FULL TITLE: Mapping and evaluating Specialist Autism Team service models

SUMMARY OF RESEARCH

Around 1 in 200 adults have high functioning autism (HFA) or Asperger syndrome (AS). Widespread concerns about the poor outcomes of adults with autism resulted in the publication of the Autism Act and Autism Strategy. A key recommendation was that each locality should have a specialist multi-disciplinary, community-based team providing: diagnosis/assessments; specialist interventions; support with employment and independent living; care coordination; and training and support to other professionals. Subsequent NICE guidance (2012a) referred to these teams as Specialist Autism Teams (SATs). At the moment there is no evidence to inform the development of these teams and, to date, a number of different models have been implemented across the country. The main aim of the proposed study is to generate evidence to inform and support decision-making on commissioning and developing SATs for adults with HFA and AS.

Research aims

- To develop a typology of the different models of Specialist Autism Teams (SATs) currently operating in England.
- To assess the outcomes for adults with high functioning autism (HFA) and Asperger syndrome (AS) of different SAT models.
- To identify the characteristics of SATs which best support the achievement of positive outcomes for adults with HFA and AS.
- To identify SAT model(s) and service characteristics which best support other services to achieve positive outcomes for adults with HFA/AS.
- To estimate the costs of different models of SATs and investigate cost-effectiveness.
- To understand the service user experience and the processes by which SATs impact on the lives of adults with HFA and AS, and their families and/or carers.
- To inform and support decision-making on commissioning and developing SATs for adults with HFA and AS.

Methods

A two-stage study is proposed, followed by a period of targeted dissemination activities. A national mapping exercise will develop a typology of SAT service models (Stage 1) and describe current provision and geographical distribution.

Stage 2 will evaluate and compare up to four different SAT service models. User-level outcomes (e.g. global quality of life, mental wellbeing, mental health, social support, daytime occupation and living situation) will be measured at assessment and the following 3, 6 and 12 months. Service-level outcomes (e.g. 'reach' to the population, time to achieve a diagnosis; take-up; interfacing services' satisfaction with support and advice) over a 12 month period will also be assessed. Multivariate analysis and statistical modelling techniques will compare outcomes across SAT models, and identify SAT service characteristics which support positive outcomes. The costs of delivering the different elements of a SAT's work (eg. diagnosis, psychosocial support etc.) will be calculated and compared across models, and a cost-effectiveness analysis will also be carried. A nested process evaluation, involving interviews with users, carers/significant others and practitioners, will explore: the processes by which SATs impact on outcomes, the impact of different service models on outcomes and service user experiences, and other factors perceived as influencing user and service-level outcomes.

Outputs and impact

The Autism Strategy requires localities to improve services and support to adults with HFA and AS. SATs have been identified as playing a key role in achieving this. The proposed project will support evidence-based decision-making by commissioners, practitioners and national bodies regarding the implementation and/or improvement of SATs in their localities. There is, currently, no existing evidence on this topic.

BACKGROUND AND RATIONALE

The prevalence of ASC is rising. Current figures suggest just over 1% of adults have ASC (4), around half of which have HFA or AS. Obtaining a diagnosis for HFA and AS remains very difficult (5, 6). Transition to adulthood is a time when difficulties often emerge and a diagnosis is sought. Adults with HFA or AS do not have learning disabilities (LD) (IQ < 70) and are not eligible for support from LD services within health and social care. However, it is clear adults with HFA or AS experience difficulties, and have poorer outcomes, than the general population in many areas of their lives (2) including: mental health (7,8); social skills difficulties and social isolation (9-12); securing and maintaining employment (13-16); and achieving independent living (17).

A lack of ASC-specific services and the absence of diagnostic, community-based support for adults with HFA and AS has been identified as contributing to poor outcomes. Indeed, it has been estimated that not providing low intensity, holistic support to adults with HFA and AS is likely to result in higher costs to individuals and society (18).

Widespread concern about the health, social and economic outcomes of inadequately supporting adults with autism spectrum conditions (ASC) culminated in the cross-government Autism Act (2009) and Autism Strategy (2010). These placed responsibilities on the NHS and local authorities to improve support and services for adults with ASC. They stipulated the need for autism-specific provision, including specialist community-based, multi-disciplinary teams to develop, coordinate and deliver services. The recently published NICE guidance for adults with ASC (1) also recommends each locality has such a team (referred to as Specialist Autism Teams (SATs)), identifying the following roles: diagnosis and assessment; delivering specialist interventions; support in accessing, and maintaining contact with, housing, education, employment services; family/carer support; care co-ordination; and training and support for other professionals.

A number of different models of SATs are currently in operation, differing in team composition, eligibility criteria, ways of working and scope. However, there has been no evaluation of these alternative models. Commissioners and practitioners are therefore faced with the task of developing specialist autism services, with progress towards this being regularly reviewed by government, but in the absence of any robust evidence about what a 'good service' looks like, either in terms of supporting positive outcomes for service users (1,19,20), or which best support other services in the locality which work with adults with ASC. Recognising this problem, NICE recommended that research is carried out on the emerging models of SATs and particularly, work which identifies the characteristics of SATs associated with positive outcomes (1). Research on this topic has been identified as a high priority (1,2,3), particularly for adults with HFA and AS (1,21)

The proposed research will provide evidence on:

- the typology(s), characteristics and ways of working of SATs which best support positive outcomes;
- the costs of the alternative models of SATs;
- what needs to be in place in the wider service context in order for SATs to function effectively.

WHY THIS RESEARCH IS NEEDED NOW

The Guideline Development Group (GDG) responsible for the NICE guidance on management of adults with ASC (2) made this comment: "while there is no doubt that guidance on the development and organisation of care for people with autism is needed, it is nonetheless very challenging to develop. In significant part this relates to the very limited evidence base...." (2, p144). Indeed, the group noted the evidence base was even more limited with respect to adults with HFA and AS compared to adults with 'classic autism' (with LD) and children with ASC. The recommendation for SATs was instead informed by the Common Mental Health Disorders Guideline (22) and studies which had explored the views and experiences of adults with ASC and carers, partners and other family members (1). Thus, whilst recommending community-based specialist teams for adults with ASC, the GDG could not advocate a particular model.

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A key reason for this lack of evidence is that until recently specialist services for adults with HFA and AS did not exist. However, the past few years, and further stimulated by the publication of the Autism Act and Strategy, have seen specialist community-based services for adults with HFA and AS being developed. Importantly, across the country a number of different approaches have been taken with regard to the design and operation of specialist autism teams. For example, some only work with adults with HFA and AS, whilst others provide support to adults across the entire spectrum. Similarly, the predominant model for some teams is to support professionals and services involved with/responsible for adults with autism, whereas other teams provide the majority of services/support 'in house'.

There are now, therefore, services/service models to evaluate and compare. Equally, many areas are still to make progress on commissioning and implementing such a service. There is, therefore, a strong argument that the proposed research is both very timely and highly relevant.

Government is committed to reviewing progress in implementing the Autism Strategy. Whilst progress has been made in autism-awareness training and strategic work, the development of specialist services, including SATs, has been very limited and patchy (3,20). This policy driver and the number of adults being diagnosed with HFA and AS mean this is, and will remain, highly relevant to the NHS.

AIMS AND OBJECTIVES

The proposed research is in response to significant gaps in evidence identified by the NICE Guideline for Autism in Adults (see Box 1). It will provide evidence on:

- the typology(s), characteristics and ways of working of Specialist Autism Teams (SATs) which best support positive outcomes for individuals with HFA/Asperger's and other services working with this population to deliver positive outcomes;
- the costs and cost-effectiveness of the alternative models of SATs;
- what needs to be in place in the wider service context in order for SATs to function effectively.

Box 1: Extract from NICE clinical guideline 142: Autism: recognition, referral, diagnosis and management of adults on the autism spectrum.

"The Department of Health's autism strategy (2010) proposes the introduction of a range of specialist services for people with autism; these will usually be built around specialist autism teams. However, <u>there</u> is little evidence to guide the establishment and development of these teams.

There is <u>uncertainty about the precise nature of the population to be served</u> (all people with autism or only those who have an IQ of 70 or above), <u>the composition of the team</u>, the <u>extent of the team's role</u> (for example, diagnosis and assessment only, a primarily advisory role or a substantial care coordination role), <u>the interventions provided by the team</u>, and the <u>team's role and relationship with regard to non-statutory care providers</u>. Therefore it is likely that in the near future a number of different models will be developed, which are likely to have varying degrees of success in meeting the needs of people with autism. Given the significant expansion of services, this presents an opportunity for a large-scale observational study, which should provide important information on the characteristics of teams associated with positive outcomes for people with autism in terms of access to services and effective coordination of care."

(2) (p 42) (applicants' emphases)

Objectives:

• To develop a typology of the different models of Specialist Autism Teams (SATs) currently operating in England.

- To assess outcomes for adults with high functioning autism (HFA) and Asperger syndrome (AS) of different models of SATs;
- To identify the characteristics of SATs which best support achievement of positive outcomes for adults with HFA and AS.
- To identify SAT model(s)/ways of working which best support other services to achieve positive outcomes for adults with HFA/AS.
- To estimate the costs of different models of SATs and investigate cost-effectiveness.
- To understand the service user experience and the processes by which SATs impact on the lives of adults with HFA and AS.
- To inform and support decision-making on commissioning and developing SATs for adults with HFA and AS.

Key research questions:

- What models of SATs currently exist?
- Is there a particular service model(s) which performs better in terms of achieving positive outcomes for its users?
- Is there a particular service model (s) which performs better in terms of advice, training and support to other health and social care professionals who work with adults with HFA/AS.
- What characteristics of SATs are associated with positive outcomes?
- What are the costs of the different models of SATs, and how are they being funded?
- How do SAT models compare in terms of costs and cost-effectiveness?
- What are the processes by which SATs achieve positive outcomes, how do the different service models impact/interfere or support these processes?
- What is the service user experience, and does it differ between models?

RESEARCH PLAN / METHODS

The proposed project has two stages. Stage 1 will identify, map and develop a typology of Specialist Autism Team (SAT) service models. Stage 2 will evaluate up to four of these models.

To some extent the specific design of Stage 2 cannot be finalised until the findings from Stage 1 start to emerge. We did consider addressing our research questions through two sequential projects. However, a single study is advantageous for a number of reasons: much-needed evidence is produced more rapidly; the study benefits from the efficiencies of maintaining relationships/buy-in from SATs gained during Stage 1; and it better reflects current practice. Senior members of the research team are very experienced researchers and all areas of expertise required for 'fine-tuning' the design of Stage 2 are represented in the team. The team will also consult with the Study Steering Committee and NIHR's Research Design Service (Yorkshire and the Humber) at this stage.

Defining the Specialist Autism Team

The publication of the Autism Strategy has stimulated developments in specialist autism provision across statutory sectors services. Keen to identify the nature of their service, agencies have labelled such provision with terms such as: 'autism-specific', 'specialist autism', 'Asperger'. Drawing on work we have conducted to develop this proposal and information held by the National Autistic Society, we know the purpose or objectives of much of this provision is uni-dimensional such as: training, outreach/community-based support, residential and day care services, or assessment/diagnosis.

The purpose of this project is, however, to support evidence-based decision-making by practitioners and commissioners as they seek to implement the Autism Strategy and NICE guidelines, and specifically the recommendation that each locality has a specialist, multi-disciplinary team. The NICE guidelines sets out the skill mix and functions of a Specialist Autism Team, see Box 2. This research, therefore, is concerned with teams/services which match the description set out in the NICE guidelines.

Box 2: The description of the Specialist Autism Team provided by NICE (1)

In each area a specialist community-based multidisciplinary team for adults with autism (the specialist autism team) should be established. The membership should include:

- clinical psychologists
- nurses
- occupational therapists
- psychiatrists
- social workers
- speech and language therapists

• support staff (for example, staff supporting access to housing, educational and employment services, financial advice, and personal and community safety skills).

The specialist autism team should have a key role in the delivery and coordination of:

- specialist diagnostic and assessment services
- specialist care and interventions

• advice and training to other health and social care professionals on the diagnosis, assessment,

- care and interventions for adults with autism (as not all may be in the care of a specialist team)
 support in accessing, and maintaining contact with, housing, educational and employment services
- support to families, partners and carers where appropriate
- care and interventions for adults with autism living in specialist residential accommodation
- training, support and consultation for staff who care for adults with autism in residential and community settings.

(NICE, 2012 (1), pp13-14)

Criteria for classifying a service/team as a Specialist Autism Team

We will use the skill-mix and functions identified by NICE as the criteria against which services/teams are defined by the project as a Specialist Autism Team. The extent to which we can rigidly adhere to <u>all</u> these criteria for each potential SAT can only be determined once we have conducted our mapping work (Stage 1).

However, existing evidence supplemented by specific work we have done in preparing this bid indicates that some flexibility may be required. For example, some teams only work with adults with High Functioning Autism or Asperger syndrome; some teams fulfil all the criteria apart from offering family/carer support; or the skill-mix is not as comprehensive as set out in the NICE guidance. We therefore propose, *for the purposes of this project*, the following adjustments. We would argue this is justifiable because our focus is on HFA and AS adults only:

- limiting the service to individuals with High Functioning Autism and/or Asperger syndrome will <u>not</u> be an exclusion criteria;
- minor shortfalls in skill mix will not preclude classification as a SAT;
- neither 'parent/family/carer support' nor 'care interventions for adults with autism living in specialist residential accommodation' will be treated as an essential criteria for classification as a SAT.

A later section of the Detailed Project Description (describing Stage 1) details the process by which these criteria will be applied.

STAGE 1: IDENTIFYING, MAPPING & DEVELOPING A TYPOLOGY OF SPECIALIST AUTISM TEAMS

The survey process

As noted earlier, a wide-range of teams/services may label themselves as 'specialist' or 'autism specific'. A staged approach to identifying SATs, using survey methodologies, is therefore required. The following process will take place:

- i. In areas where there is currently no evidence on Specialist Autism Team provision, telephone calls and web searches will be used to identify individuals/representatives in every clinical commissioning group (CCGs), acute mental health trust and local authority (LA) across England with strategic responsibility for adults with autism in their locality (e.g. LA Autism Leads, chairperson of local Autism Partnerships, clinical directors).
- ii. Brief structured phone interview with identified individual to ascertain existence of any team/service which may fulfil the definition of a SAT. Contact details of team/service manager will also be secured.
- iii. Structured interview with team/service manager. In localities known to have a team/service which may fulfil the definition of a SAT, the survey process will filter directly to this stage. This interview will collect detailed data on: team composition; eligibility criteria; referral routes; waiting times; the assessment process and subsequent care pathways (including 'speed' at which individuals move along the pathway); caseload; desired outcomes; approach/rationale; functions and services provided; funding/commissioning arrangements; the nature of joint-working; pathways from children's services; and the wider service contact.

Pre-piloting and piloting the survey instruments

An outline of topics to be covered by the two survey instruments (for use in ii and iii above) will be shared with the Study Steering Committee for comment. Draft versions will be administered to practitioner/professional members of Study Steering Committee and evaluated using cognitive interviewing techniques in order to understand what a respondent understands by a question and to identify any gaps in the instruments. Feedback from this will be used, where necessary, to revise questions. We will then carry out a formal pilot exercise with a five per cent sample (stages ii and iii) . This will test the wording, flow and administration of the instruments. If necessary, we will make final revisions to the instruments before the main data collection begins.

Data collection

Both surveys (ii and iii) will be administered via a telephone interview using an electronic survey tool (Qualtrics; <u>http://www.qualtrics.com/</u>). They will be audio-recorded. The interviewer will enter fixed-answer responses during the interview process and extended responses to open-ended questions will be entered post-interview (using the audio-recording). Once data extraction for an interview is complete, the recording will be used to check the accuracy and comprehensiveness of data entry.

Screening of services/teams for inclusion as a Specialist Autism Team

A pro-forma populated by the skill-mix and function criteria for SATs set out in the NICE guidance will be completed for each team/service. The following process will then be undertaken:

- i. Pro-formas independently reviewed by four members of the research team (TB, CP/SL, BB, WM) and judgements made on whether each team/service has fulfilled the SAT inclusion criteria, or not.
- ii. The team meets to review their decisions and discuss and resolve any differences in opinion.
- iii. A meeting with the Study Steering Committee is held at which the outcome of this process, including details of included and excluded services/teams, is reported and discussed. If required, the research team will revise the decisions it has made.

Work conducted by the applicants in preparation for the bid and existing evidence held by NAS suggest that around 20-30 SATs will be identified by this process. Data from services/teams classified as SATS will be taken forward for analysis.

Analysis

Qualitative and quantitative analyses will be used to: i) develop a typology of current SAT service models; and ii) provide a descriptive account of SATs service models and the location and coverage of SATs across the country.

After cleaning, survey data will entered into the SPSS package (v21) and analysed descriptively as a first stage, to give a simple national picture of current SATs. We will then use cluster analysis to develop a

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typology of SAT, using data on the characteristics of the services. Cluster analysis is a useful way of developing a tight typology of services, in order to assist analysis of differences and similarities between services, while at the same time preserving the underlying features of individual services. It has been used successfully in NIHR funded research (26). We will then test the typology, using bivariate analysis to ensure that it does, indeed, differentiate between different service models. Our preliminary work suggests the following are some of the dimensions along which SATs will differ:

- caseload: HFA/AS vs whole spectrum;
- 'virtual' vs co-located and team arrangements (meetings, communication systems)
- the professional composition of the SATs (the nature and quantity of input of different professionals; seniority/level of expertise of staff; core vs 'peripheral' members);
- emphasis on, and extent of, diagnostic assessment;
- service approach: deliver interventions and services vs consultation/support to other professionals/services (or 'up-skilling');
- the wider service context (local availability of other specialist ASC provision, including third sector provision);
- the level and nature of the partnership between health and social care (for example, structural integration; multi-disciplinary teams; joint commissioning).

Analysis of the qualitative data will provide a more detailed description of each service model, and any observed 'fine-grain' differences between SATs falling into the same service model. Findings from Stage 1 will be published as an interim report and a dissemination event held during month 14 of the project.

STAGE 2: EVALUATION OF DIFFERENT MODELS OF SPECIALIST AUTISM TEAMS

The design of the evaluation has been driven by the research questions and 'evidence gaps' identified by NICE Guidance for Autism in Adults (1). It was influenced and informed by MRC Guidance on the Evaluation of Complex Interventions (23).

A mixed-methods design is proposed comprising:

- a comparison of SAT models in terms of outcomes for service users and achievement of servicelevel outcomes;
- a comparison of SAT models in terms of achievement of outcomes specific to the reason an individual was referred to a SAT;
- identification of service characteristics associated with positive outcomes (global and referralspecific) and the impact of other factors on that process (e.g. local service context; ASC diagnosis; presence of co-morbidities);
- modelling the relative costs and investigating the cost-effectiveness of different SAT models;
- exploration of the experiences of service users and of services which refer to/interface with SATs;
- exploration of the processes by which SATs impact outcomes.

Selection of models for evaluation

Until much of the work on Stage 1 is complete, we will not know how many models we have or how many services fall into each. However, based on work carried out in preparation for this bid, we anticipate that 3 or 4 models will be taken forward to this second-stage evaluation. Selection criteria will include:

- the model is not constrained by particular service configurations/organisational structures which would make it very difficult to implement in other localities;
- At least some of the SATs representing the model have been established and fully operational for at least a year.
- An adequate sample size is achievable.

Sampling

The sample will be recruited from individuals who have been referred (or, for some SATs, self-referred) to SATs. Recruitment will take place at the point of assessment by the SAT. We are aware that a SAT may

provide a 'one-stop shop'/drop-in service, access to which does not require any sort of assessment. We will not recruit through this route as the nature of contact with the SAT is highly transient and substantially different to the core work of the team.

The evaluations of outcomes and costs will use the same sample. This will also act as the service user sampling pool for the process evaluation.

In order to increase the generalizability of our results, where possible we will select more than one SAT to represent each model. If we have sufficient numbers of services willing to participate within each model, we will randomly select those to be included; if we do not, we will adopt a stratified approach to sampling to ensure representation of different size teams/caseloads, rural/urban services, and population structure.

Sample size

Our primary outcome measure will be the World Health Organisation Quality of Life Instrument, Abbreviated Version (WHOQOL-BREF) (26). However, there are no prior studies that have investigated changes in quality of life (QoL) in this population (using this or any other QoL measures) which we could use to inform sample size calculations for the quantitative aspects of the evaluation. We have therefore powered the study on WHOQOL-BREF score at 12 months (nQuery +nTerim 2.0). Anagnostou et al (27) reported a WHOQOL-BREF overall mean score of 65.2 (sd: 12.3) for patients with ASCs. A sample size of 80 per SAT model will have 80% power to detect a difference in WHOQOL-BREF score of 5 or more between SAT's, at 5% significance. We will recruit 110 service users per model in order to ensure a sample size of 80 is achieved at 6 month follow-up (70% study retention rate).

Outcome measurement time-points

Individual-level outcomes and costs-related data will be collected at assessment; 3-; 6-; and 12-months postassessment. Service-level data will be collected with reference to a twelve month period.

Individual-level outcome measures

Global quality of life: will be measured using the World Health Organisation Quality of Life Instrument, Abbreviated Version (WHOQOL-BREF) (26). The WHOQOL-BREF offers a more holistic assessment of quality of life compared to health-related measures such as the SF-36 and EQ-5D (although we will use the EQ-5D for the economic evaluation). The WHOQOL-BREF comprises 26 items which capture the following domains: physical health; psychological health; social relationships; environment. It has been used to explore quality of life among populations of adults with HFA and AS (32-34). A large-scale study of its suitability in as a patient-reported outcome measure in diverse patient and healthy populations described the WHOQOL-BREF as a 'high quality, patient-centred' tool (35). The WHOQOL-BREF will be our primary outcome measure. This accords with calls for quality of life to be the priority of any intervention with adults with ASC (1, 36). The EQ-5D (new 5-level version) will be used alongside the WHOQOL-BREF, primarily to generate a measure of quality-adjusted life years (QALYs), to allow comparison with other health-focused interventions. We recognise that SATs work to improve more than just the health of the individuals they support, and so the QALY measures will only cover part of the outcome range. We will, however, explore within the first phase of the research the possibility of using the ASCOT (www.pssru.ac.uk/ascot), which is focused on social care outcomes (and which can generate a social care equivalent to a QALY), provided there is a version suitable for people with HFA/AS, but we again recognise that this tool does not span the full range of relevant quality of life domains.

<u>Mental well-being</u>: the Short Warwick Edinburgh Mental Well-Being Scale (Short form) (SWEMWBS) will be used to measure of mental well-being. It comprises seven positively worded items with a five-point Likert scale response format. A single score is obtained. The SWEMWBS has been subject to rigorous psychometric evaluation (37) and is widely used as an outcome measure at a population level (eg. Scottish Government is using it as one of its indicators for tracking national outcomes). The NHS Care Pathways and Packages Project (CPPP) is currently evaluating use of the SWEMWBS as PROM for the Mental Health Payment by Results Framework (http://www.cppconsortium.nhs.uk/prom.php). Preliminary findings from the

CPPP project will be published in September 2014 and we will be able refer to these before Stage 2 of the proposed project commences

<u>Mental health</u>: will be measured using the General Health Questionnaire (GHQ 12) (38). This widely used and robust self-report measure of current mental health focuses on two major areas – the inability to carry out normal functions and the appearance of new and distressing experiences. It has been shown to be valid and useful in both clinical and general populations. It comprises 12 items and uses a four point Likert scale. A single total score is obtained.

<u>Receipt of social support and assistance</u>: the Inventory of Socially Supportive Behaviours (Short Form) (ISSB-SF) (39) will be used. It captures the frequency with which an individual has received support or assistance in the previous four weeks. It comprises 19 items and has a four point Likert-type response format. Social support is a loosely defined concept. Some measures capture satisfaction with, or perceived availability of, support. Others seek to 'count' or measure the size of an individual's social networks. Furthermore, some only measure emotional support. The ISSB-SF was selected because it best reflects the social support outcome which SATs seek to achieve. It is grounded in a broad definition of social support (40). More recent work on its factor structure identified three sub-scales (Guidance, Emotional Support and Tangible Support) (41) which sit well with Caplan's (1976) conceptualisation of social support. The ISSB-SF has been used as an outcome measure in health interventions (42).

<u>Day-time occupation</u>: fixed response questions will ask about current day-time occupations for a typical week, and hours/week engaged in each activity:

- paid/unpaid employment
- education/training
- routine participation in other meaningful activities (eg. hobby/special interest group; exercise class; peer support group).

<u>Living situation</u>: fixed response questions will ask who the respondent is living with and type of accommodation.

<u>User-defined goal attainment</u>: simple goal attainment scaling (GAS) will be used to measure the extent to which user-defined goals have been attained. GAS quantifies the achievement (or otherwise) of goals sets against expected achievement. Now used in a diverse range of settings (social work, pain management, rehabilitation) (43), this approach was first introduced to assess outcomes in mental health settings (44). At assessment, study participants will be asked to identify one or two discrete, quantifiable goals specifically related to their referral to the SAT. The criteria for what would be a successful outcome ('expected attainment') with respect to that goal is agreed between the user and professional. The user rates their current level against this outcome ('baseline attainment').

'Actual attainment' is then rated at follow-up timepoints. The following rating scale is used:

-2=outcome achieved much less than expected

-1=outcome achieved somewhat less than expected

0= expected outcome achieved

+1=outcome achieved somewhat more than expected

+2=outcome achieved much more than expected

Service-level outcomes

The following service-level outcomes will be collected with respect to a 12 month period:

- <u>'reach' to population</u> (ie proportion of estimated population in contact with the SAT calculated using national prevalence estimates);
- for individuals referred to the SAT for diagnosis, <u>mean time to achieve diagnosis</u> from point of referral;
- <u>take-up:</u> proportion who attend assessment following referral.

 <u>ratings of satisfaction with support, training and advice</u> from services/staff who refer to the service and/or care for adults with autism in residential and community settings. As with a previous project where we were interested in referrers' views and experiences of a specialist mental health service (Beresford et al, 2008), we will construct a brief questionnaire to capture satisfaction with referral/ease of access and dimensions of 'up-skilling'.

Other evaluation data collection

The <u>Client Service Receipt Inventory</u> will capture service use data (3 month retrospective) at each outcome time-point (45) will be adapted to capture service use data and other cost-related information (such as unpaid care and support from family members, patterns of employment and receipt of welfare benefits) at each outcome time-point (using 3- month retrospective questions). at each outcome time-point (http://www.kcl.ac.uk/iop/depts/hspr/research/cemph/tools/csri.aspx).

Data collected with the CSRI can be used to calculate service costs and total costs of care (see below). A version of the CSRI has recently been adapted for use with adults with autism, and is currently in use in another study (SNAP study led by Emily Simonoff, Institute of Psychiatry). We will start with this adapted version and make further changes as needed for the SAT evaluation..

For each research participant, the SAT will provide the following information: <u>reason(s) for referral</u>, <u>history of contact</u>, <u>'onward' referrals</u>, <u>discharge/case closure</u>.

Service user recruitment and data collection processes

Recruitment

Recruitment to the study will take place at the point of assessment by the SAT. A careful discussion about the project with service users, supplemented by written information, will precede seeking consent. Recruitment materials and processes will be developed in consultation with our User Advisory Group (UAG). Following consent the practitioner will complete a Study Entry Form (SEF) covering the following information about the service user: name and contact details; preferred means of contact with the research team (see below); diagnosis/likely diagnosis; reason for referral to the service; user-defined goals. NHS support costs have been calculated to cover the staff costs associated with these activities.

Completed SEFs will be sent to research team. This will trigger an 'Introductory Contact' being made with a research participant by a member of the research team. The 'Introductory Contact' will take place within a week of the assessment. The member of the research team making the 'Introductory Contact' will remain that participant's contact throughout the course of the project.

Research participants will choose their preferred (and an alternative) method of contact with the research team (email, text, telephone or letter), and their preference in terms of completing the outcome measures (i.e. on-line; postal; via telephone interview or home visit). This strategy of providing research participants with options regarding mode of contact and research instrument completion is informed by evidence that it supports recruitment and retention (46). It also serves to overcome particular barriers to participating in research experienced by individuals with HFA and AS (47). An on-line survey system (*Qualtrics*: http://www.qualtrics.com) will be used to create and manage the electronic (ie. on-line) versions of the research instruments.

Incentives

A payment of £15 at each data collection time point will be offered. This will support recruitment and retention to the study and act as a thank-you token for time given to complete research instruments.

Time 0 (baseline) data collection

The completion of outcome measures and setting of user-defined goals will be integrated into the assessment process. We will work closely with each SAT to identify a system by which T0 outcomes data can be collected in a feasible and sustainable manner during an assessment appointment. NHS support costs have been calculated to cover the cost of these activities.

Background data about the participant will be collected during the 'Introductory Contact' between a research participant and member of the research team, and the Client Receipt Service Inventory completed.

Follow-up time -points data collection

This will proceed in the manner chosen by the research participant. A week or two prior to a data collection time-point participants will be contacted to confirm preferences and arrangements. At each data collection time-point consent will be re-checked. Reminders (using the preferred modes of contact) will be used to support response rates.

Plan of analysis for evaluation of the SAT models in terms of user- and service-level outcomes Planned analyses with respect to the research questions are set out below:

Is there a particular service model(s) which performs better in terms of achieving positive outcomes for its users?

- a) Comparison of the different SAT models in terms of impact on global quality of life (WHOQOL-BREF), health-related quality of life (EQ-5D), achievement of individual goals (GAS score) and mental well-being (SWEMWBS) at 3, 6 and 12 month follow-up
 - ANCOVA will compare 12 month scores between SAT models, controlling for baseline scores.
 - Repeated measures ANOVA to explore the changes in scores from baseline, 3, 6 and 12 months between SAT models.
 - Post hoc testing of impact of individual factors on effectiveness (eg HFA vs AS; age; mental health (GHQ-12) at T0; social support networks (ISSB) at T0). This will be undertaken by including these factors within the repeated measures ANOVA models.
- b) Comparison of the performance of the models in achieving *specific outcomes* (as determined by the reason for referral):
 - Sub-samples will be created according to the primary reason for referral;
 - For each sub-sample, ANOVA tests and multiple regression will be undertaken using relevant outcome indicators (e.g. daytime occupation, living situation, mental health (GHQ-12), social support/networks (ISSB), the achievement of individual goals as measured by the GAS score).
 - Post-hoc testing as before.

<u>Is there a particular service model (s) which performs better in terms of service-level outcomes?</u> Here the performance of the different SAT models will be compared in in terms of:

- 'reach' to population;
- mean time to achieve diagnosis from point of referral;
- take-up;
- interfacing services' satisfaction with support, training and advice.

SAT models will be compared with each other on the service level outcomes using t-tests and ANOVA for continuous data and chi-square tests for categorical data.

What characteristics of SATs are associated with positive outcomes?

We do not anticipate that each service model will have a unique set of service characteristics. Rather, there will be areas of similarity between models. For example, two models may be HFA/AS-specific but differ on other characteristics; or two models may be similar in that they not engage in much direct work with adults with HFA/AS but differ on other characteristics. The service characteristics we investigate will, to some extent, be determined from Stage 1 findings.

However, we anticipate that (at least) the following will be explored:

- HFA/AS specific vs all ASC;
- service approach (primarily direct work vs 'up-skilling' professionals in other services);
- the nature of the partnership between health and social care;
- skill-mix/professional composition and level of involvement;

- co-located vs virtual;
- the local service context (ie. availability of other ASC specific services).

We will explore the impact of service characteristics on service-level and individual-level outcomes. Linear regression will be used for continuous outcomes and logistic/multinomial regression for categorical outcomes:

- service level outcomes: 'reach' to population; mean time to achieve diagnosis from point of referral; take-up; interfacing services' satisfaction with support, training and advice;
- individual level outcomes: global quality of life (WHOQOL-BREF), health-related quality of life (EQ-5D), achievement of individual goals (GAS score), and SWEMWBS at 3, 6 and 12 month follow-up.

The economic evaluation

The economic evaluation will have four main elements.

- i) We will calculate and report the costs of each of the SATs, disaggregated if necessary by activity (to reflect that different SAT models are likely to have different components), and including professional and other inputs to SATs that are funded from other budgets.
- ii) We will estimate the comprehensive costs of care and support for individuals in the study, ranging over health, social care, welfare benefits, employment-related and other 'formal' sectors, as well as unpaid support from family members and others. We will also calculate the SAT-specific cost per individual in the study (from the activity in the bullet above). Data on service use and unpaid support will come from CSRI, and we will attach unit costs taken mainly from the PSSRU annual volume (48) and NHS reference costs. We will report costs by time-point (over the 3-month retrospective period) as well as over the 12-month period between assessment and final data collection. We will include disaggregated calculations that show costs falling to each main sector (health, social care etc), the public sector and society as a whole (in the latter case, therefore excluding welfare benefits as these are transfer payments).
- iii) We will use multivariate statistical analyses to explore variations in costs (first public sector costs, then total societal costs) between individuals in the sample, taking account of the clustering by SAT and the time-point (panel design). The analyses will examine associations between costs and individual characteristics (measured on the instruments described above) at different time points, and the mediating effects of different SAT models. In this way we can examine what effect different SAT models have on costs of care and support over a 12-month period, taking into account that individuals have different characteristics, strengths, needs and preferences. Analyses are likely to have to take account of skewed cost data.
- iv) We will examine the links between costs and outcomes over the 12-month period, again taking account of clustering, repeated measures and (probably) skewed cost measures. We will take each of the main outcome measures in turn (at each time-point) as the dependent variable in a multiple regression analysis that links it to costs in the previous period and individuals' baseline characteristics, and the characteristics of the SAT model. The analyses will take into account the potentially complex interrelationships between costs, outcomes, individual and SAT characteristics. In this way we will be able to test whether different SAT models (or component characteristics thereof) have different outcomes. Because this study is not based on a randomised design, the examination of costs, outcomes and cost-effectiveness will need careful econometric interrogation of the available data to identify the underlying relationships (cf. Fernandez and Davies 2000), and thence to compare SAT models.

The process evaluation

A process evaluation explores the ways that interventions are implemented (49-51) and the context in which they are delivered (49, 52) so that the system, the different elements of the intervention and how these interact, can be understood (53). This approach can aid understanding of, for example, the aims of an

intervention, how it is delivered and whether the intended aims are achieved. As such, it can provide valuable insights into how the intervention works in practice and the factors that affect its success, as well as highlighting unintended consequences of the intervention/service (49).

Qualitative research methods will be used to explore: the processes by which SATs impact on user outcomes; the impact of different service models on outcomes and service user experiences, and other factors perceived as influencing outcomes. It will also investigate the views and experiences of professionals working in other services in the locality who have sought advice/support from the SAT. We will look at these professionals' satisfaction with the SAT and views on barriers and facilitators to a SAT's ability to 'upskill' other services in their locality.

User, carers/significant others and practitioners (working in the SATs and interfacing services) across the case studies will participate. We will also use data collected in Stages 1 (ie. the SAT survey data); and Stage 2 (the Client Service Receipt Inventory) to provide background/contextual data and to identify and describe typical and atypical care pathways, patterns of service use, and the involvement of interfacing and other services in service users lives.

The process evaluation sample

Six 'informant' groups will be recruited to the process evaluation:

- i. Managers (interviewed on 2 occasions);
- ii. Practitioners working in the SATs;
- iii. Service users (3 and 6 months post-assessment);
- iv. A parent/family member (nominated by the service user) (~6 months post assessment);
- v. Individuals who refused assessment/the support of a SAT:
- vi. Professionals working in 'interfacing' services.

The timing of interviews with these different groups is important. First, interviews with SAT managers will take place early in Stage 2. This will be used to add depth to the data obtained through the Stage 1 survey and as well as providing important contextual information. They will also serve to confirm/identify all 'interfacing services'.

Interviews with a subsample of <u>service users</u> for each SAT service model (n=10/model), representing a range of referral reasons, will be interviewed 3 and 6 months post-assessment. These time points have been chosen as it covers the period (ie. from assessment to 6 months post-assessment) when interventions/activities to address the reason for referral are likely to have taken place. A purposive sampling frame will be used to ensure the samples achieved represent the typical population using the SAT, and representation from all teams if more than one team is representing a SAT model in the research. We will also seek one-off interviews with individuals who declined/did not attend assessment for a one-off interview. SATs participating in the study will be asked to identify these individuals. Interviews with service users will explore:

• access to, and acceptability of, the SAT and its ways of working; perceived impact on outcomes; perceived facilitators/barriers to positive outcomes; unmet needs and any negative outcomes.

At the 6 month interview, service users will be asked to nominate a <u>Significant Other</u> (eg. partner/family member) to invite to participate in the process evaluation. If they consent, these individuals will be interviewed shortly after the service user interview. We do not expect all service users to agree to/be able to nominate a 'Significant Other'. However, we hope to achieve a sample of 5 'Significant Others' per SAT model. These interviews will explore:

• perspective on the impact of SAT team involvement on own and service user's life; issues related to access; service user's and own unmet needs; any negative outcomes.

Interviews with <u>practitioners working in SATs</u> (n=12/model) will be conducted following preliminary analysis of 6 month follow-up outcomes data. This will allow us to explore any emerging differences between SAT

models in terms of global performance and/or performance with respect to particular outcomes. We will also re-interview *service managers* at this stage. These interviews will explore:

 service delivery and practice experiences and issues; views about the service model and alternatives; perceived facilitators and barriers to achieving positive user-level and service-level outcomes; experiences of negative outcomes/unintended consequences; views and explanations for differences in performance between SATs.

Finally, <u>professionals working in 'interfacing services'</u> will be interviewed (n=~10/model). This will include services referring to the SAT; services using the SAT for advice/training/support (up-skilling activities) and services which accept referrals/co-work with SATs. These interviews will explore:

 views on the role/performance of SATs in supporting user and service level outcomes; factors impacting on outcomes; service organisation and delivery issues; and unintended consequences (eg. de-skilling).

Data collection processes

Interview schedules, or topic guides, will be used to ensure consistency and comprehensiveness across interviews. These will be developed and piloted with members of our User Advisory Group (UAG).

For the interviews with service users, it will be important to offer alternative modes by which they can participate (47). We will offer the option of participating via telephone interview; face-to-face; or textual completion of an on-line questionnaire (comprising a series of questions with an open-text response format). They will be interviewed by the same member of the research team who is in contact with them regarding outcomes data collection. Service users will be able to choose to have someone with them during the interview.

Aside from the first interview with service managers, all interviews with professionals will be conducted via telephone. 'Significant Others' will be offered telephone or face-to-face interviews.

Data analysis

We will seek permission to audio-record interviews. Interviews will be transcribed or detailed interview summaries created from the audio-recording. (Transcription will be used where interviews are particularly complex.) If permission is not given to record, detailed notes will be made during and immediately after the interview. The User Advisory Group (UAG) will work actively with the research team to support the analysis and interpretation of the service user interviews.

We will analyse data within, and across, participant and SAT models using the Framework approach (Ritchie and Lewis, 2003) to managing and thematically analysing qualitative data (Miles and Huberman, 1994). The Framework approach facilitates systematic data management and allows audit trails of the data management and analytical process.

There are four stages of data management. First, researchers familiarise themselves with the data, and identify themes and key issues. Based on identified themes and any *a priori* issues, an index of themes is constructed (the thematic framework). Data are then indexed according to which theme(s) in the analytical framework they relate to. Finally, the indexed data from each case (e.g. participant, focus group) are summarised onto a series of thematic matrices (or charts). Each chart is divided into columns, allowing relevant data to be organised according to sub-themes/issues. A single row on each chart holds one participant's data. Thus reading along a row provides an overview of everything an individual spoke about in terms of a specific issue. Reading down the chart (or down a column) allows comparison between participants'. At all stages, a proportion of the data (usually 10%) is independently analysed by two researchers, followed by a review of the outcome of that analytical process. The final stage of analysis involves 'reading' of the charts, composing 'analytical notes' which describe the data, and developing interpretation and hypotheses which are then tested against the charts and raw data.

In this project, both researchers and members of the User Advisory Group will be involved in the analytical process, particularly the development of the analytical framework and interpretation of emerging findings.

In addition, for each research participant, time-ordered displays (25) will be used to represent individual care pathways. We have found these are a very useful approach when analysing longitudinal qualitative data analysis, both providing an output which supports the thematic analysis as well as being an analytical tool in their own right (53).

Synthesising findings across the streams of work in Stage 2

Project management systems will be put in place to support an on-going reflective exchange of findings emerging across the different streams of work. One of the CI's key roles will be to ensure the mixed methods approach to the evaluation is fully utilised and exploited. Care has been taken in project planning to ensure there is sufficient time once all the data has been collected and subject to analysis to allow for full exploration of what the process evaluation can offer to the research in terms of explanation and interpretation of findings, and to allow proper testing of these ideas against the data. Equally, we will be using interim findings from outcome evaluation to inform issues explored by the process evaluation.

PLAN OF INVESTIGATION AND TIMETABLE

This a 45 month project with the final 6 months entirely dedicated to dissemination activities. The timetable below sets out key activities and milestones. A flow diagram of the project and project Gantt chart have also been submitted with this application.

Months 1:	NHS REC scrutiny of Stage 1 to confirm audit status.
	Development and piloting of survey instruments commences (Stage 1).
	Study Steering Committee established.
Month 3:	First phase of Stage 1 complete and second phase underway.
	Work on NHS REC and ADASS approvals for Stage 2 underway.
Month 4:	Third phase of Stage 1 (interviews with potential SAT service managers begins.
Month 7:	NHS REC approvals obtained.
	Third phase of Stage 1 complete.
Month 8:	Review Point
Month 9:	Typology of SAT models produced.
	Recruitment of SATs to Stage 2 begins.
	Further data analysis of Stage 1 data.
	Begin Local Research Governance approvals process.
Month 11:	Recruitment to Stage 2 begins.
Month 12:	Report of Stage 1 complete.
	Process evaluation commences.
Month 14:	Publication of Stage 1 report and dissemination event.
Month 23:	Recruitment to Stage 2 closes.
	Interim findings re six-month follow-up outcomes available for process evaluation.
Month 29:	Process evaluation data collection complete.
Month 35:	Data collection for Stage 2 complete.
	Process evaluation analysis complete
	Preparation of final project report commences.
Month 39:	Final project report complete.
Month 40:	Preparation of tailored project outputs begins.
	Work on academic articles, conference abstracts begins.
Month 43:	Launch of research findings and dissemination products hosted by the All Party Parliamentary
	Group on Autism

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Mos 44-45: Day conference dissemination events in York and London Targeted distribution of tailored project outputs