant made contact over the study period. Data on services and support will be obtained from the CSRI covering a retrospective period of 3 months. It will be assumed that costs will be incurred by health and social care agencies even though some individuals make co-payments. Data will also be collected on volunteer support, befriending, telephone care-line support and unpaid support to the study participant by family and friends. To service use and support data we shall attach unit costs reflecting the long-run marginal opportunity costs drawn from available public sources. Costs per unit of measurement for each service type will be taken from a national compendium of the unit costs of health and social care produced annually; the NHS Reference Costs will be used for inpatient and outpatient attendances and for community based services, not included in the compendium of the unit costs of health and social care. Costs of unpaid care will be estimated from information on volume and type of support, the opportunity cost of lost work (wage rate) for carers in paid employment, and replacement cost for those not in paid employment based on cost of a home care worker. We shall extrapolate the three-monthly costs over the nine months.

We shall examine what effect different IST models have on costs of care over the nine month period, using multivariate statistical analyses to explore variations in costs between individuals in the sample, taking account of the clustering, the characteristics of the study participants (sociodemographic, clinical, primary and secondary measures). The analyses will examine associations between costs and individual characteristics before entry to the study and at endpoint. We shall also include mediators in the modelling. For these analyses NHS and social care services and societal costs will be used as dependent variables in turn.

We shall test whether different IST service models have different outcomes by exploring the links between costs and outcomes over the nine-month period, taking into consideration clustering and skewed costs. We shall use the primary measure of outcome, ABC, secondary outcome measures and quality adjusted life years (QALYs, over nine months), the latter calculated from the EQ-5D by applying societal weights (49) and QOL scores as the dependent variable in a series of multiple regression analyses. The cost effectiveness analyses will be conducted from a health and social care perspective and a wider societal perspective.

A head-to-head economic comparisons of the service models in terms of costs and outcomes will be conducted using extended dominance approaches (50). IST models will be ranked by cost, from the least to the most expensive, and if a strategy is more expensive and less effective than the previous model, it is said to be dominated and will be excluded from further analysis, until two IST service models are left on which to explore which of the two final IST models are cost effective. The cost-effectiveness of one IST model over another will be compared by calculating incremental cost-effectiveness ratios (ICERs), defined as difference in mean costs divided by difference in mean effects. If one model had lower costs and better outcome than its comparator it will be considered dominant. Difficulties can arise if one service model is both more effective and more costly than its comparator, leaving the decision-maker to consider whether higher costs are justified by better outcomes. Cost-effectiveness acceptability curves (CEAC) (51) will be plotted for each cost-outcome combination to show the likelihood of one treatment being seen as cost-effective relative to another for a range of (implicit) values placed on incremental outcome improvements. Using the net benefit approach, monetary values of incremental effects and incremental costs are combined, and net benefit (NB) derived as: NB = λ x (effectb - effecta) – (costb – costa). Where, λ is the willingness-to-pay for a unit improvement in effectiveness (ABC, QALYs and QOL) and subscript ‘a’ and ‘b’ denote *IST model a* and *IST model b*, respectively. This approach allows costs and outcomes to be considered on the same monetary scale, taking account of sampling uncertainty and adjusting for baseline covariates and clustering.

2.7. Qualitative exploration of stakeholders’ views

Qualitative work will allow us to investigate how IST care is experienced by service users and family carers, and to obtain a multi-perspective view of their functioning within local service contexts, based on relevant user, carer and practitioner views. Stakeholders to be included will be IST managers and professionals, professionals from referring agencies, service users, family and paid carers, and individuals who may have rejected IST care. Data will be collected using semi-structured interviews and some focus groups from all the services participating in Stage 2. Given that we anticipate identifying up to 4 IST models in Stage 1, we will aim to collect the following data for each IST model (spread across all units chosen to represent a particular model if more than one service per model is selected):

Service users: Eight to ten service users **per** IST model including those who may need support to communicate (provide by family or paid carers). We will also aim to interview a smaller sample of service users who have declined offers of IST contact.

Carers: Eight to ten family and same numbers of paid carers **per** IST model. We shall also aim to interview a small number of family carers who have recently declined IST contact.

The managers of **all** selected IST services

IST practitioners: A maximum of 8 IST practitioners **per** IST model, selected to include a range of professional backgrounds and levels of seniority.

Practitioners from services that frequently refer to ISTs: We will aim to convene one focus group with representatives of relevant referring agencies for **each** IST service (to include in-patient services, third sector organisations, Early Intervention Services, Community Mental Teams, Transition services). If this proves logistically challenging, we will collect data via smaller group interviews or individual interviews.

Total numbers for this qualitative work will be determined by the number of IST models identified in Stage 1, heterogeneity of sub-samples and saturation of themes, with project resources allocated accordingly, such that a detailed analysis and informative write-up will be achievable.

Semi-structured interview schedules for each stakeholder group will be developed with the help of the study management group, and the service user and family carer advisory group. Schedules for service users will avoid complex language and terminology, and will be modified on a case-by-case basis for respondents with ID (easy read formats). Across all stakeholder groups, interview schedules will be designed to explore views and experiences of the role and functioning of ISTs, and how they interface with other health and social care provision within their local context. Questions will cover the benefits, limitations and functioning of each IST model, and explore the factors that might affect these, e.g. access, unmet needs, negative outcomes (hospital admission, out of area transfer). Interviews with IST managers and professionals, and focus groups with referring professionals will explore views on emerging IST model differences, service delivery, facilitators and barriers to achieving stated IST objectives, and explanations for performance variations between ISTs.

IST managers and professionals will be interviewed relatively early in Stage 2 and their testimonies will be used to add detail to the data from phase 1. Service user and carer participants will be interviewed near the time of discharge or around the 9 month follow up, whichever is sooner. Clinical practice suggests that most of the assessments and onward referrals will have been completed by that time. We shall ask IST staff to contact service users and their family or paid carers who may have refused IST contact to ask whether they would be interested in participating. Finally, we shall identify the interface agencies of each IST in stage 2 and access their views using focus groups.

Interviews and focus groups will be audio-recorded and transcribed verbatim. Data will be analysed using thematic analysis (52) conducted using NVivo software for data handling (53). A staged, collaborative and primarily inductive analytic approach will be adopted, allowing us to iteratively develop a set of themes to capture key concerns and topics, as well as more abstract or underlying issues. Although numbers in stakeholder sub-groups linked to each IST model may be relatively small, triangulation of the various stakeholder perspectives will allow us to obtain a broad picture of each IST model. Thus we will be able to compare the various IST models in terms of multiple stakeholders' views, as well as analysing the dataset as a whole to understand broadly common views and experiences of ISTs.

Analysis will involve close collaboration between the qualitative researcher, the qualitative lead and other key members of the study team. The service user and carer group will also be consulted to provide their views on emerging themes and findings.

2.8. Ethical issues

We shall seek ethical approval and shall complete all statutory requirements prior to starting the study. We anticipate little distress or disruption caused directly to the participants as the measures are carer administered. However, we appreciate that some of the questionnaires may cause upset due to the nature of material they cover. The interviews with carers, especially family carers, will be handled sensitively by trained researchers. The study will include participants who both have but also lack capacity. Therefore, all participants with capacity will be asked for informed consent prior to taking part in the study, but for those lacking capacity, we shall approach a family or nominated consultee as per Mental Capacity Act 2005 requirements. The study will include a risk assessment regarding contact of researchers with vulnerable persons as well as managing challenges, e.g. lone worker, in the course of conducting the study. We have used and implemented such processes in our ongoing research. Another consideration in terms of ethical and data collection principles hinges on the recruitment of a representative sample of all service users seeking IST intervention. We propose to follow the approach described in a previous HS&DR (SDO) funded study (08/1304/75; 40). In that study, as now, obtaining individual consent from each service user for clinicians to make and give to the research team ratings about each service user's clinical status will not be feasible and likely to require resources beyond what we have available. At the time of referral and/or treatment, some participants will not have the necessarily decision-making capacity to consider participation, and their more immediate needs will often be too great for staff or participants to consider taking part in research a priority. Following a wide consultation including resources on participants without their informed consent may be valid under the following conditions: 1. where obtaining such consent is not feasible, 2. where the study has no effect on care received by the patients and does not in any way directly involve them, and 3. where an ethics committee has given its approval to such use of information. However, this guidance also requires that, if information is to be used without patient/consultee explicit consent, patients and their consultees must be informed of this use of their data and given the opportunity to object to it. Therefore, we shall propose this approach as part of the ethical review at the time of recruitment (phase 2) based on not requiring direct participation of service users of any kind, and on not there being any changes in their care as a result of taking part in the study. All service users with capacity and the consultees of those without will be informed of the planned research and use of clinical information and will be invited to tell clinicians or the research team if they object to the inclusion of their clinical details for this purpose.

2.9 Synthesis of findings from stage 2 and dissemination

During the final three months data will be cleaned and analysed. We shall produce a draft report for the funders and begin a full scale dissemination process with tailored outcomes to stakeholder groups and policy makers. We shall provide several dissemination events to share the findings and insights, with guests from the Department of Health, CCGs and NHSE. We have access to commissioners and through members of the research team to NHSE, therefore, we can arrange to hold briefings and seminars. We will write for specific service related publications, including blogs (e.g. through our connection with Mental and Learning Disability Elf), parent organisations (e.g. Challenging Behaviour Foundation) and social media (study twitter account). Further, we shall utilise wider coapplicant networks to ensure that we maximise our dissemination capacity including internationally.

2.10 Research team expertise

Hassiotis is a well known clinical academic in ID with track record of externally funded research. She has published several papers and reports on organisational aspects of community and inpatient care for adults with ID and has significant experience in recruiting successfully and maintaining research networks. **Hall** is a consultant psychiatrist in ID with extensive research experience and strength in PPI and qualitative approaches. **Crossey** is a consultant psychiatrist in ID with experience in running an IST and contributed to the patient and carer engagement in the application. **Courtenay** is a consultant psychiatrist in ID who runs an IST and sits on the TCP IST advisory group, therefore he is central to further impact of the study findings and dissemination events. **Kirchner** is Medical Director of the lead NHS organisation with experience of commissioning and service development. **Moran**t is a qualitative methodologist with extensive experience of similar projects in adults with severe mental illness. **Romeo** is an experienced health economist with extensive experience in working in projects in the field of developmental disorders. **Lloyd-Evans** is a social scientist and offers a methodological perspective of mixed methods approaches, participant recruitment and survey methodology. **Jichi,** statistician, has developed the analytical framework for the study quantitative aspects. **Langdon** is Senior Lecturer in Clinical Psychology and experienced researcher in ID. **Taggart** is Reader in nursing (ID) and NICE SCIE advisor.

All coapplicants have worked together in several projects successfully, share many publications and have fully contributed to the preparation of the application.

2.11 Study governance

We shall establish the study management group (SMG) and a study steering committee (SSC). The former will oversee the study conduct and will meet via teleconference or face to face once every three months for the duration of the study and may also communicate via email at other times. Where attendance is not possible, the research team will be asked to provide updates to the SMG.

We shall recruit a chair, a lay member, a family carer and another researcher to form the SSC. The SSC will meet once a year either via teleconference or face-to-face but will also liaise when needed via emails. Minutes from the SMG and service user and carer input will be provided to the SSC.

PPI

In the course of preparing the application we have carried out a number of consultations with service users and family carers with lived experience of challenging behaviour and/or mental illness (by Crossey and Courtenay during clinical consultations since January 2016 and Hassiotis on 4/8/2016). Courtenay also gave a presentation on IST at an educational meeting for trainees and consultants in ID (8/8/2016). The feedback received from the service users and the family carers was overwhelmingly positive and ISTs are seen as the way forward to reduce admissions and also maintain service users in the community. Comments made include: liked not having to go to hospital", "liked being seen at home", "understanding staff who listened to me". Parents especially appreciated "the team helping liaise with other professionals". They thought the research is needed and would support it. We have outlined plans as to how we would engage service users and family carers and they were in broad agreement with the tasks such as assisting with materials for patient information and consent, championing the study, looking at ethical considerations, taking part in the topic guide development and in the interpretation of findings and dissemination. Service users and family carers did caution that they needed help in fulfilling their roles and that they should not be overburdened. We reassured them that we would provide training and support and that we have experience in working with service users in other studies, whose testimonials are very positive about the experience of being in the advisory group. The specific tasks of the service user and carer input to the SMG will be:

1. Developing participant information resources
2. Managing the research
3. Contributing to the interpretation of the findings
4. Reporting and dissemination of research

The medical audience considered issues such as evidence, the wider context of the teams and the need to have robust data on what works best as they recognise that we need to improve on evidence based and cost effective practice.

The revised PPI arrangements for the study are as follows:

We have discussed with two London based service user groups (with a membership of 9-14 service users each) how we may best include service users in our project. We have agreed that we shall present a lay summary of the project and enlist interest from the service users who wish to be members of the advisory group (increase from 2 to 4). We shall hold interviews to ensure that we appoint the right mix and shall carry out a 3 hour training session in research skills and tasks over the project duration using easy read formats based on NIHR guidance (http://www.nihr.ac.uk/nihr-in-your-area/mental-health/documents/UserCarerResearcherGuidelinesMay2014_FINAL.pdf). The service user advisory group will be facilitated by two facilitators in case of illness or leave. Further, regarding the family carer representatives to the study, we have now decided to manage that from within the research team who will seek pragmatic input from family carers through local carer groups in coapplicants' sites. The family carer input will include two family carers to be recruited via CRN and carer groups, costed as per INVOLVE budget advice for lay participation (http://www.invo.org.uk/wp-content/uploads/2014/11/10002-INVOLVE-Budgeting-Tool-Publication-WEB.pdf).

Table 1: Overview of the study

	Module	Methods	,Measures
1	Lead in	Obtain approvals and recruit staff	
2	National survey of Community ID Services Development of IST typology Selection of ISTs	Telephone and on-line survey of team managers	Questionnaire to be developed for the study
3	Recruitment and assessments of service users of selected ISTs agreed to take part in the study	Sociodemographic information and health ratings provided by staff	Questionnaire†, clinical records†, ABC*, PASADD Checklist*, TAG*, QOL*
4	Stakeholder experiences -Participants with ID -Family carers -IST service managers -Other service managers relating to IST	Semi structured interviews and focus groups	Topic guides to be developed for the project
5	Cost and cost -effectiveness of IST models	Collection of service use data supplemented by electronic records where necessary	EQ5D*, CSRI*
6	Satisfaction of referrers and others in contact with ISTs	Questionnaire completed by managers/staff of other services	To be developed for the study
7			

*: To be collected at baseline and 9 months; †: to be collected at baseline

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