Specialist Autism Team provision for autistic adults without learning disabilities: a mixed methods investigation and evaluation

The SHAPE project

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**Key words**: autism, adults, diagnosis, post-diagnostic support, mental health, daily functioning, service organisation and delivery,

**Competing interests**: Lucy Stuttard: member, HS&DR Board: 2014-2018.

**Word count – main body of report:** 52367

**Total word count:** 75478

Abstract

**Background**

NICE recommends every locality has a ‘Specialist Autism Team’ (SAT): an autism-specialist, community-based, multi-disciplinary service responsible for developing, coordinating and delivering care and support. It recommended this novel delivery model was evaluated.

**Objective(s**)

* identify services fulfilling NICE’s description of a SAT;
* describe practitioner and user experiences;
* investigate outcomes;
* identify factors associated with outcomes;
* estimate costs and investigate cost-effectiveness.

**Design**

Stage 1: desk-based research and survey to identify SATs. .

Stage 2:

* mixed methods observational study of cohort of SAT users, followed for up to two years from assessment appointment. Users either referred for ‘diagnosis and support’ (D&S) or, if already diagnosed, ‘support only’ (SO))
* nested qualitative study of senior practitioners.
* exploratory comparison of D&S group with a cohort accessing a diagnostic assessment service (‘diagnosis only’ (DO)).

**Setting (Stage 2)**

Nine SATs; three also provided a regional diagnostic assessment service (used to recruit DO cohort).

**Participants (Stage 2)**

* SAT cohort: n 252 (D&S =164, SO=88).
* DO cohort: n=56.

Thirty-seven participants (across both cohorts) recruited to the qualitative evaluation and eleven practitioners to the nested qualitative study.

**Main outcome measures**

WHOQOL-BREF Psychological Domain, GHQ-12.

**Data sources**

Self-reported outcomes, qualitative interviews with users, and focus groups with practitioners.

**Results**

Stage 1

Eighteen SATs were identified, all for autistic adults without LD. Services varied in their characteristics. Resources available, commissioner specifications and clinical opinion determined service design.

Stage 2:

Staff reported increasing referral rates without commensurate increases in funding. They called for an expansion of SATs’ consultation/supervision function and resource for low-intensity, on-going support.

For the SAT cohort, there was evidence of prevention of deterioration in outcomes and positive benefit for the D&S group. Users of services with more professions involved were likely to experience better outcomes; however, this may not be considered cost-effective. Some service characteristics were not associated with outcomes, suggesting different structural/organisational models are acceptable. Findings suggests one-to-one work for mental health problems was cost-effective and an episodic approach to delivering care plans more cost-effective than managed care. Qualitative findings generally align with quantitative findings; however, users consistently connected a managed-care approach to supporting improvement in outcomes.

For the DO cohort, no changes in mental health outcomes at T3 were observed. Interviews, comparing D&S and DO individuals, suggests extended psychoeducation post-diagnosis impacts immediate and longer-term adjustment.

**Limitations**

Sample size prohibited investigating association between some service characteristics and outcomes. Comparison of DO cohort and D&S group underpowered. Economic evaluation limited by incomplete costs data.

**Conclusions**

The study provides first evidence on the implementation of SATs. There is some evidence of benefit for this model of care. Service characteristics that may affect outcomes, costs and cost-effectiveness were identified. Finding suggest extended psychoeducation post-diagnosis is a critical element of SAT provision.

**Future work**

We recommend:

* comparative evaluation of SATs vs diagnostic-only provision
* evaluation of models of providing consultation/supervision and low-intensity support.

**Funding**

This project was funded by the National Institute for Health Research (NIHR) Health Services and Delivery Programme and will be published in full in XXX Journal; Vol. XX, No. XX.

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List of Abbreviations

AMH adult mental health services

AS autism

Assist psy assistant psychologist

BE subscale ‘Belonging’ subscale of Interpersonal Support Evaluation List

CCG clinical commissioning group

CI confidence interval

CMHT community mental health team

D&S Diagnosis and Support

df degrees of freedom

DO Diagnosis Only

EQ-5D-5L EuroQol-5 Dimensions, five level version

GDG Guidance Development Group

GHQ-12 12 item General Health Questionnaire

GP general practitioner

IAPT Improving Access to Psychological Therapies

ISEL Interpersonal Support Evaluation List (ISEL)

LD learning disabilities

MH mental health

MHP mental health problem(s)

NICE National Institute for Health and Care Excellence

OT occupational therapist

QALY Quality adjusted life year

SaLT speech and language therapist

SAT Specialist Autism Team

SD standard deviation

SO Support Only

SSC study steering committee

WHOQOL-BREF World Health Organisation quality of life assessment, abbreviated version

Plain English Summary

Autistic adults without learning disabilities struggle to access diagnostic services and find mainstream services do not provide support in ways they find helpful. In the past decade, some places in England have set up autism-specialist, multi-disciplinary services to address these problems. National clinical guidance describes these as Specialist Autism Teams. This study was the first to evaluate such services. We found not many places in England have a Specialist Autism Team, and their funding varies greatly. Staff in these services report a growing demand. They would like more funding so they can spend more time helping mainstream services to care for autistic adults, and so they can offer on-going support such as drop-in services. People using Specialist Autism Teams have a wide range of needs; some people’s needs are more severe. We found that Specialist Autism Teams work to address the different concerns in people’s lives. We also found evidence of measurable benefit for some people. Particular service characteristics, such as a wide range of skills and a holistic approach, appear to support positive impacts and are highly valued by service users. However, achieving some of these benefits may lead to higher costs, and so these approaches may not always be considered sufficiently worthwhile. We also compared people diagnosed by a Specialist Autism Teams with those receiving a diagnostic assessment but no post-diagnosis support. The two groups differed in how they felt about their diagnosis. This seems to be because Specialist Autism Teams provide extended support to help people understand, accept and see the positive sides of their diagnosis. This makes people feel more able to manage everyday life and, for some, address mental health or other concerns. The findings from this study will be valuable to people trying to develop services for autistic people without LD.

[297 words]

Scientific Summary

**Background**

Government strategy and NICE guidance recommend localities have an autism specialist community-based, multi-disciplinary team to develop, coordinate and deliver services to, and support mainstream services caring for, autistic adults. This recommendation arose from significant concerns about autistic adults’ outcomes, difficulties accessing autism-specialist diagnostic services, and mainstream services’ ambivalence about providing care and support to this group. NICE called this provision ‘Specialist Autism Teams’ (SATs). This was a novel type of service and had no *specific* evidence underpinning it. NICE recommended once SATs had been developed, they were subject to evaluation in order to generate an evidence base for subsequent service development.

**Objectives**

* describe the implementation and delivery of SATs;
* if distinct delivery models are identified, compare service models in terms of outcomes
* describe the outcomes of using SATs at 12 months after entry into the service
* investigate features of service organisation, delivery and practice, and individual characteristics, associated with user outcome
* estimate the costs of different delivery models and investigate cost-effectiveness
* describe service user experiences
* compare outcomes and experiences of individuals diagnosed and then supported by a SAT with a cohort of individuals receiving diagnostic assessment only.

**Methods**

***Stage 1***

Services in England that fulfilled NICE’s description of a SAT were identified through desk-based research, a national survey and semi-structured interviews with service leads.

***Stage 2***

Stage 2 comprised a mixed methods observational study of two cohorts (the SAT cohort and the ‘Diagnosis Only’ cohort), and a nested qualitative study of the views and experiences of senior SAT staff. Nine SATs, broadly representative of all SATs in England, acted as research sites.

The *SAT cohort* comprised SAT users. It was composed of those referred to the SAT already diagnosed with autism (*‘Support Only’ (SO group)*) and those referred for diagnostic assessment and on-going support (‘*Diagnosis and Support’ (D&S group)*. Three sites also provided a regional diagnostic assessment service for individuals living outside its CCG/LA boundaries; this provision does not include any post-diagnosis care. The ‘*Diagnosis Only’ (DO) cohort* was recruited from these services.

Recruitment took place at the time of their first full assessment appointment (T0). Quality of life and mental health, indicators related to managing everyday life, access to autism-specific networks, and service/resource were assessed at T0, and at 3 (T1), 6 (T2) and 12 (T3) months via standardised measures and questions designed specifically designed for the study. Those recruited early to the study were also followed up at 18 (T4) and 24 (T5) months.

Over four hundred individuals (n=424) were recruited; 114 subsequently became ineligible because they were not diagnosed with autism. Of those remaining, 260 (83.9%) were retained at T3 (SAT cohort=208 (D&S group=133; SO group=75); DO cohort=52). In-depth, semi-structured interviews with thirty-eight individuals purposively sampled from the two cohorts were carried out, plus nine interviews with family members. A nested qualitative study (using focus groups methodology) investigated senior SAT staff’s experiences. Data on service costs were also collected.

**Results**

***Stage 1***

Eighteen localities were identified as having a service that aligned to NICE’s specification of a Specialist Autism Team (SAT). This suggests that individuals living in less than a sixth (25/152, 16%) of local authorities in England have access to a SAT. All served autistic adults without learning disabilities (LD). Many reported the decision to focus on this population arose from the (total) lack of autism-specialist services for this group within their locality and significant concerns about their welfare and well-being. SATs differed with respect to structural, organisational and delivery characteristics (e.g. sole vs joint commissioned, use of one-to-one vs group work, diagnosis and on-going support functions delivered by same or different services). All sought to upskill and support practitioners in mainstream services who work with autistic adults without LD; however, they varied in the extent to which this was resourced or was regarded as a core way of working. A distinct typology of SAT service models did not emerge.

***Stage 2***

*Research with senior SAT practitioners*

Practitioners reported unanticipated rates of referral and difficulties achieving onward referrals, or discharging service users. Despite this, none had received a commensurate increase in resource. In response, all had restricted their service offer and/or changing delivery model which, they believed, had adversely affected responsiveness and quality of care. Despite this, all strongly supported the notion of SATs. Autism expertise, the multi-disciplinary approach and provision of psychoeducational and self-development interventions were highlighted are key features supporting positive outcomes.

There was clear evidence that service design, delivery and practice had, and was, evolving. This was driven partly by resource constraints and pressures on services. Alongside was the fact that SATs were a new model of service provision, set up in the relative absence of a body of clinical experience to draw on, and no evidence base on service design, delivery and intervention effectiveness.

Senior practitioners identified three factors key to ensuring sustainable improvements in support for autistic adults without LD.

* whilst retaining SATs function as provider of autism-specialist interventions and support, commissioning arrangement should allow SATs to place greater emphasis, and investment in, upskilling and supporting mainstream services to work with autistic adults;
* SATs’ approaches to care and support should seek to nurture self-management skills;
* drop-in services or other forms of low intensity, on-going support should be a core feature of SAT provision.

However, senior practitioners noted that wider resource constraints means other services may be unwilling, or not have the capacity, to change how they work with and use SATs.

*Service user views and experiences*

The majority of respondents reported using a SAT had a positive impact on their lives. Responses revealed the potential for SATs to have a positive impact across many life domains. However, for some (and across all groups), negative impacts or insufficient support rendered this positive impact partial. Where respondents reported the service used had little/no impact, or a negative impact, this was typically because they had not received any support/interventions in addition to the diagnostic/needs assessment.

Interviewees described a number of pathways into the service and a diversity in the severity and type of presenting needs. These included understanding, coming to terms with an accepting the diagnosis; needing support to develop strategies to better manage everyday life and situations; specific mental health and social needs; and emotional support needs.

*Change in outcomes: SAT cohort*

A statistically significant improvement in the proportion of study participants scoring below the GHQ-12 clinical threshold (sample mean) was observed in the D&S group but not the SO group. No statistically significant change in the study’s primary outcome (WHOQOL-BREF Psychological Domain) or other standardised outcome measures were observed in the D&S group. In the SO group, a statistically significant deterioration in social quality of life was observed

With respect to our categorical outcome indicators, in the D&S group, a statistically significant proportion of study participants reported no longer having severe or moderate problems managing the usual activities of daily living at T3. This was not observed in the SO group. No other statistically significant changes were observed for our categorical indicators of daytime occupation/activities.

In terms of access to autism-specific networks and support. For D&S group, whilst the change in the proportion in membership of an autism-specific organisation/community did not change, a statistically significant proportion who reported no contacts with such organisations at T0, reported at least one contact in the four weeks prior to T3 data collection. We found no statistically significant changes in membership or contact in the SO group.

*Individual and service characteristics associated with outcomes and costs*

Five characteristics of service delivery and practice were identified by service users as impacting the extent to which SATs had addressed their needs. These were: i) scope of, and access to, psychoeducation about autism; ii) overall model of care delivery; iii) availability of an alternative to group-delivered interventions; iv) timeliness of group-delivered interventions; and v) approach taken to managing referrals to other services.

We also analysed our quantitative outcomes data to investigate the association between individual and service characteristics on mental health outcomes. We found no evidence of an association between T3 mental health outcomes and diagnostic status at referral (i.e. D&S vs SO), functioning at referral, or contact with autism-specific communities. Costs over the 12-month follow-up period were *lower* for people already diagnosed with autism (SO group) compared to those not previously diagnosed (D&S), males, people living with parents, foster carers or guardians, those with better mental health at baseline, and those with lower costs in the period preceding the start of the study.

We also found no evidence of an association between T3 mental health outcomes and a number of service characteristics including: service structure (single vs multi-team), autism vs neurodevelopmental service, predominant mode of delivering post diagnosis psychoeducation (group vs 1:1). Findings from our economic evaluation, however, indicate that neurodevelopmental services are associated with higher costs than autism-specific services.

Moderate evidence of an association between at least one mental health outcome and age (favouring younger people) and gender (men fare better) was found. There was also strong evidence of an association (in a positive direction) between mental health outcomes at T3 and perceived social support and greater sufficiency of information. Furthermore, there was strong evidence that richer skill mix (that is, a greater number of professions working for the service) was associated with better mental health outcomes, but this was achieved at a higher cost, and so may not be considered cost-effective. In addition, weak evidence of an association was found between how the care plan was delivered (managed vs episodic) and mental health outcomes (favouring managed care), but again the more effective arrangement was also the most costly. Evidence regarding the association between access to drop-in provision and/or a named contact and outcomes was equivocal.

*Comparing outcomes for SAT users with those accessing a diagnostic assessment service*

The final component of the evaluation compared the experiences and outcomes of a cohort of individuals who had only accessed a diagnostic assessment service (DO cohort) with those diagnosed by a SAT (D&S group within the SAT cohort). Key differences between these groups are the intensity and duration of post-diagnosis psychoeducation and access to interventions and support to address identified health and social needs.

In terms of our qualitative data, almost all D&S group interviewees had accessed and spoke very highly of the psychoeducational support they had received in terms of its content and the influence and impacts it had on them. Those who attended group-delivered psychoeducation noted the value of hearing positive stories from peers and the opportunity to hear others’ experiences. A small number, however, had not accessed this intervention. This was usually because it was a group-delivered intervention and they had felt unable to attend, and the service did not offer 1:1 sessions as an alternative.

DO cohort interviewees described an insufficiency of psychoeducational input. For some, this, in itself, was a very difficult experience, with notions of abandonment emerging from their accounts. In addition, there was a consensus among these interviewees that provision of written information was of limited value and advice to use the internet to locate further information carried risks. None had pursued services to which they had been signposted.

We carried out our interviews six to nine months after diagnosis. At that time, all participants could identify a positive impact of being diagnosed with autism. However, the nature and extent of this varied considerably. An increased understanding of self and a reduced sense of isolation (brought about by simply knowing others had the same experience) were often described. However, some DO cohort interviewees reported long-standing or unresolved difficulties associated with the diagnosis. Almost all the DO cohort wanted further help understanding and coming to terms with the diagnosis. A few believed receiving the diagnosis had caused a deterioration in their mental health. In all instances, this was attributed to the lack of psychoeducation and other post-diagnostic support. Family members’ accounts broadly aligned with those of their relatives.

Turning to our quantitative evidence, there was some evidence of a potential difference in the impact of diagnosis on mental health between the DO cohort and D&S group, with a deterioration observed in the DO cohort in the immediate post-diagnosis period At the 12 months follow-up (T3), no statistically significant changes in outcomes were observed in the DO cohort. This contrasts with findings for the D&S group where some positive changes were observed. Our comparison of mental health outcomes at T3 of the DO cohort and D&S group found no significant difference; however, these analyses were underpowered.

**Conclusions**

Whilst still an unusual model of provision, services aligning to NICE’s recommendation for each locality to have SAT were identified in eighteen localities. These demonstrate that it is possible to implement this new model of service provision. Different structural, organisations and approaches to the delivery of care were observed. This study is the first to investigate such provision.

We found qualitative and some quantitative evidence of benefit, though this is limited and further evaluation is required. Moreover, some of the service arrangements associated with better outcomes were also associated with higher costs. Interpretation of the cost-effectiveness findings should be cautious given the top-down approach to costing SATs (especially given how widely those SATs varied in terms of service arrangements and scale) and associated data quality. In future research, micro-costing of SAT activities should be considered.

Post-diagnosis experiences of those diagnosed by a SAT were markedly better than diagnosed by a ‘diagnosis only’ service. The intensity and duration of post-diagnosis psychoeducation and availability of interventions to address identified health and social needs appear to play key roles in this difference. Our quantitative comparison of outcomes of these two groups was underpowered.

SAT practitioners reported referrals and caseloads increasing year on year. Resource to extend consultative support/supervision to mainstream services, and (further) develop provision of low intensity, on-going provision were identified as key ways to ensure sustainable, autism-specialist support was available for autistic adults without LD.

Key research recommendations:

* large scale comparative evaluation of SATs and services providing diagnostic assessment only;
* evaluation of approaches to providing a ‘consultation and supervision’ function to mainstream services;
* evaluation of post-diagnostic psychoeducation interventions;
* evaluation of low intensity, long-term autism-specialist support to autistic adults without LD.

**Funding details**

This project was funded by the National Institute for Health Research (NIHR) XXX programme and will be published in full in XXX Journal; Vol. XX, No. XX. See the NIHR Journals Library website for further project information.

**Word count**: 2396

# Background and study overview

## About autism

Autism is a spectrum of developmental conditions which change the way people communicate and experience the world around them.1 Diagnostic characteristics are pervasive difficulties since early childhood and include reciprocal social communication and restricted, repetitive interests and behaviours.2 Around half of autistic adults have learning disabilities (LD). Earlier diagnostic classifications imposed diagnostic labels according to the presence of learning disabilities or functional ability. For example, Asperger syndrome, high functioning autism. Whilst no longer used as diagnostic labels, some autistic people choose to continue to use them for themselves. Improved recognition and awareness of autism over the years has seen a substantial rise in estimated prevalence from 4/10,000 in the mid-1960s’s to the current estimate of ~1% of the adult population,3 with around half diagnosed as autistic without learning disabilities.

## The health and well-being of autistic adults

There is now a robust evidence base on the health and other outcomes of autistic adults. Autistic adults without LD experience have poorer outcomes than the general population in many areas of their lives4, 54, 54, 54, 54, 5,6 including: mental health, particularly anxiety and depression;7-12 social isolation 13-16; employment 17-20; and achieving independent living.21 More recent evidence also points to poorer physical health outcomes and increased risk of suicide.22, 23 Co-occurring mental health problem may be the primary source of impairment 24 and, in themselves, may directly impact other outcomes such as managing everyday life, work and independent living. Other studies have highlighted potential impacts on family members, particularly parents, with reports of unmet information and support needs and negative impacts on health outcomes. 25

Despite this evidence, a number of studies – conducted in different countries - report difficulties accessing diagnostic service and wide-ranging unmet needs.26, 27 A lack of autism-specialist adult services – particularly for autistic adults without LD – is a key reason for this. 28 Indeed, it has been estimated that not providing long-term, low intensity, holistic support for this population is likely to result in higher costs to individuals and society.29

## The notion of a Specialist Autism Team

In England, widespread concern about the health, social and economic outcomes of inadequately supporting autistic adults culminated in the cross-government Autism Act (2009) and Autism Strategy (2010). These placed responsibilities on the NHS and local authorities (LAs) to improve support and services for autistic adults. Both stipulated the need for autism-specific provision, including specialist community-based, multi-disciplinary teams to develop, coordinate and deliver services. NICE guidance published shortly after30 also recommended each locality had such a team, referring to them as Specialist Autism Teams (SATs), and further specifying their multi-disciplinary nature and roles, see Box 1.

The term used by NICE in its more recently published Guidance Implementation Resources (GIRs) 31, and by the government in their updated strategy for autism (Think Autism)32, is ‘multi-agency local autism team’. Overall, the proposed functions, or roles, were generally unchanged. However, compared to the 2012 Guideline30, the 2014 GIRs appear to place additional emphasis on particular roles or functions, namely: ‘up-skilling’ professionals in other services; and the provision of autism-specific, preventive social inclusion and well-being interventions. These are interesting developments, reflecting a wider re-emphasis on supporting self-management and prevention. They also appear to signal a recognition that, for a population with an (unexpectedly high) prevalence, exclusively ‘specialist’ provision is not a sustainable model and an important part of the role of a specialist service should be in upskilling other professionals and services.

Box 1 NICE’s30 description of the Specialist Autism Team

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, pp15-14)

## The lack of evidence underpinning policy and practice

The Guideline Development Group (GDG) responsible for the NICE guideline on management of adults with ASC6 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….” (p144). Indeed, the group noted the evidence base was even more limited with respect to autistic adults without LD compared to autistic adults with LD and autistic children.

Thus, in terms of their recommendation for the development of Specialist Autism Teams, the GDG drew on the Common Mental Health Disorders Guideline33 and studies which had explored the views and experiences of autistic adults and carers, partners and other family members 6. As a result, whilst advocating the broad principles and role of Specialist Autism Teams, they could not advocate a particular structure, or model, of service delivery.

The dearth of evidence faced by the NICE GDG in 2012 remains a significant issue and barrier to evidence-informed care, management and service development, as well as policy development.28, 31, 34, 35 A number of reports identify the relative underinvestment of health and care services research concerning the care and support and autistic adults compared to other life-long conditions.35, 36 Others make the point that, historically, within autism research the attention and investment has been neuro-biology and cognitive research which has had little or no impact on the lives of autistic people.37

### The call to develop an evidence base on SATs

The Autism Act and NICE guidance’s recommendations that localities have a ‘Specialist Autism Team’ tasked commissioners and practitioners with developing a new type of provision in the absence of any robust evidence about what it should look like in terms of its organisational, service structure and delivery, and practice characteristics. The NICE GDG recognised this and one of its key research recommendations was that as SAT provision emerged and developed this should be evaluated, with particular attention paid to identifying service characteristics associated with positive outcomes, see Box 2. This study was developed specifically in response to this call for evidence. To our knowledge this remains the only study of this sort of provision for autistic adults without LD.31

Box 2: Extract from NICE clinical guideline 142

“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, there is little evidence to guide the establishment and development of these teams.

There is uncertainty about the precise nature of the population to be served (all people with autism or only those who have an IQ of 70 or above), the composition of the team, the extent of the team’s role (for example, diagnosis and assessment only, a primarily advisory role or a substantial care coordination role), the interventions provided by the team, and the team’s role and relationship with regard to non-statutory care providers. 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.” (p 42)

## Study aims

This was the first study of ‘Specialist Autism Team’ –type provision. Its overall aim an evidence base on this novel model of care and support for autistic adults which would be pertinent and valuable to commissioners, practitioners and the autism community and could support evidence-informed implementation of national policy, and service and practice development. Whilst specific to the English context, the dearth of provision for autistic adults mean the findings may be a useful resource more widely as other countries seek to improve services and support for autistic adults.28

The key research questions it sought to address were:

* What models of providing Specialist Autism Teams (SATs) currently exist?
* Is there a particular service model(s) that performs better in terms of achieving positive outcomes for its users?
* What characteristics of SATs are associated with positive outcomes?
* What is the ‘added value’ to individuals of the support and care functions of a SAT beyond the diagnostic assessment process?
* What is the service user experience, and does it differ between SATs?
* What are the costs of the different models of SATs, how are they being funded, and how do they compare in terms of costs and cost-effectiveness?

## Study design and structure

To address these questions, a two-stage study was conducted.

**Stage 1 (the mapping study)** identified services in England which fulfilled the NICE criteria of a Specialist Autism Team, described their service characteristics and investigated whether it was possible to create a typology of different SAT service models.

**Stage 2 (the evaluation study)** was a mixed-methods investigation of SATs which sought to:

* describe the implementation and delivery of SATs;
* describe the outcomes of using SATs at 12 months after entry into the service and, where possible, at 18 and 24 months after entry into the service;
* identify and explore features of service organisation, delivery and practice, and individual characteristics, which are associated with user outcomes
* estimate the costs of different models of SATs and investigate cost-effectiveness
* describe the experiences of using a SAT;
* conduct an initial comparison of outcomes for individuals diagnosed and then supported by a SAT with a cohort of individuals who received a diagnostic assessment only.

Figure 1 illustrates the overall design and flow of the study.

**Figure 1: overview of study**

**Stage 1:**

 All localities in England which Specialist Autism Team (SAT) provision identified. Detailed information collected on each Specialist Autism Team identified

**Stage 2:**

A mixed methods observational study of individuals using a Specialist Autism Team (SAT cohort) and those using a regional diagnostic assessment service (diagnosis only (DO) cohort).

[SAT cohort: cohort comprises those referred via diagnostic pathway (Diagnosis &Support (D&S) group) and those already diagnosed (Support Only (S) group)]

* Diagnosis only (DO) cohort: Individuals referred to a regional diagnostic assessment

A sample of SATs selected to represent key distinguishing service characteristics taken forward to Stage 2

Purposively selected sub-sample take part in semi-structured interviews. Interviewees asked to nominate family member to recruit to interview.

Senior SAT practitioners participate in a series of focus groups.

Outcomes and resource use data collection at baseline, 3, 6 & 12 months after first full assessment appointment. Those recruited early to the study complete 18- and 24- month follow-up questionnaires.

Data analysis and data synthesis

### Stage 1: the mapping study

Multiple data sources (survey of Autism Leads across England, searches of CCGs and LA websites, published reports) were used to identify services in England that, potentially, fulfilled the NICE guideline description of a SAT in terms of functions and staffing. All identified services were subject to a two-stage screening process with additional data collected direct from services potentially fulfilling the NICE criteria after the first stage of screening. Data on services identified as SATs were subject to structured content analytical techniques in order to describe them, identify service characteristics that distinguished them and tested whether they could be organised into a typology of SAT service models. Purposive sampling techniques were used to identify SATs to act as research sites for Stage 2. Stage 1 took place late 2014 and 2015.

### Stage 2: the evaluation of Specialist Autism Teams

Stage 2 comprised a mixed methods observational study of two cohorts (the SAT cohort and the ‘Diagnosis Only’ cohort), and a nested qualitative study of the views and experiences of senior members of SATs.

**The SAT cohort** comprised users of Specialist Autism Teams, recruited at the time of their first full assessment appointment. Individuals in this cohort included those referred to the SAT already diagnosed with autism (the ‘*Support Only’ (SO) group*) and those referred for diagnostic assessment and on-going support (the ‘*Diagnosis and Support’ (D&S) group*).

Three of the research sites also provided a regional or national diagnostic assessment service for individuals living outside its CCG/LA boundaries via block contracts with neighbouring CCGs or on a case-by-case basis. **The ‘Diagnosis Only’ (DO)** cohort comprised individuals who accessed these sites diagnostic assessment service via this pathway. Thus, these individuals did not receive any post-diagnosis support from the SAT.

SAT and DO cohorts were followed up for 12 months from the point of the first full assessment appointment (T0). Outcomes and resource use data was collected at three- (T1), six- (T2), and twelve months (T3) for the whole cohort. T3 was our primary outcome time point. For those recruited early to the study, and to provide initial data on longer-term outcomes, it was decided to collect outcomes data at 18 (T4) and 24 (T5) months.

A purposively selected sub-sample of service users from both cohorts were recruited to take part in a semi-structured, depth interview about their experiences as service users, perceived outcomes and views on factors (service and individual level characteristics) which impacted on outcomes. Where the interviewee gave permission, a family member (e.g. parent, partner) nominated by the interviewee, was also invited to take part in an interview.

The nested qualitative study of senior SAT practitioners used individual interviews and focus group discussions to collect data on their views and experiences of setting up, managing and delivering a SAT, factors affecting outcomes, and ensuring sustainable developments and improvements in the care and support for autistic adults without LD.

Finally, for the economic evaluation element, SAT service leads were asked to provide relevant financial information.

#### Study delivery

Stage 2 recruitment and data collection took place between February 2016 to November 2018 with all study participants followed up to at least the 12-month follow-up time-point.

We encountered two obstacles to delivering the study. First, recruitment of research sites to the study, originally scheduled to take 4 months, took over a year. Reasons for this included: i) needing to bring additional sites on board to replace a large research site which withdrew well into study set-up due capacity and commissioning issues; ii) two sites having to pause study set-up due to re-commissioning processes; and iii) in some sites, limitations to the local R&D support available and/or a lack of autism expertise among clinical studies officers. Second, resource limitations meant the majority of sites could not collect or provide data on service-level outcomes (e.g. intervention take-up and retention) for Stage 2 of the study.

On a separate note, a proposed element of Stage 2 (i.e. seeking views on support, training and advice from services/staff who refer to the service and/or care for adults with autism in residential and community settings) was not pursued. This was for a number of reasons. SATs were only providing services to autistic adults without LD, almost all of whom live independently. The two research sites which had most integrated a formalised consultation offer within their provision withdrew from the study prematurely due to capacity (and a third site also operating in this way failed to open), thus accessing referrers/services with the experience of using the SAT for more than one case was significantly affected. In addition, the majority of referrals were via the diagnostic pathway or self-referral.

## Ethics considerations

Stage 1 (the mapping study) was defined as a service audit by the Health Research Authority (HRA) and did not require ethics approval. The HRA’s North West - Greater Manchester West Research Ethics Committee (REC) reviewed and approved Stage 2 (REC reference 15/NW/0708) and all substantial amendments.

## Public and service user involvement

When developing the funding application, we surveyed members of the National Autistic Society (NAS) to ascertain their interest and support for the project and their views on the key questions the research should address. Strong support for the study was expressed, this appeared to be driven by experiences of high levels of unmet need and the lack of autism-specialist services.

A Project Advisory Group (PAG), comprising autistic adults without LD, was appointed. PAG members were recruited through an advertisement placed on the National Autistic Society’s website that provided details of the application process, including hyperlinks to an information sheet (explaining the project and its objectives and what being on the PAG would involve) and short application form. The application form collected information that allowed us to ensure a range of experiences and characteristics were represented on the PAG (e.g. age, age at diagnosis, experience of using any autism-specific services, geographical location). Over 70 individuals applied. Applications were reviewed by the research team, and fourteen individuals invited to an afternoon ‘Project Advisory Group Recruitment Event’ held at the Head Office of the National Autistic Society. The purpose of this event was for applicants to meet the research team and experience some of the tasks and activities they might be expected to do as a member of the PAG (e.g. reviewing information sheets, small group tasks and discussions). It also provided the research team with the opportunity to observe the group working together. Eleven attended the event and, at the end of the event, all indicated they were willing be on the PAG.

We used face-to-face meetings to consult with the PAG. These were held in a central London at a venue routinely used by NAS and previously checked as being suitable for use by autistic adults. Those unable to attend meetings had the opportunity to share comments and views via a telephone call with a member of the research team or via email. In between meetings, we consulted with the group via a closed Facebook group. This was something that the majority asked to be created in preference to using email for communication. We also provided project updates via Facebook.

All elements of the project were discussed with the group, with particular attention paid to those elements where autistic adults without LD were directly involved as research participants. Examples of the sorts of issues we brought to the group include:

* content and layout of all Stage 2 recruitment materials,
* the wording of questions for the demographic and resource use questionnaires used for the outcomes evaluation,
* formatting and layout of the outcomes evaluation questionnaire,
* the reminders process when questionnaires are not returned,
* content, and ordering, of the topic guide for the user interviews (process evaluation),
* tools to use to facilitate interviews,
* issues to consider when recruiting to and setting up interviews for the process evaluation (reported in Appendix 6),
* adjustments required to interview technique,
* minimising anxiety associated with anticipating and during interviews.

In addition, individual members of the PAG met with the member of the research team who conducted the service user interviews. These meetings were both used to review draft topic guides and as a training experience for the researcher with respect to interacting with and interviewing autistic adults without LD. We cannot emphasise enough the contribution the PAG made to this project.

# Stage 1: identifying and describing ‘specialist autism team’ services

## Introduction

Stage 1 was a necessarily preliminary to the evaluation stage of the project. It identified and described services across England that fulfilled the NICE’s30 definition of a ‘Specialist Autism Team’ (SAT) (see Box 1, *Chapter 1*), thus allowing us to identify our research sites. It also generated important standalone evidence regarding the way, and extent to which, localities are implementing SAT provision.

The key objectives were:

* to identify SATs currently operating in England;
* to describe their characteristics (structure, delivery, ways of working) and examine the differences and similarities between them;
* to test whether service characteristics cluster together in such a way that a typology of SAT service models can be recognised.

## Methods

### Identification of services potentially fulfilling SAT criteria

An overview of the process by which SATs were identified is set out in Figure 1. Data collection instruments are available (Supplementary Material 1).

A survey of Autism Leads across England, web searches and reviews of documentary evidence identified services that, potentially, fulfilled the NICE description of a SAT in terms of functions and staffing. Information gathered on identified services (n=96) was independently scrutinised by at least two members of the research team. It soon became apparent that the predominant population served by potential SATs were autisitic adults without learning disabilities (LD). In response, one of the functions of SATs set out in the NICE guidance - “care and interventions for adults with autism living in specialist residential accommodation” - was not used as an inclusion criterion. Where insufficient information had been identified to allow a screening decision, services were taken forward to next stage of data collection. Twenty-eight services were taken through to this stage. Main reasons why services were lost at this screening stage were: i) diagnostic assessment service only, or ii) social care provision with no integrated pathway to/from a diagnostic assessment service.

Structured telephone interviews with service leads of ‘potential SATs’ (n=28) gathered further data. These were conducted between late 2014 through to mid-2015. Interviews, lasting 50-75 minutes, were audio-recorded and a detailed summary subsequently generated. Topics covered included: commissioning and funding arrangements, population served and eligibility criteria, structure of service, service/team composition, the diagnostic assessment process, approach to meeting presenting health, social care and other needs (e.g. deliver interventions, refer on and/or ‘up-skill’ other services); the wider service context (local availability of other specialist ASC provision, including third sector). Interviewees were asked to supply any relevant publicly available documentary evidence (e.g. annual reports/audits, service commissioning briefs, invitations to tender for services) not already collected. Where interviews were not achieved (n=6/28), further extensive efforts were made to gather publicly available documentary evidence.

Using the data gathered, a detailed ‘Service Description’ of each potential SAT was created and organised under the following high level headings: service history and overview; staffing, skill-mix and location; structure of the service and commissioning and funding arrangements; eligibility criteria and referral; services/interventions offered; ways of working; the care pathway; discharge and caseload.

Figure 2 Process of identifying Specialist Autism Teams

**Potential SATs identified through:**

* Survey of English Local Authority Autism Leads (47% response rate)
* Review of submissions to DoH 2013 Autism Act Self-Assessment Exercise
* Targeted searches of all English NHS mental health trust & Local Authority websites
* Review of other relevant publicly available text-based/documentary evidence

**Telephone interviews with service leads and further collection of documentary evidence:**

* *either* intial screen suggests service fulfills SAT criteria
* *or* insufficient information to complete initial screen

Initial screening  
(n =96)

Service excluded  
(n =68)

Initial analysis leads to the following function not being included within screening criteria: “SAT provides care and interventions for adults with autism living in specialist residential accommodation”.  
(n = )

Service does not fulfill SAT criteria  
(n = 10)

Second wave of screening   
(n = 28)

SATs identified   
(n = 18)

Further adjustments to screening criteria:

* minor deviations from skill mix does not preclude classification as a SAT;
* minimal levels of ‘support to families/partners and carers’ acceptable.

Before the final screen and informed by an initial analysis of the data, further adjustments to the inclusion criteria were made. First, minor deviations in skill mix from the NICE guidance were not used as an exclusion criterion. Second, any degree of intensity of ‘support to families/partners and carers’ was acceptable.

‘Service Descriptions’ were independently scrutinised by at least two members of the research team. Where necessary, follow-up telephone calls/emails with services gathered additional information. Final decisions regarding the classification of a service (or configuration of services) as a Specialist Autism Team, or not, were made in the context of a review of evidence and discussion involving two or more members of the research team.

### Data analysis

We had proposed using cluster analysis to analyse the data and support the generation of a typology of models of service delivery. However, a first look at the data made it apparent that this was neither feasible, nor indeed appropriate. First, there were just 18 SATs in our sample. Second, it was clear that these were complex and highly idiosyncratic services and there were no patterns in the co-occurrence of certain features or characteristics. Third, and related to the previous point, no relevant existing evidence was available which could inform selecting certain service characteristics/organisational features to prioritise in the development of a typology.

Service Descriptions were therefore subject to structured content analysis.38 Qualitative data were interrogated for descriptive evidence on service characteristics and explanations given for service characteristics or ways of working etc. Data were also extracted into excel spreadsheets to facilitate comparison between SATs and the identification of any consistent clustering of service characteristics or features. Analytical writing, with iterations shared and commented by all members of the research team, supported data analysis and conclusion drawing. We also carried out a brief descriptive analysis of all relevant quantitative and qualitative data collected to generate high-level information about autism-specialist provision in localities without a SAT.

## Results

Services identified as SATs varied according to a number of service characteristics. There were no consistent patterns in the way certain characteristics co-occurred and, as a result, it was not possible to develop a typology of SAT service models into which services could be allocated.

### Number of SATs identified and their broad characteristics

Eighteen localities in England were identified as having a Specialist Autism Team (based on the revised inclusion criteria reported in the Methods section above).

A number of factors influenced both the original ‘design’ of services and changes to service features/characteristics over time. External influencers were the funding available, service specifications set out in commissioning briefs and the nature and extent of multi-agency working. These were, to some extent, inter-dependent. Internal influences were personal clinical opinion and cumulative clinical experience acquired through running a SAT.

The majority of SATs came into existence from 2009, with just two existing prior to that date (Figure 3). For those more recently established, the Autism Act, Autism Strategy and NICE guidance (2012) were identified as providing the impetus or justification for the development of the SAT.

Figure 3 Number of SATs in existence by year (missing data = 2)

### The loss of SATs

A very number small of services were identified which, previously, would have been regarded as fulfilling the criteria for a Specialist Autism Team. Due to reduction in NHS funding, and/or loss of Local Authority involvement, services had constricted to being a diagnostic service.

### Population served

Entry into the service was commonly via a diagnostic assessment. The majority of SATs (n=16/18) also accepted referrals of adults without LD already diagnosed with autism. The proportion of ‘already diagnosed’ referrals within these services varied from between <10% and to around half. Just a quarter of SATs accepted self-referrals. All SATs operated an eligibility criteria of IQ>70. The explanation for this selective approach was a perceived gap in support for autistic adults without learning disability (LD) and a belief that there were significant differences in the types of provision and expertise needed for autistic adults with LD compared to those without LD.

### Organisational features

#### Autism-specific vs neurodisability service

The majority of SATs were autism-specific services (n=15), but three were based within a wider neurodisability service.

#### Organisational structure and funding arrangements

A number of different organisational structures and funding arrangements were identified. Within each, different commissioning and funding arrangements were observed.

The majority of SATs were a single service (n=12), typically based in the local community mental health trust. A number of different commissioning and funding models were reported:

* CCG sole commissioner with SAT fully funded from health budget.
* CCG sole commissioner, with Local Authority-seconded social worker post.
* CCG lead commissioner in joint health/social care commissioning arrangement; SAT mainly funded by health and LA contributing a relatively small proportion of funding for a social work post.
* Local Authority lead commissioner (as per role of Autism Lead for locality) in joint health/social care commissioning arrangement; approximately equal financial contributions from health and LA.

Where the CCG had geographical boundaries covering more than one Local Authority, financial contributions and involvement by Local Authorities varied.

Three SATs comprised two services jointly delivering SAT provision to a locality. Diagnostic assessment was provided by an NHS service and support with social/everyday living support needs provided by the LA (adult social care teams) and, in one locality, in partnership with a third sector provider. Two types of commissioning arrangement were observed. First, the SAT was jointly commissioned (LA as lead commissioner) and approximately equal financial contributions coming from health and LA. Second, the two services were separately commissioned by the CCG and LA but had established joint working practices.

Finally, a ‘hub and spoke model’was observed. Here three localities had commissioned a neighbouring, well-established (single service) SAT to deliver diagnostic assessment, mental health intervention and advice services. Different commissioning arrangements (CCG sole commissioner vs CCG lead commissioner with Local Authority involvement) meant there were differences between localities in terms of Local Authority social work/social care involvement. In two localities these staff were seconded into the service, in the other a joint working arrangement was in place.

### Staffing and skill mix

The size of the team (in terms of whole time equivalents (w.t.e.)) did not necessarily reflect the size of a locality’s population. Constraints in funding were reported. The NICE guidance recommended a multi-disciplinary team, with a range of professions represented. All SATs were multi-disciplinary but considerable variation in approaches to staffing observed.

Clinical psychology was the only profession represented in all SATs, with diagnostic assessment the dominant aspect of their role. Within each SAT, the proportion of staffing resource assigned to clinical psychology ranged from under 15% to 50%. Differences in the time requirements of diagnostic assessment protocols and whether the SAT delivered specific mental health interventions, rather than referring onto another service, appeared to determine this. Typically, if psychiatry featured in the staff team, it represented a small proportion of staffing resource. The exception was one service where the diagnostic assessment was led by psychiatry and not clinical psychology.

Around two thirds of SATs had a (mental health or social care) social work post. Many also had generic posts where a set of competencies and autism expertise, rather than a particular professional qualification, was required. Speech and language therapy (SaLT), social worker, mental health nurses and/or occupational therapists (OT) were occupying these posts. The whole time equivalent (w.t.e.) of total staffing resource allocated to generic posts ranged between 25% and 35%. Specific SaLT and OT posts were unusual, though in some SATs had relatively high whole-time equivalents.

Around two thirds of SATs also employed staff who did not hold a professional qualification. These were typically assistant psychology posts, but other ‘support’ posts were used. The roles they assumed included initial/screening assessments, supporting diagnostic assessments, co-facilitating group-delivered interventions. Support workers were more likely to be involved in meeting social/social care needs, such as involvement in running ‘drop-in’ sessions/support groups and providing individuals with community-based ‘low intensity’ support. A few SATs also employed ‘employment support workers’. The proportion of staff resource assigned to ‘support worker’ posts ranged between 20% and 50%.

### The diagnostic assessment

SATs differed in their diagnostic assessment protocols and each was unique. Protocols varied in terms of:

* use of published diagnostic tools and/or clinical interview protocols (e.g. Diagnostic Interview for Social and Communication Disorders (DISCO))
* approaches involving informants for the developmental history;
* number of sessions (1-~4);
* the professionals involved (1-3);
* the decision-making process;
* the process by which the outcome of the assessment is shared with the client.

There was a wide variation in reported rates of diagnosis between SATs, ranging from less than 50% to over 80%. SAT professionals believed this variation could be attributed to a number of factors including: referrals to longer established services may be ‘harder’ to diagnose (that is, present more subtly), between clinician differences, and differences in diagnostic assessment protocols.

### Psycho-educational support regarding diagnosis

All SATS offered a psychoeducation intervention after diagnosis. As an approach, such interventions integrate psychotherapeutic and educational elements. Their objective is to develop understanding, and acceptance, of autism, address information needs and support the development of adaptive strategies to manage everyday life. Content of psychoeducation interventions was broadly similar across SATs. Some SATS used a multi-session, group-delivered intervention, others two or more individually delivered sessions; a few offered flexibility regarding mode of delivery based on the individual’s needs.

### Needs assessment and ‘care planning’

All SATs conducted a comprehensive needs assessment (covering mental health, social care, employment, housing and sensory needs). This took place either within the diagnostic assessment process or when ‘already diagnosed’ referrals entered the service. This resulted in a ‘care plan’ that incorporated the ‘offer’ from the SAT in terms of interventions and support, and any planned onward referrals or signposting. Services varied in the extent to which the care plan was co-produced with the service user.

### Types of care provided by SATs

The interventions being delivered by SATs can be organised in terms of two ‘levels’ of care, both of which were included in the care plan:

* Supporting self-management: that is, interventions that increase knowledge and understanding of the condition, improve or develop coping/problem-solving skills and self-efficacy, and develop informal support networks.
* Managing or addressing specific mental health and/or social needs where the specialist nature or severity of needs and/or individual’s capacity to self-manage mean professional support/intervention is required.

Most SATs did not case manage forensic cases or individuals with significant, or ‘high risk’, mental illnesses. If involved they typically assumed an advisory/consultancy role.

### Supporting self-management

A range of interventions to support self-management were reported, see Table 1. Information provision and psychoeducation were provided by all SATs, and almost all offered informal support groups. Provision of other self-management interventions was idiosyncratic.

SATs differed according to the priority given to offering interventions which supported self-management. Commissioning arrangements, clinical opinion and/or availability of autism-specific voluntary sector groups/services in their locality accounted for this. A small number of SATs were distinctive in the relative high priority and investment given to this aspect of their service. Others reported they had plans to expand this aspect of their work. Whilst psychoeducation was delivered soon after diagnosis, other self-management interventions were not confined to a specific time-point in the care pathway. Practitioner judgement (particularly in terms of clients’ readiness) and, in the case of rolling programmes of group-delivered interventions, the availability of an intervention influenced when an individual might access such interventions. In some SATs they were explicitly used as a way of ‘stepping down’ care.

Table 1 Types of self-management interventions offered & ‘prevalence’ across SATs

|  |  |  |
| --- | --- | --- |
| INTERVENTION | NOTES / FURTHER INFORMATION | ‘PREVALENCE’\* |
| **Supporting knowledge and understanding of autism** | | |
| Psychoeducation intervention | Typically manualised, group-delivered interventions. | Universal |
| Written information. | One service also provided DVDs. | Universal |
| One-off seminars/workshops | Programme of topic areas covered. | Unusual |
| **Facilitating connections with peers and wider autism (or other) community** | | |
| Sign-post to third sector / user led autism groups | Verbal recommendations, provision of written information. Includes local community-based, virtual & national groups. | Universal |
| Informal support group | Regular, informal gatherings, often held in a public venue (e.g. local café). ‘Hosted’ by SAT staff. (One SAT occasionally introduced social outings; another organised a walking group.) | Common |
| ‘Drop-in’ service \*\* | Regular (weekly, bi- or monthly); comprising advice/ information provision, opportunity for informal contact with staff & other autistic people. May offer 1:1 appointments. Social activities (eg. social/interest groups) may also take place. | Less common |
| Support peer-led social/interest groups | SAT supports initial set up (eg. introducing potential members) and/or maintenance (venue, admin. support) of a peer-led interest /activity group (eg, badminton, music, theatre). | Unusual |
| Signpost to local mental health recovery group. | Achieved through information provision & advice nearing discharge. | Unusual |
| **Developing coping / problem-solving skills** | | |
| Psychoeducation intervention | Typically manualised, group-delivered interventions. | Universal |
| Training in problem solving/ coping skills | Often delivered as manualised group intervention.  One SAT also offered mindfulness classes. | Universal |
| **Information and advice about services / sources of support etc..** | | |
| Written information | For example, contact details; information leaflets about other services, benefit entitlements etc etc. |  |
| Informal support group | ~ see earlier notes in table ~ | Common |
| ‘Drop-in’ service \*\* | ~ see earlier notes in table ~ | Less common |
| Telephone advice service\*\* | If available staff cannot provide information, referred as ‘duty query’ to team meeting for discussion | Less common |
| **Facilitating inclusion / access to mainstream/community activities** | | |
| Support inclusion in ‘mainstream’ group /club | Staff actively support ‘introduction’ into existing mainstream  /community based groups/clubs (eg. local arts project, sports club). | Unusual |
| **\***Estimates of ‘prevalence’ classified as follows: Universal = observed in all SATs; Common = observed in > 2/3 SATs; Less common = observed in 1/3 - 2/3 of services; Unusual= observed in less one third of SATs.  **\*\*** Available to those in locality not currently on SAT caseload | | |

### Management of specific mental health and/or social needs

Where identified mental health, social care, employment, housing and sensory needs were sufficiently severe to require direct therapeutic intervention from a suitability qualified professional, there were substantial differences in the ways this was approached.

* One-to-one work: as well as direct work with the individual, this could also include contacts with other agencies/organisations (e.g. employer, landlord, Local Authority housing department) in advocacy role.
* Manualised, group-delivered interventions.
* ‘Supported referral’ to another service. By ‘supported referral’ we mean SAT staff support engagement with the service (e.g. attending assessments, supporting individual to complete application for benefits, co-working with the service during assessment and care planning). Services/agencies which SATs referred to included:
  + community mental health services for psychological well-being interventions;
  + local authorities for assessment for eligibility for statutory social care provision;
  + secondary adult mental health services (more severe mental health difficulties)
  + specialist employment support services (statutory and third sector);
  + welfare/benefits services

SATs differed in the types of need that were managed within the team and those which were routinely managed through a ‘supported referral’. This variously depended on commissioning arrangements, the perceived suitability of mainstream services, an individuals’ ability to engage or cope with a mainstream intervention, the skills/competencies of the team, and, in terms of accessing statutory assessment of social care need, the nature of the involvement of the LA in the SAT.

In some SATs, management of employment, welfare and/or housing needs only occurred when significant mental health needs were also present. Where this was not the case, signposting (e.g. providing information about sources of support, contact details for agencies etc..) was used.

For mental health needs, a small minority of SATs reported that it was highly unusual for them to undertake direct work. More common was a time-limited intervention (e.g. cognitive behaviour therapy for anxiety). Sometimes this preceded a referral to mainstream psychological well-being service. In one SAT mental health interventions were spot-purchased as the CCG only commissioned the diagnostic assessment. In terms of social needs (i.e. social care, employment, housing and welfare needs), commissioning arrangements and the skill mix of the team determined whether a SAT was directly involved or used a supported referral to address a need. Finally, SATs varied considerably in extent of resources directed to specialist sensory processing interventions; this reflected differences in clinical opinion regarding their effectiveness.

### Management and oversight of the care plan

There were two broad approaches to overseeing implementation of the care plan:

* managed care
* episodic involvement

In the majority of sites (n=14), a named member of the team held responsibility for coordinating and overseeing its implementation, we refer to this as ‘managed care’. In some SATs, this individual was also presented to the service user as their ‘named contact’ whilst in the service. In 12 SATs there was no pre-defined duration for an individual to be in the service but there was an aspiration to achieve discharge (or the client only using drop-in type provision) for the majority of clients within at least a year. Two SATs, however, all referrals were eligible to receive up to a maximum number of sessions (11-12). In one SAT, there was no time limit by which sessions had to be delivered. Both these SATs used ‘named contacts’ and one-to-one work was a core feature of both.

A second approach was ‘episodic involvement’. Here the individual is placed on waiting list(s) for each intervention identified in the care plan, receiving each intervention when it becomes available should they choose. Two SATs adopted this model. There is no review prior to discharge, rather the individual is regarded as no longer ‘in the service’ once last intervention has been delivered / offered.

### Type of discharge

The majority of SATs operated closed discharge. Two used an open discharge system by which individuals could re-refer themselves to the service within the first 12 months of discharge. A further two used stepped discharge, offering monthly contact from the service for the first 6 months post-discharge.

### Changes in delivery models and practice

Many, and particularly the longer established, SATs reported ways in which their service had changed or evolved. These were driven by one of more of the following factors:

* unprecedented levels demand for the service caused by unanticipated numbers of referrals and/or high levels of unmet need;
* changes in commissioning arrangements;
* reductions in funding.
* observing existing practices (e.g. open-ended involvement) were creating a dependency on the service;
* cumulative clinical experience of working with adults with autism;

Changes implemented included introducing triaging of referrals in terms of level of need; shifting from individual to group-delivered interventions; the introduction of/or increased investment in preventive and low-intensity support in terms of social inclusion and self-management.

### Advice and training to mainstream services and professionals

One of the functions of SATs stipulated in government strategy and clinical guidance is to up-skill other professionals and services in their locality. All SATs were delivering on this though the resource and priority allocated to this varied according to whether such activities were included in service specification and staff views on the suitability of mainstream services/interventions for autistic adults.

Some delivery models were fundamentally based on up-skilling and co-working with other services to deliver care and support to autistic adults. Here clinical leads believed this was the only sustainable way to meet demand for autism-specialist provision. Aside from this, SATs reported upskilling a wide range of professionals/services including mental health LD teams; adult social care MH and LD teams; GPs; police, prison service; employers and local industry. Table 2 summarises the types of up-skilling work that SATs undertook.

Table 2 Up-skilling activities undertaken by SATs

|  |
| --- |
| * Design and/or delivering of training to staff working in services that interact with/support adults with autism. |
| * Routinely provide other agencies/professionals opportunities for consultation with team member/whole team regarding management of a particular case or more strategic supervision / advice. Most SATs provided this in a responsive way, one offered bookable, 30 minute consultation slots with the whole team (two available each week). |
| * Supporting mainstream services to deliver interventions (e.g. statutory social care assessments, employment support, mental health therapies), or co-delivering intervention with mainstream staff. |
| * Co-creation of autism-suitable interventions/adaptation of generic interventions delivered by mainstream services (e.g. well-being interventions delivered by primary care/community mental health teams). |

### Access to the SAT by the wider community of autistic adults

In order to make themselves available to the wider population of autistic adults without LD living in their locality for low-level support and advice, a small number of SATs offered an open drop-in service. However, service leads reported it was highly unusual for someone not previously known to them to attend or, indeed, had never occurred. One SAT ran a programme of open workshops/seminar on various topics related to autism.

### Support to family members and supporters of autistic adults

Supporting family members is the final identified function of SATs. This aspect of provision was not prioritised and SATs undertook limited or no direct work in this area. Where it was provided, the types of support offered included:

* provision of written information;
* responding to simple requests for advice (raised at ‘drop-in’ or via phone call to service);
* leading informal ‘family member’ support group meetings;
* enabling and hosting a peer-led support group;
* extending an existing ‘drop-in’ services for use by family members;
* organising and hosting occasional social events for autistic adults and their families
* at diagnosis, offering the opportunity to attend an individually-delivered post-diagnosis psycho-educational intervention with individual being diagnosed.

Many SATs regarded local third sector groups and peer-led networks as an important source of support for family members. Where this was the case, SATs signposted and promoted them. There were instances of joint-work with these organisations (e.g.support groups,social events). Some SATS, however, reported such partnerships were not available in their locality.

### Autism specialist provision for adults with autism/no LD in localities without SATs

In localities that did not have a SAT service, one or both of the following types of provision were observed.

#### Diagnostic services

Autism diagnostic assessments were reported as being provided by one of the following arrangements:

* non-autism specialist local NHS service
* service level agreement with autism-specialist diagnostic assessment service in the region
* spot purchasing of autism-specialist diagnostic assessments.

Some of the autism-specialist diagnostic services we collected data during Stage 1 reported a frustration at the limitations placed on them, and the services and support they could provide, by funding/commissioning arrangements.

#### Services solely commissioned/provided by Local Authorities

As expected, we identified a large number of specialist services for autistic adults solely commissioned/ provided by Local Authorities. Sometimes these services were delivered ‘in-house’ or autism-specialist third sector providers had been commissioned. These included organisations specific to a locality and national organisations (e.g. National Autistic Society). They included both ‘autism without LD’ and ‘whole spectrum’ services. None of these services, on their own, fulfilled the criteria for a Specialist Autism Team. If an autism-specialist diagnostic/mental health service existed in their locality (which was unusual), there were no joint working arrangements.

## Summary

This mapping study has revealed whether, and how, localities in England have implemented the Autism Act and NICE’s recommendation for a Specialist Autism Team. We did not identify a single instance of the NICE ‘Specialist Autism Team’ model being *fully* implemented with respect all autistic adults. Rather, it has stimulated the development of new provision specifically for autistic adults without LD. Indeed, many services reported that decision to focus on this population arose from the recognition of a (total) lack of autism-specialist services for this group and significant concerns about their outcomes / well-being. Their situation was contrasted to autistic adults with LD who were perceived to be (relatively) well served by NHS and LA LD services.

Given the specific focus of SATs on autistic adults without LD, it is not surprising to find that the SATs identified dis not *wholly* align with the NICE guidance on Specialist Autism Teams. First, typically, whilst always *multi-disciplinary* and delivering multiple functions, they are not typically *multi-agency*. However, all reported systems or pathways that connected them to other agencies, particularly Local Authority social care and housing departments and autism-specialist third sector organisations. Second, except for individuals with complex mental health problems, their emphasis was on delivery of care and support, referring on to and supporting access to other services, rather than assuming a care coordination role. Finally, their work with carers/supporters was typically minimal. This might simply reflect prioritisation of work in within the context of constrained resources and/or may indicate lower levels of need among family members of autistic adults without LD compared to autistic adults with LD. Alternatively, it may reflect a lack of understanding or recognition of the support needs of this group.

An objective of Stage 1 was to discover if SATs can be classified according to a typology of service models based their structural and organisational characteristics and ways of working. Our work has revealed the *complexity* of SATs. This partly arises from the fact that the functions and roles of SATs are so wide ranging. Thus, there is potential for differences between SATs both in the emphasis given to the different roles/functions, *and*, within each role/function, differences in practices and ways of working. Furthermore, staffing of a service is often one of the dimensions used to define service model typologies.39 However, we found that, for some posts, generic competencies and an expertise in autism were more important than specific professional qualifications. Layered on top of these issues, *but not necessarily influencing*, are the more ‘straightforward’ organisational dimensions (such as commissioning arrangements and the organisational location of the service).

A consequence of this complexity, and the relatively small number of SATs currently operating, meant that a distinct typology meaningful across the *entire set* of roles/functions of a SAT was not identified. It is, however, very clear that there are a number of service-level characteristics (as well some higher-level structural/organisational characteristics) on which SATs differ.

In our study protocol, based on work carried out to support development of the funding application, the following service characteristics were identified as potentially distinguishing between SATs. These were:

* caseload: autism without LD vs all autism
* ‘virtual’ vs co-located teams
* professional composition
* extent of diagnostic assessment
* deliver interventions vs consultation/support to other services
* the wider service context (local availability of other specialist ASC provision, including third sector)
* the level and nature of partnership between health and social care.

Findings from this mapping work indicate that many of these characteristics did indeed serve to distinguish between SATs. The exceptions are that SAT provision is for autistic adults without LD only and diagnostic assessment is a consistently a core and substantive aspect of provision and, in a minority of SATs, the only pathways into the service.

The implications of these finding for Stage 2 of this project were that, in the absence of a typology of service models, the focus shifted from a comparison of service models to exploring the impact of service-level (and some individual) characteristics on outcomes, costs and cost-effectiveness. Indeed, this had always been a key research objective as set out in the protocol.

# The research sites

## Introduction

This chapter describes the services that acted as research sites for the evaluation study. We focus on reporting whether research sites represented service characteristics identified by the mapping study (see *Chapter 2*) which distinguished between services.

## Characteristics of the sites

### Socio-demographic and population characteristics

Sites varied in size of population served and geographical size. Most were localities representing a single Clinical Commissioning Group (CCG) and Local Authority (LA). They represented a range of deprivation and urban/rural characteristics, see Appendix 1 (Table 25).

### Organisational characteristics

Four sites were neurodevelopmental services, the remainder were autism-specific, see Table 3. Two (Sites D and H) were ‘multi-team’ services, with separate teams delivering the diagnostic assessment and on-going support functions; these teams were not co-located. One multi-service SAT (Site D) was commissioned entirely by the local CCG. In the other (Site H), the diagnostic assessment service was commissioned by the CCG and the on-going support service by the LA. Close joint-working arrangements ensured continuity of care between the services.

The different patterns of commissioning and funding identified in the mapping study (see *Chapter 2*) were represented in the research sites. Among the single service SATs, three of the seven had no LA involvement. In another (Site A), the LA contributed to the funding to the drop-in service. One (Site J), however, was jointly commissioned (with relatively equivalent levels of funding) by the LA and NHS. In two other sites (Sites F, IA), the CCG was lead commissioner, with the LA seconding social work posts. However, in Site F – with three LAs within its boundaries – LAs varied in whether they invested in the service.

Thus, the range of organisational characteristics observed across all SATs identified in the mapping study (see *Chapter* 2) were represented in the sites recruiting to the study.

Table 3 Organisational characteristics of the research sites

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Site ID** | Year established | Autism or ND service | Commiss’er | Local Authority (LA) funding / resource contribution | Single vs multi-team | Hold & coordinate complex cases? |
| A | 2003 | Autism only | CCG | Part-fund social inclusion hub (via Carers Grant)a | Single | No |
| B | 2014 | Autism only | CCG | None | Single | No |
| CAb | 2009 | ND | CCG | None | Single | No |
| Dc | 2009 | Diagnostic assessment service is ND | CCG | None | Multi | Yes |
| E | 2011 | ND | CCG | None | Single | Yes |
| F | 2012 | Autism | CCG | In some districts, part-time social work post seconded to serviced | Single | No |
| H(a & b)e | 2013 | Diagnostic asssessment service is ND | CCG: Ha  LA: Hb | Funds Hb | Multi | No |
| IAb | 2014 | ND | CCG lead | LA social work posts seconded to service | Single | No |
| J | 2014 | Autism | Joint, LA lead | Joint funded by LA & CCG | Single | No |
| a In the past, LA seconded part-time SW into service – withdrawn soon after recruitment opened.  b These sites also provide an ‘out of area’ diagnostic assessment service and recruited to the ‘Diagnostic Assessment Only’ cohort (Site IDs CB & IB respectively).  c Commissions Site E to deliver diagnostic assessment service.  d Other LAs within service boundaries have withdrawn from this arrangement  e Separate teams (Ha (diagnostic assessment, ASC-specialist mental health ), Hb (on-going support))  with formal joint working arrangements together provide SAT service in locality. | | | | | | |

### Service lead and skill mix

Seven research sites were clinical psychology led, the remaining two were nurse-led (Site CA) and psychiatry-led (Site J), see Appendix 1 (Table 26). The only profession represented across all sites was clinical psychology. In majority of services (n=7), four or more professional disciplines (e.g. psychiatry, clinical psychology, MH nursing, speech and language therapy, occupational therapy) or roles (e.g. autism clinical specialist, autism specialist support worker). The remaining two both had clinical psychology and autism clinical specialists/support workers, with the latter working across a range of needs. Sites varied in the relative resource allocated to staff with the same professional qualification. However, as reported in Chapter 2 (and also discussed in Chapter 5), care should be taken on placing any interpretation of this given that services reported, on occasion, prioritising autism expertise and a generic skill set over discipline-specific expertise. Overall, research sites represented the different patterns of staffing and skill mix observed in the mapping study (see Chapter 2).

### Eligibility and referral pathways

The research sites represented both open and closed referral processes observed in the mapping study (see Chapter 2). Four of the nine sites operated an open referral process, including self-referrals, see Table 4. The majority (n=6) accepted referrals of those already diagnosed. A further two accepted such referrals, but only for those on their complex care pathway. This represented a very small minority of their caseload. Just one service triaged referrals at the intake assessment stage, prioritising in terms of severity of mental health symptoms or social need.

Table 4 Eligibility and referral pathway characteristics of research sites

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Site ID** | Accept self-referral? | Services able to refer | Accept those already diagnosed? | Does service triage referrals? |
| A | Yes | Open | Yes | No |
| B | Yes | Open | Yes | No |
| CAa | No | Any statutory health / social care | Yes | Exceptionally |
| Db | No | Any statutory health / social care | No, except complex care pathway | No |
| E | No | Any statutory health / social care | No, except complex care pathway | No |
| F | No | GP | Yes | Yes |
| H(a & b)c | Yes | Open | Yes | No |
| IAa | No | Any statutory health care | Yes | No |
| J | Yes | Open | No | No |
| a These sites also provide an ‘out of area’ diagnostic assessment service and recruited to the ‘Diagnostic Assessment Only’ cohort (Site IDs CB & IB respectively).  b Commissions Site E to deliver diagnostic assessment service.  c Separate teams (Ha (diagnostic assessment, ASC-specialist mental health ), Hb (on-going support)) with formal joint working arrangements together provide SAT service in locality. | | | | |

### Diagnostic assessment processes

The majority of research sites were using a standardised diagnostic assessment tool, see Table 5. The number of sessions used to complete the diagnostic assessment process ranged from 1 to 4 or more. Rates of diagnosis ranged from 36% - 90%. Where the assessment was completed in a single session, this tended to be a half-day appointment. Practice varied in terms of number of staff involved and when service users learnt the outcome of the assessment. The majority of services conducted a single feedback appointment after which service users were offered a psychoeducational intervention. In one site (D) the mental health and social needs assessments were split between the two teams delivering the service. This range of approach to diagnostic assessment in the research sites was expected given findings from the mapping study indicated services were idiosyncratic in their approach and practice. Work soon to be completed by the University of Newcastle40 on diagnostic assessment practices in England provides further analysis of this issue.

Table 5 Diagnostic assessment process by research site

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Site ID** | Typical no. session | Standardised assessment  tool? | Staff involved | Told diagnosis at assessment appointment | How report of diagnostic (& needs) assessment & care plan) shared | Timing of feedback appt.(s) | Typical number of feedback appointments | Proportion diagnosed |
| A | 1 | DISCO | 1 clinician (clin psy,AS spec nurse, AS clin spec.)  Then consult team. | No | Posted to service user before feedback appointment. | Not specified | 1 | 60% |
| B | 1 | ADOS  ADIR | 1 clinician (clin psy,AS spec. nurse). Then consult team. | No | Posted to service user before feedback appointment | Not specified | 1 | 90% |
| CA | 1 | ADOS  ADIR | 2 members of team (clin psy, nurse consultant, SaLT | Yes. Unless need to consult with team. | At feedback appointment. | Specify 4 weeks | “User determined” | 53% |
| D | ~4 | *See Site E* | | | | | 3a | 61% |
| E | ~4 | ADOS | 2 members of team (including clin psy).  If necessary, consult team. | No. | At feedback appointment. | Not specified | 2-3 | 47% |
| F | 3 | No | 1 clinician (clin psy). Then consult team. | No. | Draft report sent to service user. | Not specified | 1 | 85% |
| H | ~4 | ADOS  DISCO (if complex) | 1 clinician (clin psy) | No | At feedback appointment. | Specify up to 4 weeks | 1 | 47% |
| IA | 1 | No | 1 clinician (clin psy, pscyh.), SaLT may also be involved | Yes. Unless need to consult with team. | Posted to service user before feedback appointment | Within weeks | 1 | 50% |
| J | 1 | No. Plan to introduce ADOS | 2 members of team, led by psychiatrist. Then consult team. | No | Posted to service user before feedback appointment | Within weeks | 1 | 36% |
| Feedback appointment with diagnostic assessment service attended by Site D staff. Two further with on-going support service (includes further needs assessment) | | | | | | | | |

### Delivery of the care plan: key features

A range of delivery and practice characteristics were represented in the research sites, see Table 6. The three approaches to the management and oversight of the care plan identified in the mapping study (see *Chapter 2*) and approaches to addressing specific presenting needs (direct work vs supported referral) were represented. The range of intensity of involvement with supported referrals reported by mapping study was not fully represented by the research sites. Unfortunately, the service which had most invested in supporting non-specialist services to deliver care and interventions had to withdrew from being a research site.

In terms of group-delivered interventions, each service had developed their own; none were published, manualised interventions. With respect to communication/social skills interventions, in some services this was led by a speech and language therapist, in others this was not the case.

The research sites also represented the three types of discharge observed in the mapping study (see *Chapter 2*), and the use, or not, of drop-in provision. Unfortunately the service where drop-in provision was (perhaps) most developed had to withdraw from acting as a research site.

Table 6 Key features of delivery of the care plan by research site

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Site ID** | Management and oversight of care plan | Dominant mode of delivering psychoeducation | Routinely do 1:1 work re MHPs | Management of presenting social care needs (daily living skills, Community Care Assessment) | Communication /  social skills interventions (1:1 and/or group) | Approach to employment support | Type of discharge | Drop-in type provision whilst in service? | Drop-in type provision after discharge? |
| A | Managed, no named contact | Group | Yes | Supported referral | No | Supported referral | Stepped | Yes | No |
| B | Managed, no named | Group | Yes | Supported referral | No | Supported referral | Stepped | No | No |
| CA | Managed & named contact | 1:1 | Yes | Supported referral | Yes, SaLT led | Supported referral | Open | No | No |
| Da | Managed & named contact | 1:1 | Yes | In house | Yes, not led by SaLT | Direct work | Open | Yes | No |
| E | Episodic | 1:1 | No | Supported referral | Yes, not led by SaLT | Supported referral | Closed | No | No |
| F | Episodic | Group | Yes | Supported referral | No | Direct work | Closed | No | No |
| H(a & b)b | Managed & named contact | Group | No | In house | Yes, not led by SaLT | Direct work | Open | Yes | Yes |
| IA | Managed, no named contact | Group | Yes | In house | Yes, SaLT led | Supported referral | Closed | No | No |
| J | Managed & named contact | 1:1 | Yes | In house | Yes, SaLT led | Direct work | Closed | Yes | No |
| a Commissions Site E to deliver diagnostic assessment service.  b Separate teams (Ha (diagnostic assessment, ASC-specialist mental health ), Hb (on-going support)) with formal joint working arrangements together provide SAT service in locality. | | | | | | | | | |

### Provision for carers

The research sites varied in provision for carers, see Appendix 1 (Table 27). Ranging from signposting to, in Site CA, receiving, where appropriate, care and support alongside their family member. Three services (Sites D, E and H) described their provision as being limited to a psychoeducational intervention post-diagnosis. Another service (IA) provided limited access to a more general support group type provision. A couple of services noted that take-up of carers support was higher among parents than other family members. All but one service (Site J) reported there were active local autism carers groups to which they routinely signposted. This sort of provision was not available in Site J’s locality. This range of provision for carers and, overall, its limited nature is representative of the wider findings from the mapping study (see *Chapter 2*).

### Training and consultancy

Training and consultancy was a core element of the range of services provided by the SATs acting as research sites. All but one site were commissioned to routinely deliver autism awareness training and/or more specialist training in their Trust and, often, to other statutory services, see Appendix 1 (Table 28). Less common, reported by just three sites, were autism awareness activities in the local community among the public. All sites reported providing advice to services/professionals in their locality on a case-by-case basis, though one site reported this was unusual. Such input was not restricted to NHS or Local Authority services. One site (Site F) in addition offered an ‘advisory clinic’ (two appointments available per week) whereby individual professionals or whole teams could consult with the SAT. Again, this was used by a range of statutory agencies. In addition to these services and activities, one site (Site C) had, developed e-learning packages for their Trust and Local Authority.

## Summary

This chapter reports the characteristics of the research sites. Overall it demonstrates that the range of service characteristics identified as serving to distinguish between SATs in England (see *Chapter 2*) were represented in our research sites. However, some elements of service delivery and practice were not fully represented, including the full range of drop-in provision and the more intensive approaches to ‘upskilling’ professionals working in mainstream services (e.g. GPs, community mental health teams and IAPTs). This was principally due to the withdrawal of a research site during study set-up.

# Leading and delivering a Specialist Autism Team

## Introduction

This chapter concerns senior practitioners’ views and experience of leading and delivering a Specialist Autism Team (SAT). The material reported in this chapter was collected during interviews with service leads during Stage 1 and a workshop for senior practitioners. (See Appendix 2 for methodological report). A unique identifier system is used in this and the following chapter to ensure anonymity of services but allow scrutiny of representativeness of quotes. We divide the chapter into three main sections:

* the challenges facing Specialist Autism Teams
* aspects of services working well
* ensuring sustainable improvements in support for autistic adults without LD.

## The challenges facing specialist autism teams

### Increasing numbers of referrals

A very significant concern for all services was volume of referrals. All reported a year on year in increase. In addition, all reported an increase in the proportion of referrals who had complex needs. Critically, none had received an equivalent increase in funding. Indeed, a minority had experienced a constriction in available resource (e.g. loss of funding for posts, post being frozen, withdrawal or reduction of Local Authority involvement).

*We’ve constantly historically doubled over [the four years existed]. …. And*

*pretty much the same amount of money. (SAT1)*

*…the number of referrals are constantly increasing. We thought seven years ago that we’d have a mass input and then it would slow down. Unfortunately it hasn’t, and we’ve got no more staff than we had to start with. (SAT2)*

As well as increasing rates of autism diagnoses in children, services believed there were three main reasons for this situation. First, mainstream/generic services could be unwilling to work with this population, even with supervision from a SAT. Second, other services were referring to the service as means of managing their own caseload. Third, the absence of any other non-LD, autism-specialist provision in the locality.

### Issues with service throughput

Services operating a more open-ended care pathway were, unsurprisingly, more likely to identify issues with service throughput. More generally, a reluctance of mainstream services (e.g. CMHT, IAPT) to accept referrals, and the absence, or loss, of low-level community support services such as third sector services, peer-led groups/networks and LA provision were identified as adversely affecting throughput.

*…the [third sector organisation] withdrew everything… virtually all their volunteering services and all that sorta stuff, which was a big loss… and unfortunately the cutbacks in terms of the voluntary sector and local authority and all of those sorts of thing (means) virtually all support has gone. (SAT2)*

Services acting as care coordinators for those with complex needs reported the additional difficulty of being unable to discharge these service users due to the complexity of their needs or the absence of another autism-specialist service on which to refer. This further compounded the issue of long waiting lists.

*We’re only supposed to care coordinate eight people. We’ve got eleven people at the moment and a lot waiting. …massive pressure of people coming through who are very, very complex, that do need specialist care coordination but we can’t do it. And it’s a real area of stress for us trying to find out where those people can go. It’s very difficult to ‘review and move’ on the people that we have got because their needs remain constant and they don’t get better… so it’s really difficult, that. (SAT4)*

### Increasingly constrained resources

Increasing numbers of referrals, and growing caseloads, within the context of unchanged levels of resource meant all services reported increases in wait times, both at referral to the service and delivery of the interventions set out in the care plan. Inadequate financial resources were attributed both to commissioners’ demands and within-Trust cost improvement programmes.

*They (commissioners) are putting a lot of pressure on us to change our practice and looking at really limiting what interventions we’re going to be able to do. (SAT3)*

All services had changed their service offer or aspects of practice to manage these pressures. Staff described the strain and sense of conflict experienced when they felt the quality of care, and service users’ outcomes, were being compromised.

*…we’re just getting bigger and bigger waiting lists. … and how do you deal with that? Do you sacrifice to some extent the quality of your assessment and try and just do it as best, you know, when your commissioners are just saying, “Well the NICE guidelines are only guidelines, the quality standards are just guidelines”. (SAT5)*

*Cos that’s what we’re talking about, trying to change our referral process, our assessment process and still maintain quality, because people aren’t giving us any more money. (SAT4)*

Concerns about negative impacts of changes in practice/provision on the quality of provision and user outcomes particularly centred on the diagnosis and assessment process (e.g. in clinic rather than at home, conducting the assessment in a single session), wait times for interventions once diagnosed, and the intensity of support that could be provided. Examples given here include increased used of group-delivered interventions, which may not suit all service users, and reducing intensity or duration of 1:1 work.

*There are some cases (undergoing diagnostic assessment) that we talk about an awful lot and deliberate about a lot. And people are different at home and different when they come to the office, different in, you know, different environments*.

*People do need time to process their diagnosis….but they shouldn’t be waiting months in-between getting the diagnosis and getting the intervention.*

*We [now only] offer eight (1:1) sessions. That’s only very recently – we did have a much more on-going approach but, cos obviously, the amount of referrals [mean] we’ve got to limit that… (SAT6)*

*We’re doing more groups now to try and free up some of our time to do more of the one to one stuff. Having clinics as opposed to going out and doing that kind of more bespoke stuff, even though it’s not preferable, that’s kind of helped us, managed to keep our heads above water. (SAT5)*

Resource constraints had also meant some services found that their community-based provision were delivered in less-than-adequate venues, an issue particularly for those with sensory sensitivities.

*...the financial squeeze means we’ve got no money to pay for anything, so you’re trying scrambling about trying to find some free rooms somewhere, and usually they’ll end up in some horrible old NHS community building which isn’t great. It’s that kind of practical thing.... And you know if you don’t get it right then it won’t work.*

*(SAT2)*

At the same time, services noted that constrained resources had specifically driven, or were driving, what was regarded as positive service innovation. Examples include introducing a weekly drop-in service for individuals on waiting lists for interventions, setting up a ‘supervision and consultation’ service to support mental health locality teams. We return to the issue of managing demand and ensuring sustainability in a later section (see *Ensuring sustainable improvements*) of this chapter.

### The impact of wider resource constraints across statutory services

Services also noted the impact of the wider issue of (increasingly) constrained resources across statutory services. They partly attributed the perceived reluctance of other services to accept referrals as part of a wider strategy by these services to manage demand.

*Everyone is under massive amounts of pressure with the resources they have. We see a pattern…. We try and refer to Adult Social Care, they come back to us because they don’t have a learning disability, or we try and signpost them to the Community Mental Health Team [and we get the response]..”no, they’ve autism, they’re not eligible. So we just keep finding these barriers for this client group.*

*Our clients do go to the commissioner for mental health to request funding [for specialist psychological interventions]. It’s very hit and miss as to whether they get it unfortunately. (SAT6)*

Alternatively, where referrals are accepted, long wait times were a strong possibility.

*…we do have a referral pathway for Community Care Assessments….if you’ve got two years to wait to get one. So it’s not, that’s not great. (SAT5)*

### The impact of the commissioning cycle

A minority of services described the impact of an annual or bi-annual commissioning cycle. It was regarded as affecting recruitment and a significant barrier to strategic planning. Delays in commissioning decisions had led to one service being commissioned on a month-to-month basis for a period.

*…cos of the commissioning recruitment’s been a massive problem, because we can’t offer people three to four week posts…no one has a job like that; and also, forward planning. (SAT8)*

## Aspects of services working well

The previous section has described the challenges faced by SATs and the (potential) threats to quality of care and service users’ experiences. Despite this, all senior practitioners readily identified features of their service that, they believed, were working well.

### Core service features

Those with very holistic multi-disciplinary teams consistently identified this as a very positive aspect of their service, including the contribution of all disciplines to the diagnostic and needs assessment process. Depth of autism expertise was another feature services highlighted as key to accurate diagnoses and needs assessments. Many services spoke very positively about specific group-delivered psychoeducational and skills development interventions.

### Specific features

Further specific examples of service provision regarded as working well identified by senior practitionersincluded:

* involving ex-service users in developing information resources, acting as peer mentors in psychoeducational interventions, volunteering at drop-in services, and running autism awareness/training programmes;
* commissioning a third sector provider of specialist employment support to deliver work/employment interventions;
* offering a drop-in service for those waiting to receive 1:1 sessions;
* implementing stepped discharge arrangements, here examples included: after formal discharge, service users being able to telephone into the service for a 6 month period; providing access to a ‘drop-in’ type service;
* in localities with strong user- or carer-led groups, collaborative working with these groups in to support access to some form of on-going support and autism-specific network.

### Motivated and committed staff team

Finally, a number of senior practitioners noted that, despite the challenges, staff were highly motivated and committed to the service. One service lead gave evidence of this in the way staff were prepared to assume additional roles to enable the service to function.

## Ensuring sustainable provision

From the outset of our interactions with SAT practitioners, there was a recurring theme of evolving delivery models and practice driven by both the wider (limited) resource context and cumulative clinical experience. Many services reported a degree of naivety when setting up their service in terms of how they would work and the level of demand for their service.

*When we first started we were really naïve. We thought we’ll be an all singing all dancing do everything for everybody service, and we’ve learnt very quickly that you can’t. (SAT2)*

When asked about future re-developments in the functions and balance of work carried out by Specialist Autism Teams required to ensure sustainable improvements in support for autistic adults without LD, four features of service design, delivery and practice by SATs were identified:

* greater emphasis on the ‘consultation and supervision’ function
* continued and greater resource and attention to supporting self-management and minimising dependency
* working, where possible, with local peer-led networks
* introducing/ increased resourcing of drop-in services and other low level support

Services differed in terms of the extent to which they addressed, or had changed their ways of working to reflect, these features. However, and importantly, for each, at least three services had extensive experience each of these aspects of service delivery, design and practice. The following sections report senior practitioners’ views about, and experiences of, these features, including potential barriers to implementation.

### Greater emphasis on ‘consultation & supervision’ function

Service leads believed a change of emphasis, or attention, to acting as autism consultants and offering supervision to mainstream services was one of the key solutions to ensuring adults with autism (without LD) accessed services in a timely way. This might involve specific joint working or supervision of a specific case, supporting services with adjustments to their services and interventions (e.g. IAPT, Community Care Assessments), and more general autism awareness and education across the workforce.

Whilst recognising that integrating a consultative function within their delivery model was key, a note of caution was sounded in terms of the potential risks it posed for inappropriate, and potentially harmful, care and mis-diagnosis.

*…. and you get people coming on a day’s training thinking they’re expert. That’s a danger, especially with diagnosis sometimes. [SAT9]*

For SATs to achieve a greater emphasis on consultative support to mainstream services, senior practitioners stressed that shifts in understanding and attitude both within SATs, among professionals in other services, and at a Trust level was required.

#### Changes required to shift to a ‘consultation and supervision’ approach

For SATs, senior practitioners noted that staff have to be prepared to work in this way, with the consequence of having less direct contact with service users. There also had to be an acceptance of working in this way may not rapidly result in efficiencies; it required significant ‘upstream’ investment of time.

*…[it is] necessary to conceptualise [it] as long-term goal. It’s gonna take five years, and then take another five years; it’s an on-going piece of work, isn’t it? (SAT9)*

However, current pressures on SATs meant it was very challenging to work with this longer-term view. This was identified as a significant barrier to putting more resource into taking this approach.

*And I just don’t have the time, nor does everybody else. … It takes as long to do consultations as it does to see people really. It’s time-consuming to do it properly. (SAT5)*

For mainstream services, it was noted there had to be an understanding and acceptance of this new way of working. All services reported this to be very challenging and a number of reasons were identified. Firstly, the ‘consultation and supervision’ model is relatively unusual in mental health services and, thus, as a way of working it is poorly understood.

*I think the default mode is, if you’re a specialist service you will take more responsibility. (SAT9)*

In addition, it was service leads’ experience that some professional groups (GPs and adult psychiatry were mentioned here) were very difficult to engage. This was attributed to a lack of understanding of autism (e.g. regarded as a childhood condition), a lack of interest and/or time.

*Some are interested but, to be quite frank, the vast majority are not and they don’t have time to be interested. (SAT2)*

*They’re not really, not enough people coming to, for supervision, or to training days…but we just keep plugging away. You’ve just got to keep doing it. (SAT9)*

Furthermore, it was noted that the process of ‘educating’ other services about using SATs for consultation and supervision, rather than a service to refer on to, needed to be continual due to staff turnover. The example was given of IAPT services which use assistant psychologists who do not typically stay long in a post.

*There’s new staff and… then new service managers. So it’s just reiteration. (SAT9)*

Finally, senior practitioners noted that resistance to a ‘consultation and supervision’ model may be stronger in situations where a well-established SAT was trying to shift more to this approach.

*I think you’re in a better position if you’ve said that from the start than if you suddenly try and change along the way. (SAT5)*

To address this, one service reported they were developing a ‘consultation contract’, which set out the roles of the SAT and mainstream services.

For Trusts, senior practitioners stressed the need for recognition of the resource implications to mainstream services of taking on greater responsibility for the care of autistic adults, and to ensure staff training needs are properly met.

*Trust’s need to see the value. So we need the Trust to want the people to be able to do that and to give them the time to do that in the context of everything else they’ve got to do, like you said, otherwise you’re just fighting a losing battle...*

#### Ensuring the correct balance between consultative approaches and direct work

Despite support for an increased emphasis by SATs on providing consultation and supervision to mainstream services, there was also strong agreement that such an approach does not obviate the need for SATs to do any direct work or deliver interventions to autistic adults without LD. This was because mainstream services are, by their nature, generalists and staff cannot be expected to have autism specialist skills nor to deliver autism-specific interventions.

*It’s about reasonable adjustments, I suppose, isn’t it? Just like you would your workplace. You can’t expect [mainstream] providers to do the things we may want them to do. But you could expect them to make some tweaks, to make it more accessible. (SAT9)*

*...there’s not a lot of services out there to do a lot of the work we want done. If it’s anxiety and depression, great, IAPT. If it’s primary care, go to your GP. But what about psychosexual work, what about the whole range of things that people with autism struggle with? (SAT9)*

### Supporting self-management and minimising dependency

Service leads agreed the overall approach of SATs should be to minimise service users’ dependency on the service and develop their self-management abilities. This was an aspect of provision that had often already seen significant changes in some services.

A post-diagnosis psychoeducation intervention, covering information autism and living with autism, was regarded as the critical starting point to supporting self-management.

*…enable people to get to this point where they’re very aware of their condition, they’re very aware of what’s going to be difficult, and what then to do about it. And also people need to take that responsibility too, about making those choices about [for example] who you’re going to disclose to…*

All services also offered other interventions, typically group-delivered, related to acquiring skills and understanding which enabled or supported self-management (e.g. social skills, coping skills, anxiety management).

Group delivery was, typically, a positive decision rather than regarded as solution to very limited resources. Indeed, a lack of adequate, protected time for practitioners to prepare for, deliver and review group-delivered interventions affected the quality of the intervention and the outcomes achieved. Identified benefits included the opportunity to hear, and learn from, others’ experiences and using ex-service user as co-facilitators, or speakers. In addition, the opportunity for self-development simply associated with going along to a group was stressed. A potential additional benefit was that groups (or some members) sometimes chose to continue to meet informally after the intervention is completed.

*…we’ve got some self-sustaining groups that go on from there [group delivered intervention]. (SAT7)*

However, whilst advocating group-delivered interventions, practitioners made clear that this required investing time in preparing and supporting individuals to attend.

*Lots of people with autism would say, “I can’t do a group”, but actually they can, it’s just they’re very anxious and it’s something that’s really scary to them. So, a lot of preparation work with them helps them go into that group. …. And making sure facilitators in that group are people who can hold that group, which is a skill in itself when you’ve got lots of different people…. (SAT7)*

In addition to specific interventions, senior practitioners described more general ways of working with service users that supported self-management and minimised the risk of individuals becoming dependent on the service. Oftenthese had been developed in response to observing undue dependency and/or a realisation that previous approaches to care were unsustainable.

*..[we give the message from the start that] …we cannot scoop you up and fix you, that’s the message, because everybody comes and families come thinking you’re going to scoop them up nicely, fix them, and then give them back, and we’re not able to do that. …Because it’s not fixable. (SAT2)*

*Yes, I’m an information giver, I’m somebody who can enable, but they don’t look to me to solve anything they want.*

*We made a decision several years ago now about things that we wouldn’t do …. and it might sound really simple, but it’s things like not filling in forms with people. So we spend probably as much time not filling in forms as we would if we actually filled it in for them. So it’s about that emotional resilience to show them that they, they can do it. So it’s kind of short-term pain for long-term gain really. (SAT2)*

### Working with local peer-led networks

Services with strong local peer-led groups (including those for carers) consistently identified them as a core element to a sustainable framework of long-term support for autistic adults without LD and their families. Connecting individuals to these groups was seen by some service leads as a key function of their service, and a whole team awareness of potential support groups/networks was important.

*It’s just about using what’s out there and being really knowledgeable as a team about what is out there.*

It was noted that information provision may not be sufficient, and that more proactive support may be required to enable service users to engage which such provision.

*I think it’s about signposting to whatever services there are out there, to get them to be engaged with those services…. Linking them into local groups, getting them into them. Getting the carers into anything you can get them into so that the carer feels they’ve got somewhere to go to as well. ….*

*We’ve got to use what we’ve got and it’s a matter of getting people into them. Making them, helping them to feel that they’ve got something outside of your service.*

Practitioners suggested that the geographical characteristics of a locality (i.e. rural vs urban) may affect the number and range of peer-led networks and other third sector organisations with which SATs can partner.

### Drop-in services and other low level support

A number of services used drop-in services or telephone contact as a means of providing on-going, low level support. For some, access to such support was time-limited, and was the way in which stepped discharged was managed.

*So we have this step-down service now where they can still link in with the service for six months after, perhaps have a telephone clinic each month; and then they tend to kind of just go off and obviously if they need to come back they can come back, but that seems to have worked really well. (SAT5)*

Others, however, offered service users the open facility to telephone the service for one-off contact, and four services provided a weekly drop-in that was open to ex-service users. All those providing this sort low-level, on-going support were strong believers in its value. Specifically, it was identified as serving to pre-empt problems or crises, nurture independence and self-management skills and reduce the sense of isolation.

*I’ve got somebody who rings me twice a year who’s been discharged for four years but they still they still ring twice a year. But that’s what keeps them going, they don’t go into crisis and end, end up, using loads and loads of services. And it’s generally only a quick phone call about probably nothing but it’s just a, a check in that we’re still there and they’re still there and it’s a five minute call and they’re gone; and, and I think that, you can’t replace that really, that’s, that’s really invaluable. (SAT5)*

*..it’s the ‘there when you’re needed’ level of support. It might be a five minute conversation it might take half an hour. But just holding their hand through some difficulties until they learn to do it themselves. I think it’s really valuable and I have increasingly less contact with people as they learn to manage these situations themselves. They generalise a lot better from that than from didactic teaching. People can turn up for half an hour and then we won’t see them again for six months, and then they’ll come again. But they know it’s there. (SAT6)*

*With (our drop-in service), the idea of that is to help people network and then move on to back into mainstream. (SAT5)*

*Light touch, access when you need it. Drop-in services are great. ….a little bit can, can go a long way, can’t it? (SAT9)*

There was a high level of interest among those not currently offering such services. However, some spoke of the difficulties of persuading commissioners that provision such as this should be included in their service specification.

## Summary

This chapter has reported senior practitioners’ experiences of leading and delivering a Specialist Autism Team. Unanticipated rates of referral and difficulties with securing onward referrals or discharging service users were presented as putting SATS under considerable strain. This was compounded by a lack of a commensurate increase in resource. All services had restricted their service offer, or changed models of service delivery, to manage this situation. Unsurprisingly, this was felt to impact on the quality of care they were able to provide. Despite this, all believed in the value of their service and identified elements that were working particularly well. Autism expertise, multi-disciplinary teams and psychoeducational and self-development interventions were highlighted. Specific innovative practices or models of service delivery were described.

There was clear evidence that service design, delivery and practice had, and was, evolving. This was driven partly by resource constraints and the pressures on services. Alongside was the fact that SATs were a new model of service provision, set up in the relative absence of a body of clinical experience and knowledge to draw on, and no evidence base on service design, delivery and intervention effectiveness.

In reflecting on this learning, senior practitioners identified four features of SAT delivery models and practice that, they believed, would help ensure sustainable improvements in support for autistic adults without LD. These were: i) placing greater emphasis, and investment in, upskilling and supporting mainstream services to deliver care and support; ii) working in ways, and delivering interventions, which nurtured self-management skills and did not foster a dependency on the SAT; iii) where possible, collaborating with peer-led networks; and iv) providing drop-in services and other forms of low intensity, on-going support. However, senior practitioners noted the challenges associated with seeking to invest in and implement such developments within a context of immediate and pressing demands on their own services. Furthermore, the more general context of resource constraints meant services may be unwilling, or not have the capacity, to change how they work with and use SATs.

# Factors affecting outcomes: practitioners’ views

## Introduction

This chapter reports the second element of the findings from nested qualitative study of SAT practitioners. Here we report on two main themes. First, understanding and assessing outcomes of SATs. Second, individual- and service-related factors which may affect outcomes. These findings, and those presented in the subsequent two chapters reporting service users’ views, provide important and useful contextual evidence before we turn, in Chapter 8, to report findings from the quantitative evaluation of SATs. A description of the methods can be found in Appendix 2.

## Understanding and assessing outcomes

Practitioners emphasised the diversity of the population referred to their services in terms of functioning, complexity and need. They believed it significantly affected the support individuals wanted and needed from the SAT, and the changes that a SAT can effect or support to take place.

*Some people don’t want anything, they’ll go “Thanks a lot, that’s my diagnosis, I’m fine with that, cheers!”. Other people will be like, you know, living in terrible circumstance and socially isolated*.

Related to this point was the extent to any change associated with using a SAT - particularly in the lives of individuals with more complex needs - may, or may not, be observable or amenable to measurement.

*There is improved outcomes, but there may not be a lot of change. So there might be more scaffolding around their lives and more access to support, which does improve the outcomes for them and will mean there are differences in their day-to-day life, but they might not massively change their routines or their social isolation particularly, but they’ll be more supported. It’s still an improved outcome, but it’s not a lot of change.*

Practitioners also spoke about potential conflicts between outcomes and individual differences in the priority given to different outcome domains.

*People that have really severe anxiety…you can encourage them and enable people to become more socially aware and involved, but that increases their anxiety so that it will be negative for them. But it’s about what’s the biggest gain, isn’t it, really? It’s whether it’s worth it for your anxiety to go up.*

Finally, a lack of understanding of autism, and resultant unrealistic expectations of the service, could result in disappointment and frustration among service users.

*….they’re expecting everything to be cured by the diagnosis or the intervention.*

## Person-centred factors associated with outcomes

### Functioning and complexity of need

As already noted, practitioners reported a great range in functioning and complexity of need among those referred to their services. These were felt to affect the type of impact a SAT could expect to achieve. For some, maintaining existing health and functioning, or preventing further decline, are appropriate outcomes. For others, positive change, sometimes quite specific to a particular aspect of their lives, can be hoped for or expected.

*Some of it’s about current functioning. So, like for our complex clients, it’s still improved outcomes, but it’s not a lot of change. And then we’ve got people who are, have jobs, they have families and that kind of thing. They have more of an idea about what they want to do [achieve from using the service].*

### Ownership of the referral

Practitioners identified three types of referrals: those highly engaged and positively wanting an autism diagnosis, those with mixed feelings and anxiety about the process, and passive participants. The latter group typically comprised those where parents have driven the referral.

*There’s a massive range, isn’t there? There’s some people that are incredibly motivated and really want a diagnosis, and some people that are a bit ambivalent, and some people that other people are saying: “Oh, I think this is an issue for you.”*

### Reaction to the diagnosis

A strong and consistent theme within practitioners’ discussions was the way service users’ reactions to the diagnosis affected longer-term outcomes. For some, this reaction was closely related to ownership, or not, of the referral. Thus, in some cases, the diagnosis fulfils a (potentially long-term) desire to make sense of their lives. Here, seeking a referral, or self-referral, may not be precipitated by a particular difficulty or crisis, but a readiness or desire to make sense of themselves and their lives.

*There are individuals where the diagnosis can give them sort of a clarity. It can give them an understanding of what it, why they’ve had these difficulties. Those people that are kind of, almost on a sort of quest of understanding why. ….It’s a positive thing in a way cos it kind of makes sense.*

*It’s about acceptance of the diagnosis when you’ve always felt different and lost and, you know, having an explanation of how that can help you understand yourself and move with things.*

Importantly, psychoeducation was regarded as playing a critical role in supporting positive outcomes from being diagnosed.

### Engagement with the interventions offered by the service

Practitioners believed that engagement with the service following diagnosis was affected by ownership of the referral and reaction to the diagnosis (as described above). Crucially, they may affect engagement with psychoeducation interventions – the first intervention typically offered. Lack of engagement with this was regarded as having the potential to stymie on-going engagement with the service and/or the potential for positive impact of subsequent interventions.

*Outcomes would be improved for people who either will or can engage in [psychoeducation interventions]. But it’s whether they have that ability, or whether they have severe anxiety, to be able to do that.*

Mental health difficulties, such as anxiety and depression, were also implicated. More generally, practitioners referred to service users’ having different levels of motivation in terms of service users’ wanting, or feeling able, to make changes in their lives.

*…its’ about the level of motivation to want to do something and change something.*

### Family support

Senior practitioners agreed that family members’ responses to the diagnosis can differ widely. For example, a diagnosis of autism may improve one couple’s relationship as it provides an explanation for why a partner behaves in the way they do. For another couple, however, an individual may find the realisation that certain things about their partner cannot be changed is a catalyst for ending the relationship. Overall, therefore, families were regarded as having the potential to facilitate or hinder positive outcomes. This was attributed partly to existing family relationships and dynamics, but also family members’ ability and willingness to understand of the additional challenges faced by autistic people and what they can do to accommodate specific needs.

*It can be a really, really positive thing if they have a supportive family. …then having that diagnosis will possibly enable some more empathy or understanding around the difficulties and can improve things like family dynamics at home.*

Across these discussions, the value of family members’ receiving psychoeducation related to the diagnosis of autism was highlighted.

### The intersection of individual need and service characteristics

Another key factor thought to affect user outcomes was the ‘fit’ between the support and interventions provided by a SAT and individuals’ needs. This was not necessarily about severity or complexity of need. In some instances, for example, it concerned whether or not services were able to offer low-level support on an *ad hoc* basis for those individuals who, for the majority of the time, managed their everyday lives independent of formal support.

*[There are some] who don’t need very much support but need to be able to access informal support, so a telephone call or a ‘cuppa tea’ kind of chat as and when they need it as opposed to something formal, eight sessions kind of thing. And if that can be made available to them, they seem to have very, very good outcomes.*

However, practitioners also noted that the types of needs presented by service users, and their ability to identify specific and realistic aspects of their lives which they wanted to change, could affect whether substantive changes in outcomes were observed. They explained that some needs or difficulties are more amenable to change or address; or, it is reasonably straightforward to equip individuals with self-management skills.

*People who have sensory issues, so where you can actually [help them with] coping strategies for dealing with those things, you know, practical things that can help on a day-to-day basis.*

*The people that are goal-driven but also have realistic expectations. They’ve gone into the service with a clear idea of what their chosen outcome is and then work with someone towards it.*

## Service characteristics associated with outcomes

One of the sessions at the senior practitioner workshop explored views about aspects of service design and practice perceived to affect service user outcomes. We used a small group-work activity in which participants ranked thirteen service characteristics in order of their relative impact on service user outcomes. Rankings were then used to stimulate a whole group discussion on this issue.

### The quality of the diagnostic assessment process

There was strong consensus that the quality of the diagnostic and needs assessment process was important in terms of supporting positive outcomes. All believed their service provided this, and this service characteristic was stressed as distinguishing SATs from other diagnostic pathways.

### Skill mix with autism expertise

Skill mix of the team – specifically its multi-disciplinary nature – was consistently regarded as one of the most important service characteristics in terms of supporting positive outcomes. Pracitioners noted that some key skills are shared across different professions and it may be the case that it is the skill-set, rather than the professional qualification, which is the key issue. Integral to this was autism expertise. Indeed, some noted that, on occasion, when considering the skill mix in a team, this expertise was prioritised over a particular professional being represented on the team. Practitioners from one service described the value of having someone with direct experience of autism within the team.

*The skill mix of the team is vitally important.*

*We all bring different things to the team from our professional backgrounds so it’s useful to have a mix of professions with experience… (of supporting autistic people without LD).*

*We need skill mix, but it isn’t so much your profession, it’s about your skills and knowledge of autism.*

### Alternative modes of intervention delivery

Another service characteristic seen to impact outcomes was, in order to accommodate and respond to individual difference, the flexibility of the service to provide care and support in alternative ways. Two components were identified: overall delivery model (time/session-limited vs open-ended contact) and mode of delivery (i.e. individual vs group). The first quote below comes from a senior practitioner working across two SATs, one mainly using group-delivered interventions, and the other using individual work alongside groups:

*You can see the difference being able to offer groups and individual work alongside, or just individual work. It makes quite a big difference.*

*There’s so many positives of both approaches [time/session-limited vs open-ended].*

*There are so many people that identify as our services as “I’ve been using you for years, and I don’t use you very often but I’ve got that if I need it”. Whereas other people respond so much better to “I’ve have these sessions and I go and then I’m never going to see you again”. I just think they’re both equally as important.*

*Services should be able to be flexible around the individual’s needs.*

### Having a ‘named contact’

Service users having a ‘named contact’ in the service was regarded as, potentially, impacting outcomes. It was also noted it was very relevant to service user experience

*A key worker is really important for people. Like a contact, somebody that you can form a relationship with and contact.*

*We have a named contact primarily because of feedback from the service users. They [said they] don’t like being passed from pillar to post [because] they might move through different professionals in the team. So one person holds responsibility for that service user while they’re moving through. Then, if they need to ring, they leave a message specifically for that person.*

Not all services had a formal ‘named contact arrangement’. However, it was reported that this could happen informally on an *ad hoc* basis.

*…they will tend to ‘take’ to one of the members of staff and call them.*

### Local Authority involvement

Some practitioners regarded Local Authority involvement in the SAT as one of the more important factors potentially affecting service user outcomes. Specifically, it was seen as supporting an holistic approach and direct access to Community Care Assessments.

*…in terms of Local Authority involvement, we all felt it was really important and crucial to a holistic autism service with social work involvement.*

### Features of service organisation and delivery with less influence on outcomes

Service characteristics identified as being less likely to affect individual outcomes were if a service was autism-only or a neurodevelopmental service, and whether the service was delivered by a single team or two/three teams, each delivering specific functions.

## Engagement with SAT by other services involved

Finally, the extent to which other services also involved with a service user (e.g. due to co-existing mental or physical health conditions) sought advice and input from the SAT was felt to have the potential determine to the extent to which SATs could support improvements, or maintain the status quo, in people’s lives. Practitioners commented that there was still room for significant improvement in understanding of autism within mainstream provision.

*If you’ve got somebody that is already getting regular support from the physical or mental health service, it would help [these] professionals to actually understand the difficulty, where they [service user] might be coming from, and what the difficulties might be.*

## Summary

This chapter reported senior SAT practitioners’ views about the outcomes SATs can expect to achieve, and the impact individual and service user characteristics may have on outcomes.

The great diversity among service users in terms of complexity of need, and what they hope to achieve from a referral to a SAT, was emphasised. A number of individual characteristics were identified as having the potential to affect outcomes. These included functioning and complexity of need, ‘ownership of the referral’, reaction to the diagnosis, engagement with interventions offered by the SAT, and the quality and nature of family support. The fit between service users’ needs and the support and interventions provided by a SAT was also identified as key to the extent to which positive outcomes were achieved.

Service characteristics regarded having the potential for greatest impact on user outcomes included: richness of skill mix/the multi-disciplinary nature of the team, being able to offer alternative ways to receive an intervention (e.g. group vs one-to-one sessions), service users having a ‘named contact’, and Local Authority involvement. Whether the SAT service was autism-only or a neurodevelopmental was regarded as relatively unimportant, as was the organisational structure (single vs multi-team).

Lastly, the extent to which other services also caring for, or supporting, the service user implemented autism-specific adjustments to their own practice or delivery was regarded as having the potential to impact the outcomes achieved by a SAT.

# Impacts of using a SAT or diagnostic assessment service

## Introduction

This chapter is the first of three reporting the views and experiences of service users. Here we present qualitative data generated from a question included in the study questionnaire at 12 months follow-up (T3). The question sought to capture, at a high level, study participants’ descriptions of the impacts on their lives of using a Specialist Autism Team (SAT cohort) or, for our comparator cohort, a diagnostic assessment service (DO cohort).

## Method

Data was collected at T3 (i.e. twelve months after attending their first full assessment appointment) through two questions included in the T3 Outcomes Questionnaire. The first, a fixed response question, asked: ‘*Overall, how would you describe the impact (or difference) that the [name of service] has had on your life?*. Response options were: ‘positive impact’; ‘little or no impact’, or ‘negative impact’. Respondents were then invited to explain their chosen response with the instruction: ‘*If you wish, please tell us in what ways the [name of service] has impacted on your life, or why it has not had much impact’*. A blank text box (equivalent to A5 size in hard copy version) was provided.

These questions were originally included to inform topic guide development for the qualitative interviews with service users and the impact rating question contributing to sampling. However, given over half chose to provide a brief account of their experiences, it was decided that this data set should be subject to analysis using qualitative content analysis techniques. Appendix 3 provides an account of the analytical process.

### The sample

Over half the T3 sample (138/260) completed both questions, as follows:

* SAT cohort: n=106/164
  + Diagnosis and Support (D&S) group: n=74/133 (55.65)
  + Support Only (SO) group: n=32/75 (42.7%)
* Diagnosis Only (DO) cohort: n=32/52 (61.5%).

Appendix 4 (Table 29) provides an overview of the sample characteristics.

## Findings

### Overall impression of the service

60.4% of respondents reported the service had a positive impact on their lives, 33.8% little or no impact, and 5.8% reported a negative impact. However, examination of the qualitative data suggests a positive impact rating does not necessarily indicate a singularly positive experience and outcomes. Rather, a more mixed experience was possible with some describing the support they had received as insufficient, see Table 7. This table also displays the difference between cohorts. Thus, whilst 60.0% of SAT-D&S respondents and 56.3% of DO respondents reported a positive impact, this figure was much lower (28.1%) for SAT-SO respondents.

Table 7 Service users’ rating of the impact the service had on their life

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | DO cohort | | SAT cohort | | | | Whole sample | |
|  | D&S group | | SO group | |
| Impact rating | n (%) | *rank* | n (%) | *rank* | n (%) | *rank* | n (%) | *rank* |
| Positive | 18 (56.3) | *1* | 45 (60) | *1* | 9 (28.1) | *2* | 72 (51.8) | *1* |
| Positive but insufficient | 6 (18.7) | *3* | 5 (6.7) | *3* | 1 (3.1) | *4* | 12 (8.6) | *3* |
| Little/no | 7 (21.9) | *2* | 22 (29.3) | *2* | 18 (56.3) | *1* | 47 (33.8) | *2* |
| Negative | 1 (3.1) | *4* | 3 (4.0) | *4* | 4 (12.5) | *3* | 8 (5.3) | *4* |
| Total | 32 | | 75 | | 32 | | 139 | |

In explaining the reason for a non-positive rating, a range of unmet needs (e.g. mental health difficulties, family understanding of autism, access to social care) and/or inadequacy of support was described. DO cohort respondents typically wrote more generically about insufficiencies, often stating simply that they needed more follow up support after diagnosis than had been offered, both for themselves and for their family. The following sections report further findings from the content analysis that shed light on why respondents from different cohorts may have had different experiences.

### The accounts of positive impact

Table 30 (Appendix 5) summarises results of the content analysis of respondents’ accounts of thepositive impact(s) the SAT had had on their lives. It shows that positive impacts were wide ranging in nature, with eighteen different types of impact identified. These were grouped into seven broad categories:

* understanding and acceptance of diagnosis and self
* improved mental health and coping
* help with employment and education
* access to other services
* improved social skills, relationships and networks
* contact with supportive practitioners
* reduced sense of isolation.

The number and range of positive impacts experienced varied between cohorts (see Table 30, Appendix 5). All types of positive impact were reported by at least one D&S group respondent. However, the range of positive impacts experienced by SO group and DO cohort respondents was more limited (10/18 and 7/18 respectively). It notable that ‘contact with supportive practitioners’ was only reported by SAT cohort respondents. This impact category includes a number of different aspects of supportive practice including: being made to feel valued, feeling understood, being treated with respect, staff being expert in autism, easy to contact and responsive to individual need. The follow extract illustrates the significance of such an experience:

*Being understood and being treated with such respect and compassion was a hugely beneficial experience after not having been very understanding or compassionate with myself. (SU37, SAT cohort: SO group)*

The most frequently reported type of positive impact – and observed across the three cohorts - was ‘greater understanding of self’. Examination of the qualitative data linked to this code provides some explanation as to what this concept means and why it was valued. First, it referred both to their current lives and pastexperiences. Second, ‘greater understanding of self’ had allowed respondents to be more accepting and forgiving of themselves. They described both specific effects, or changes, (e.g. worrying less about why they behaved as they did, ceasing to label themselves as ‘weird’, changing job/career to one more suited to them) and also more global positive impacts such as increased confidence and self-esteem, and improved well-being and/or mental-health.

*I no longer worry or analyse my thoughts and actions like I used to. I feel much more at ease and finally feel that I understand myself as a person. Although I still struggle with anxiety, I am grateful that I have been given answers. The fact that I am now aware I have Asperger’s is great, it makes sense and provided me with what I have needed all my life - answers and closure. (SU39, SAT cohort: D&S group)*

*I can now learn to live with who I am and what I am capable of/ and what I am not. I don't feel I have to push myself as much to fit in (which caused me the most stress). I still have other problems with moods and sensory issues. I am learning more about this condition all the time. (SU40, SAT cohort: D&S group)*

It is worth noting here that whilst respondents across all cohorts reported ‘increased understanding of self’, only respondents in the D&S and SO groups reported that they had benefited from ‘help with accepting and/or seeing the strengths of their diagnosis’. Comments such as the following were made:

*It’s given clarity in my life. I know the reason why I’m the way I am. And thanks to [name of service] I look at my condition in a positive manner. (SU41, SAT cohort: D&S group)*

Given the connection respondents made between greater understanding and acceptance of self, it perhaps not surprising that improved mental health (including self-esteem) was also one of the most frequently reported positive impact. Indeed, scrutiny of responses related to improved self-esteem or mental health revealed that such changes were most frequently linked to improved self-understanding. However, for a minority improved mental health was attributed to other interventions provided by the service (e.g. sessions with a psychologist, joining hobby groups, receiving additional support at university)

*I feel strongly that if I had not been sent to the* [name of service] *team when I had I would not be in such a positive place as I am today. I will always have difficulties with mental health but I now have coping mechanisms and a support system in place which I would never have had without this team. Thank you. (SU42, SAT cohort: D&S group)*

### The accounts of little or no impact

Table 8 provides an overview of respondents’ reasons for why the services they used had little or no impact on their life. This group represented 22/75 of D&S respondents, 18/32 SO respondents, and 7/32 DO respondents. Across all groups the most frequent reason for little or no impact (27/ 47) was that no support had been received.

Table 8: Reasons for ‘little or no impact’

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | DO cohort  (n=7) | | SAT cohort | | | |
|  | D&S group  (n=22) | | SO group  (n=18) | |
|  | Freq. | *Rank* | Freq. | *Rank* | Freq. | *Rank* |
| Not received any support | 7 | *1* | 12 | *1* | 8 | *1* |
| Support provided was insufficient | 0 | *-* | 4 | *3* | 3 | *3* |
| Support provided was unsuitable | 0 | *-* | 5 | *2* | 5 | *2* |
| Decided did not want help | 0 | *-* | 1 | *4* | 2 | *4* |

As would be expected, among DO cohort respondents, little or no impact was solely attributed to not receiving any input or support from the service after the diagnostic assessment process was complete. Notions of isolation were evident and this could off-set any positive impacts of being diagnosed. For example:

*They diagnosed and left me. The diagnosis was positive as it helped me claim PIP* *[Personal independence Payment]*.  *Being left alone and questioning my entire life due to my diagnosis was a negative, left entirely to my own devices.*  *(SU43, DO cohort)*

These respondents also described the types of issues they continued to struggle with or the types of support they wanted. These included coming to terms with the diagnosis, managing mental health problems, help with relationship difficulties, finding out about/connecting with support groups/services for autistic people, and managing difficulties with employment/workplace.

Among the SAT cohort, not receiving input or support from a service was attributed either to the service not being in touch since the diagnostic or needs assessment, or the respondent was still on a waiting list for a group intervention(s). A sense of frustration wasobserved in many responses:

*After my first 2 appointments in which I was assessed and then told the result, I have not had any further contact with* [name of service] o*ther than when I inquired when I would receive the report of my assessment, which I did not get until almost 12 months after my diagnosis. Since my diagnosis I have not been given any information about help/support that is available*. *(SU44, SAT cohort: D&S group)*

*They have totally failed to put on group sessions. I've not heard from them in months (SU45, SAT cohort: D&S group)*

The second most frequently reported reason among the SAT cohort for a service having no impact was the support received did not (fully) address the individual’s needs. This was either because the desired support had been unavailable or not offered (e.g. employment support, explaining the diagnosis to relatives etc.), or due to a respondent being discharged from a service before they felt ready.

*It's a bit like having the carpet pulled from under your feet. It would only have an on-going positive impact if the support was on-going. It's a bit like trying to help a homeless person by giving him exactly 6 nights of accommodation and then nothing.* *(SU46, SAT cohort: D&S group)*

A third reason SAT cohort respondents rated the service they used as having little or no impact was that the support/interventions offered, or provided, were regarded as unsuitable. Where further detail was provided it typically concerned being offered a group-delivered (as opposed to one-to-one) intervention(s). Finally, a small proportion of SAT cohort respondents reported declining any/further input because of other demands on their time or they felt too old to change how they lived their lives.

### The accounts of negative impact

Just 8/139 respondents rated the service they had used as having a negative impact on their life. In the majority of cases (6/8) this was because the respondent had not been offered any post-diagnosis support.

## Summary

This chapter has reported findings from our analysis of responses to two questions used in the T3 (12 months follow-up) questionnaire to explore study participants’ views on the impact(s) on their lives of using a Specialist Autism Team or a diagnostic assessment service. Over half the T3 sample completed both questions. These data provide a useful, first, and high level, insight into service users’ views and experiences. This compliments data from our in-depth, semi-structured interviews with a smaller sub-sample of study participants and reported Chapters 7 and 9.

The majority of respondents reported the service they used had a positive impact on their lives, for some (and across all cohorts) negative impacts or insufficient support rendered this positive impact partial. The types of reported impact reveal the potential for SATs to have a positive impact across many life domains. However, the full range of impacts was onl*y* represented in the accounts of respondents from D&S group. SO respondents less likely to report a positive impact. It is not clear from this data why this may be the case.

Where respondents reported little/no impact, or a negative impact, this was typically because they had not received any support/interventions in addition to the diagnostic/needs assessment. Other reasons included: still waiting to receive an intervention (in all instances, this was for a group-delivered intervention), and interventions/support offered regarded as unsuitable. Group, as opposed to 1:1, delivery was the most common reason to refuse or drop out of an intervention. Other reasons for little or no impact included insufficient intensity or duration of support or the service did not address their priorities. A small minority of respondents reported choosing not to engage with the service due to pressures of time or they felt were too old to change well-established coping strategies.

# Experiences of using a Specialist Autism Team

## Introduction

This chapter turns to the experiences of individuals who used a Specialist Autism Team and forms part of the study’s qualitative evaluation. Appendix 6 provides an account of methods. Briefly, twenty-nine individuals, representing all research sites, were recruited around 12 months following their first full assessment appointment. A purposive sampling frame ensured representation of age, gender, and reported impact of the service. Semi-structured, in-depth interviews explored pathways into the service, expectations, outcomes, views on factors affecting outcomes, and service user experiences. The chapter is organised into the following sections:

* pathways into the service
* hopes and expectations at the outset
* views about the specialist nature of the services
* experiences of the diagnostic assessment process
* the extent to which individuals’ needs were met
* the impact of characteristics of service delivery and practice on outcomes
* practical barriers affecting access to SATs

## Pathways into the service

Of the twenty-eight individuals recruited, twenty had not previously been diagnosed with autism (D&S group). The majority had initiated the referral to a SAT. For some this had been triggered by their own research into autism or experiences of difficulties at work, social or with their mental health. Others had made or sought a referral at the suggestion of others. For a minority, a parent or health professional (e.g. GP, psychiatrist) had decided upon and organised the referral. A further eight interviewees were already diagnosed with autism (SO group). For the majority, their referral had either been instigated by a professional already working with them or by a family member. A minority had self-referred withall also reporting being helped or encouraged to do so by a parent. One individual had used the SAT previously.

## Hopes and expectations at the outset

Among those not previously diagnosed, the diagnostic assessment was regarded as having the potential to offer an explanation for the various struggles experienced over their lives. A number spoke of how they hoped having a diagnosis would give them ‘*peace of mind*’, ‘*closure*’ or ‘*validation*’.

*I was just looking for validation, and to have a word to explain my difficulties so I didn't just need to put them down to me being a bit "weird’. (SU14, 18 years)*

*I said [to GP] that I’ve got like twenty years left and I just want some sort of peace, because I beat myself up about how I feel and I’m, I feel I’m inadequate’. (SU21, 62 years)*

Some were not seeking, or felt the need for, any further assistance from the SAT. Others, however, wanted help with one or more, sometimes quite substantial, difficulties in their lives (e.g. mental health, social isolation/social skills, independent living, accessing adjustments at work or college). A few also hoped having a diagnosis would help others (e.g. family, work colleagues) to understand them better.

Those already diagnosed were typically much more specific about the help or support they wanted, perhaps reflecting a greater understanding of autism, its potential impacts and intervention options. Needs were wide-ranging (mental health difficulties, social isolation, managing day-to-day life, sleep difficulties, sensory issues, work/employment issues).

Regardless of diagnostic history, many interviewees reporting mental health needs indicated that they had previous, not necessarily successful, experiences of generic/mainstream mental health provision.

## Views about the specialist nature of the services

When speaking of their experiences of using a SAT, interviewees often described or referred to ‘autism-friendly’ practices. These, in themselves, were regarded as evidence of the specialist nature of the service. A number of interviewees specifically described ‘feeling understood’ or referred to the fact that the SAT was staffed by professionals with an expertise in autism. Feeling they were using a service which understood them was an emotional support in itself. Together these engendered confidence and engagement with the service.

*By offering support for it and stuff like that, and they work with people that have it. So that, that put my mind at ease, that I’m definitely not alone and, that there is people that understand it and that offer support for it. (SU9, 18 years)*

*They are understanding, kind, caring and all that type of stuff. They don’t judge you, they’re amazing at what they do. If you come in with a problem they’ll listen to you and that type of stuff, so yes, I would recommend someone who’s got autism to go and see them. (SU25, 21 years)*

## Experiences of the diagnostic assessment process

All SATs had a unique diagnostic assessment protocol (see *Chapter 3*). There were, however, no noticeable differences in interviewees’ overall level of satisfaction with the way the assessment process was managed, which was either positive or neutral. There were no spontaneous complaints, for example, about the number of sessions involved or the duration of the process.

That was not to say, however, that some found it a difficult process which caused them anxiety and unease. Being the centre of attention, having to describe private matters or admit to struggling with, what others might regard as, straightforward, everyday tasks caused embarrassment. The use of open-ended questions and having more than one assessor involved were sources of anxiety. Finally, a few were unhappy that their parents had to be involved, and some reported finding some of the assessment tasks (e.g. story-telling, shape completion) childish and patronising.

Some interviewees found the requirement to recall childhood experiences particularly difficult. Undergoing this brought back difficult memories and had caused some interviewees to become upset during the assessment. One interviewee described this as ‘*re-traumatising*’.

The predominant emotional response to being diagnosed with autism was a sense of relief – at having suspicions confirmed or having an explanation for, and validation of, struggles through life. However, for many, this was followed by a more mixed set of emotions. (We explore this in more depth in a later chapter (*Chapter 9*) which focuses particularly on experiences of the diagnostic assessment process from the perspective of SAT users and those only accessing a diagnostic assessment.)

In terms of other short-term outcomes, some described the way an autism diagnosis *per se* enabled, or opened, access to a particular form of support such as welfare benefits (e.g. Employment and Support Allowance) or adjustments at work or college. Indeed, for some, this had been the primary motivation for the referral to the SAT with some subsequently self-initiating access to these. The great majority of our interview sample, however, had additional needs requiring further input and support from the SAT.

## Extent to which individuals’ needs were met

Within interviewees’ accounts, four broad areas of need, varying between individuals, were identified:

* understanding and coming to terms with/accepting the autism diagnosis
* strategies and skills to support successfully managing everyday life and situations
* mental health or social[[1]](#footnote-1) needs presented at referral or identified/emerging during the time with the service.
* emotional support to overcome or endure a period of difficulty.

Based on the evidence contained in their interviews, we allocated interviewees to one of three groups in terms of levels of unmet need at discharge from the SAT (or, if still with the service, ~12 months after first full assessment appointment).

* Needs predominantly met, this group can be further distinguished:
  + lower levels of need at referral
  + higher levels of need at referral
* Met and unmet needs, this group can be further distinguished in terms of why some needs remained unmet:
  + service did not address the full range of presenting needs
  + some needs only partially met by discharge
* Needs predominantly unmet

Organising the sample in this way allowed us to investigate systematically whether and how features or characteristics of service delivery and practice affected service users’ accounts of the ways a SAT did, or did not, help them. This was one of the primary objectives of this element of the overall project and we report our findings in a later section in the chapter (*Characteristics of service delivery and practice: impacts on outcomes*). First, however, we offer a broad description of these three groups and their experiences.

### Needs predominantly met

Eight of our interviewees, across six SATs, reported their needs to be fully or predominantly met by the service. This included individuals not previously and already diagnosed with autism. Some individuals had very substantial and wide-ranging difficulties at the point of referral (e.g. homelessness; redundancy; depression; suicidal ideation) and described the considerable impacts that receiving support from a SAT had on their lives.

*When I was diagnosed I was not far off being incapable of work and now I’m six months into a new job and coping incredibly well despite massive upheaval and significant change. And I’m doing that at the same time as trying to move house and coping with the rug being pulled out from under my identity in terms of my diagnosis. There is no universe in which I would be coping half as well if it wasn’t for the support I’ve received. (SU35, 33 years)*

*I felt they went above-and-beyond, and I am truly grateful. I wanted to complete this interview to express that, as I can't thank them enough. (SU22, 37 years)*

Others had sought referral to the SAT for a diagnostic assessment and did not identify themselves as having any additional support needs. In these instances, often the diagnosis enabled individuals to self-initiate any changes, or resolve problems, in their lives and they had not required support from the SAT to achieve this.

*The main thing I really wanted was the diagnosis for work. I had support that I needed from ex-wife and friends so I wasn’t really looking for any sort of ongoing support from the service. (SU18, 62 years)*

### Met and unmet needs

Thirteen interviewees, across seven SATs, were allocated to the ‘mixed experience’ group with some of their needs remaining unmet, or only partially addressed. Whilst half regarded themselves as still ‘in the service’, none were actively engaged when we interviewed them. Unmet, or partially met, needs were attributed to ‘ineffective’ interventions and limitations of the SAT in terms of format, duration, intensity, scope and flexibility of the support available: we return to these issues in detail in the following section (*Characteristics of service delivery and practice: impacts on outcomes*). Reports of refusing, not using, or dropping out of, interventions/support offered were much more common in this group compared to the ‘needs met’ group. The cause of limitations to support received was most frequently attributed to funding constraints within the NHS and participants expressing sympathy for SAT practitioners. Nevertheless, a number of people expressed disappointment at the help received.

### Needs predominantly unmet

Seven interviewees, across four SATs, were allocated to the unmet needs group. All reported that, aside from the diagnostic assessment, the support received had not helped them. All had been discharged, or they had dis-engaged from the service. Unmet needs reported were wide-ranging and, in some cases, quite significant or dehabilitating. They were consistently attributed to limitations in the support offered by the SAT and/or support/interventions being delivered in a way which they could not access (e.g. group-delivered interventions). We return to these issues in detail in the following section (*Characteristics of service delivery and practice: impacts on outcomes*).

Some presented the experience of being discharged and/or offered intervention/support regarded as inadequate or inaccessible with language which indicated a sense of rejection and a perceived lack of compassion on the part of the service. For example: *‘thrown out of the service’*; *‘pleased to tick my name of a list’*. And…

*The service is like, is almost like detached, it’s like doesn’t even wanna try and help. ....I feel like I’m not getting across, like I can’t get across how bad it is kinda thing. . (SU47, 20 years)*

Another common theme in this group’s accounts was a frustration that needs had been articulated or identified during assessment, but not then addressed.

*It felt like there was a disconnect between the person doing the diagnostics and the follow up*. *Identifying an issue is isn't the same as providing solutions or help with the issue. (SU12, 28 years)*

A noteworthy difference in experience between the ‘unmet needs’ group and the ‘needs met’ or ‘mixed experience’ group was that they were more likely to describe waiting times for the diagnostic assessment as being problematic.Some had waited more than two years. It is possible that these wait times increased the severity of personal difficulties or the hope vested in how the SAT would impact their lives which in turn heightened or coloured their emotional response to their experiences of using a SAT. Despite this sense of frustration and disappointment, as with the ‘mixed experience’ group, interviewees also referred to the high level of demand for services and lack of funding as an explanation as to why they had received so little support.

## Service characteristics: impacts on outcomes

This section reports characteristics of service delivery and practice which, based on our analysis of interviewees’ accounts, appear to be associated with outcomes (that is, the extent to which needs were met). They are as follows:

* scope of, and access to, psychoeducation about autism
* the service’s overall model of care delivery
* availability of an alternative to group-delivered interventions
* timeliness of group-delivered interventions
* approach to managing referrals to other services

### Scope of, and access to, psychoeducation about autism

A range of emotional reactions and responses to an autism diagnosis were described. Positive (e.g. relief) and negative (e.g. anger, distress, grief) emotional responses were reported, with some individuals experiencing both, simultaneously and/or over time. . All SATs offered an extended psychoeducation intervention (i.e. an intervention seeking to increase understanding of autism, self-understanding and self-management skills) either via group- or one-to-one sessions. However, not all SATs offered one-to-one work for those unable to attend a group; we return to this specific issue in a later section.

Individuals in the ‘needs met’ and ‘mixed experience’ groups typically spoke very highly of the psychoeducation they had received.

*It ended a lifetimes worth of feeling inadequate and feeling worthless. (SU36, 21 years)*

Aspects of psychoeducation identified as particularly helpful included: content which gave insight into how autism may affect them, including the positive aspects of the condition; sharing experiences, including speakers with positive stories of living with autism, (group-delivery only); and learning coping techniques for dealing with difficulties commonly experienced by autistic people (e.g. sensory overload, anxiety etc.). A dominant theme in these individuals’ accounts was the impact on the way they viewed themselves: feeling more accepting or forgiving of themselves. Some also spoke of feeling less need to mask autistic behaviours, and/or seeing the positive side of the condition.

*It [the diagnosis] could have been life-changing in a way that left me stranded and in fact it has been life-changing in a way that’s given me enormous support and enormous hope, and a new capacity for thinking about myself and the world around me*. *(SU35, 33 years)*

In contrast, those in the unmet needs group had either not accessed this intervention (either due to long waiting lists or feeling unable to attend a group), or dropped out early due to finding it unhelpful. Being unable to access (good) psychoeducation appeared to be a key influence in whether individuals had been able to resolve any negative emotional reactions to the diagnosis.

### The service’s overall model of care delivery

All the individuals in the ‘met needs’ group with support needs extending beyond the diagnostic assessment had attended SATs which provided individualised, managed care overseen and coordinated by a single member of the SAT who also acted as the ‘named contact’ for the service user. For individuals experiencing a mental health crisis, being able to contact their ‘named contact’ outside of appointment times was consistently regarded as extremely valuable. As well as responding to needs the individual was aware of on referral or identified in the assessment process, this model of care was also able to respond to needs emerging during the time the individual was in the service. Furthermore, in adopting this model of care, these services typically had the skills and expertise within the team to respond directly to a wide range of support needs. Where required, they supported referrals to other services/agencies.

*It has been individualised to me, I’ve felt seen and heard and respected during the entire thing, but the breadth, but also that the breadth of professionals involved has meant that I’ve had several different appropriate touch points, each of which has had a measurable significant impact like, and it, it’s been, yeah, it’s been fantastic. Considering, considering what a shitty, complicated weird situation it has been it has been, the, the service has been brilliant. (SU35, 33 years]*

*She does things that I wouldn't have ever known about, having the one-to-ones. …I think they've exceeded what I expected with it, they've explained it [the diagnosis] to me so I understand it, and try to put coping methods in place. That's exceeded what I expected. (SU15, 47 years)*

There was some evidence that limiting the duration of individualised, managed care (e.g. the SAT only able to offer a fixed number of sessions) could mean some needs remained unmet at discharge. This was observed among individuals in the ‘mixed experiences’ group attending such services, especially those with complex and long-standing difficulties. However, even in SATs not working to a fixed number of sessions, a few individuals in the ‘mixed experience’ group believed they were discharged before they were ready to leave.

*I was hoping to stay a client. But they thought that I had all the support I needed, that’s why, but I don’t feel that, because they thought I was finished but I wasn’t, and I didn’t get a chance to explain that to them. (SU9, 18 years)*

In contrast, interviewees whose SATs did not work within an individualised model of care, offering instead a limited range of interventions and referring elsewhere to address other needs, consistently typically reported (at least some) unmet needs. A later section (*Approach to managing referrals to other services*) further explores practices around referring to other agencies or sources of support, and how this may be implicated in needs remaining unmet.

### Availability of alternative to group-delivered interventions

Many SATS used groups to deliver one or more interventions. Typically, this was a positive choice, with group delivery perceived as the best approach to achieve the specific objectives of that intervention (see *Chapter 4*). However, not all SATs offered one-to-one sessions if the individual felt unable to attend a group-delivered intervention. The lack of an alternative to group-delivery of an intervention was a frequently cited reason for a need remaining unmet. In these cases, the individual had either refused or dropped out of the intervention early on. In both situations, no alternative (i.e. one-to-one sessions) was offered.

The most common reason for refusing or dropping out of a group-delivered intervention centred on social anxiety, and/or a lack of confidence, about being in a group. For some, past experiences of finding groups emotionally draining or distressing contributed to this decision. Other reasons, less frequently described, included: an unwillingness to spend time with and/or be seen with other autistic people, particularly if they were perceived to be more severely affected; fears that hearing others’ experiences may be upsetting; and not believing sharing experiences would be of use or value. An experience of a poorly facilitated group (e.g. not keeping to time/agenda, feeling distressed participants were not well supported) was another reason for dropout.

Two interviewees spoke positively about the support given to attend a group-delivered intervention. Valued practices included: pre-meetings with the group facilitator to hear more about what would happen, having the chance to view, or be reassured about, the suitability of the venue in terms of lighting etc., and allowing and supporting participation in group discussions via written, as opposed to verbal, contributions. Similar, or complimentary, practices were suggested by interviewees who had not taken up a group-delivered intervention, but felt that, with support, it might have been possible. These interviewees also suggested offering a mentor, or buddy, to accompany individuals.

### Timeliness of group-delivered interventions

Some of the interviewees who attended SATs using group-delivered interventions spoke of long gaps between the offer of support being made and the relevant group starting. This increased the risk of needs remaining unmet in a number of ways. Individuals’ willingness to attend diminished, or the intervention was regarded as no longer relevant or seen as coming too late to be useful. Some interviewees described how the presenting need increased in severity during the waiting period making attending the group more problematic. Finally, and in addition, a lack of communication from the SAT whilst waiting for a group to start (this could be several months) was, for some, a source of further anxiety with concerns that the SAT had forgotten about them.

### Approach to managing referrals to other services

The ways in which individuals were referred to other agencies or sources of support to address needs which could not be met by the SAT also appeared to influence whether needs were met. We use the term ‘supported referrals’ to describe where SATs assisted with completing application forms (e.g. benefits); arranged and/or accompanied individuals to appointments with other agencies or organisations (e.g. employers, housing officers, social services); and/or acted as an advocate in meetings with other agencies. These sorts of practices were consistently reported by individuals in the ‘needs met’ and many of those in the ‘mixed experience’ group.

*She’s very like to the point, very like, this is what she needs, this is what she’s like entitled to type of thing. I do think they like fight your corner for you, not that you should have to fight your corner, but like I do think it’s quite like a driven service. (SU7, 27 years)*

Experiences such as these contrasted with those who had been ‘signposted’ (i.e. provided with information and contact details for other agencies or other potential sources of support) with regard to an identified need. There was very little evidence that signposting was actively used or successful. As a result, needs remained unmet. For example, two interviewees spoke of being given the contact details for social or housing services. One had made no attempt to contact the service, the other had attempted to visit the service, but it had been closed and he had not returned.

## Practical barriers affecting access to SATs

A few interviewees reported practical barriers to accessing services or interventions offered by their SAT and which resulted in needs remaining unmet. This included, for those in employment, only running groups during working hours. Others had not attended group sessions or used a drop-in service because it would have involved them using public transport and/or journey times were considered too long. Finally, some reported forgetting, and therefore, missing appointments.

## Summary

This chapter reported on findings from interviews with users of SATs which explored experiences of using, outcomes experienced, and the perceived impact of service characteristics and ways of working on outcomes. A key analytical tool used was to split the sample into three groups according whether, at 12 months after entry into the service, interviewees reported needs were, as follows: predominantly met, a mix of met and unmet needs, and needs predominantly unmet. We then investigated whether and how service characteristics and ways of working played a role in these experiences and outcomes.

Interviewees described a number of pathways into the service and a diversity in the level and type of presenting needs. Many were hoping the diagnostic assessment process might yield answers or confirm suspicions. Despite experiencing very different diagnostic assessment protocols and processes, overall, interviewees were quite satisfied with the way the assessment process was managed though many found it an uneasy and anxiety-provoking experience. For a few, the diagnosis enabled them to independently address specific difficulties or support needs. Many, however, had a number of needs for on-going support from the SAT. These included understanding, coming to terms with an accepting the diagnosis; needing support to develop strategies to better manage everyday life and situations; specific mental health and social needs; and emotional support needs.

Five characteristics of service delivery and practice were identified as affecting the extent to which SATs had addressed service users’ needs. They were as follows: i) the scope of, and access to, psychoeducation about autism; ii) the service’s overall model of care delivery; iii) the availability of an alternative to group-delivered interventions; iv) the timeliness of group-delivered interventions; and v) the approach taken to managing referrals to other services. Finally, a few interviewees reported some practical barriers to accessing support and interventions offered by the SAT.

# The quantitative evaluation & factors affecting outcomes

## Introduction

This chapter reports the quantitative elements of our observational study. After a description of the study design and methods, findings are reported with respect to the three main objectives.

## Objectives

The objectives of this aspect of the study were as follows:

* to describe changes in outcomes between entry into a Specialist Autism Team and 12 months later (T3), and to offer an initial description of longer term outcomes.
* to explore whether individual and service characteristics are associated with T3 outcomes.
* to explore whether outcomes differ between individuals diagnosed and then supported by a SAT, with a cohort of individuals who received a diagnostic assessment only.

## Study design

An observational study of two cohorts: the main ‘Specialist Autism Team’ (SAT) cohort and a smaller ‘Diagnosis Only’ (DO) cohort.

### The SAT cohort

This cohort comprised users of Specialist Autism Teams, recruited at the time of their first full assessment appointment. Individuals in this cohort included those referred to the SAT but already diagnosed with autism (the ‘Support Only’ (SO) group) and those referred for diagnostic assessment and on-going support (the ‘Diagnosis and Support’ (D&S) group).

### The ‘Diagnosis Only’ cohort

Three of the SATs acting as research sites also provided a regional or national diagnostic assessment service for individuals living outside its CCG/LA boundaries via block contracts with neighbouring CCGs or on a case-by-case basis. The ‘Diagnosis Only’ (DO) cohort comprised individuals who accessed one of these regional diagnostic assessment services. Thus, these individuals did not receive any post-diagnosis support from the SAT.

## Methods

### Setting

Nine SATs (referred to as ‘research sites’) broadly representative of the range of service characteristics and ways of working observed in current SAT provision in England (see *Chapter 3*).

### Study participants

SAT cohort inclusion criteria were:

* diagnosed with autism by the SAT, or already had confirmed diagnosis when referred;
* able to give informed consent, as judged by SAT practitioner in the research sites.

DO cohort inclusion criteria were:

* living outside the geographical commissioning boundaries of the Specialist Autism Team to which the individual has been referred;
* referred to a Specialist Autism Team’s regional/national for diagnostic assessment service;
* able to give informed consent, as judged by SAT practitioner in the research sites.

### Variables: standardised outcome measures

Outcomes were captured immediately prior to, at, or immediately after the first full (diagnostic/needs) assessment appointment (T0), and at the following follow-up timepoints: 3 months (T1), 6 months (T2) and 12 months (T3) after T0. For those recruited earlier in the study, 18 (T4) and 24 (T5) month follow-up were also possible. The following suite of standardised outcome measures and categorical outcome indicators was used (further details are provided in Appendix 7):

#### Primary outcome:

* World Health Organisation Quality of Life Instrument, Abbreviated Version (WHOQOL-BREF) Psychological Domain *(Higher scores = better outcome)*

#### Secondary outcomes: standardised measures

* General Health Questionnaire (twelve item version) (GHQ 12) *(Higher scores = worse outcome)*
* EuroQol-5 Dimensions, five-level version (EQ-5D-5L) *(Higher scores = better outcome)*
* Interpersonal Support Evaluation List – Short Form: Belonging Support (BE) subscale *(Higher scores = worse outcome)*
* World Health Organisation Quality of Life Instrument, Abbreviated Version (WHOQOL-BREF) – Social Domain *(Higher scores = better outcome)*
* World Health Organisation Quality of Life Instrument, Abbreviated Version (WHOQOL-BREF) – Physical Domain *(Higher scores = better outcome)*
* World Health Organisation Quality of Life Instrument, Abbreviated Version (WHOQOL-BREF) – Environment Domain *(Higher scores = better outcome)*

#### Secondary outcomes: categorical indicators - day-time occupation/usual activities

* difficulty with managing usual activities of daily living: EQ-5D-5L item: “*Usual activities (e.g. work, study, housework, family or leisure activities)*”; response options: no, slight moderate or severe problems.
* availability of information needed for daily living: Question 13, WHOQOL-BREF: “*How available to you is the information that you need in your day-to-day life?*”; response options: not at all, a little, moderately, mostly, completely.
* employment status: working vs seeking work vs not working due to sickness/disability
* satisfaction with capacity for work: Question 18, WHOQOL-BREF: “*How satisfied are you with your capacity for work*”; response options: very dissatisfied, dissatisfied, neither satisfied nor dissatisfied; satisfied, very satisfied.
* satisfaction with leisure time: Standalone question: ”*I am satisfied with how I spend my free time*”; response options: definitely true, probably true, probably false, definitely false.

#### **Secondary outcomes: access to autism-specific networks and support**

The following items from the study’s Client and Services Receipt Inventory (CSRI) were used as indicators of connections with, and use of, autism-specific networks:

* membership of an autism-specific regional or national third sector organisation
* membership of an autism-specific online-only group, community or forum
* in the past four weeks, number of contacts/use of either of the above

#### Other service evaluation data

At T3, respondents were asked to rate the impact of the SAT on their life as either positive impact, little or no impact, or negative impact. This was followed by a space in which respondents were invited to describe the ways the SAT had impacted on their life, or why it has not had much impact (Findings reported in *Chapter 6*). At T3, respondents reported their status with the SAT (still using or discharged) and used a checklist to indicate the concerns on which the SAT had worked with them.

### Study recruitment and retention

Recruitment and T0 (baseline) data collection took place within the following time window: no longer than 3 weeks prior to start of full assessment (that is, diagnostic and needs assessment or, for those already diagnosed, or needs assessment) to no later than 7 days after. (See Appendix 8 for an account of the recruitment and data collection process.) Figure 4 summarises recruitment and retention to the study. The recruitment rate was 57.2% (422/741). Over a quarter (n=103; 26.88%) became ineligible for the study after the diagnostic assessment did not diagnose autism (n=103) or the individual withdrew from the diagnostic assessment process (n=11). Retention to the study at T3 (primary follow-up time point) was: SAT-D&S group = 133/164 (81.1%); SAT-SO group = 75/88 (85.2%); DO cohort = 52/56 (92.8%).

Figure 4 Flow chart - recruitment & retention (not all participants complete each wave)

**Total Recruited**

**N= 424**

**T0**

**N= 310**

**T1**

**N= 266**

**T2**

**N= 259**

**T3**

**N= 260**

**Total approached for consent to contact**

**N= 757**

Between T0 and T2:

Not diagnosed with AS: n= 103

Withdrew from diag. assessment process: n=11

**T4**

**N= 195**

Recruited too late for T4 follow up: n=66

**T5**

**N= 112**

Recruited too late for T5 follow up: n=83

Consent to contact declined: n=187

**Consented to contact**

**N= 570**

Did not consent: n= 130

Not eligible: n= 16

### Analytical plan

The statistical software Stata® 14.2 (StataCorp, College Station, TX, USA) was used.

#### Sample characteristics

Descriptive statistics were used to describe the socio-demographic characteristics of the SAT and ‘Diagnosis Only’ (DO) cohorts. For continuous variables, means, standard deviations, median, maximum and minimum values were calculated. Categorical data were calculated as counts and percentages.

#### Outcomes

Standardised outcome measure scores and outcome indicator data were summarised descriptively at each time point. Mean score, standard deviations, median, and range were used to describe scores on standardised measures. Categorical data were explored using frequency counts and percentages.

Within the SAT cohort, the D&S and SO groups were treated separately for the descriptive analyses. The reason for this was two-fold. First, the nature and range of support and interventions available to the two groups differed, particularly in terms of psychoeducation. Second, their demographic and outcome characteristics differed. Findings from the process evaluation suggesting the two groups differed in their motivations and objectives for seeking support from a SAT (see *Chapter 7*) support this approach. T-tests compared mean scores on standardised outcome measures at T0 and T3, and effect size calculated. Categorical outcome indicators were analysed using contingency tables, McNemar’s chi-square and chi-square tests of symmetry, where necessary response options were collapsed. Similar tests were used to conduct exploratory descriptive analyses of outcomes at 18 (T4) and 24 (T5) months follow-up.

#### Service and individual characteristics affecting SAT cohort outcomes

To investigate the association between individual and service characteristics on T3 outcomes, generalised linear regression modelling techniques were used. Characteristics were added one at a time to the model, with only those significant (p<0.05) retained for the final model. All analyses controlled for age, gender and outcome score at baseline, and accounted for clustering by site.

#### Comparing the DO cohort and D&S group

For the comparison of T3 outcomes of the D&S group and DO cohort, the same approach to an initial analysis of baseline and outcomes data. We then conducted two sets of ANCOVA:

* first, using only WHOQOL-BREF Psychological Domain scores at 12 months
* second, including the following: baseline WHOQOL-BREF Psychological Domain, age and gender.

Analyses were repeated for GHQ-12 (Likert scoring). It was not possible to repeat for EQ-5D-5L because distribution of scores was asymmetric.

## Results: Sample characteristics

Appendix 9 (Table 31) presents the characteristics of study participants.

### Sociodemographic characteristics

***Diagnosis & Support (D&S) group****:* the mean age was 31.1 years (range 18-69 years). Over half (57.1%) were male. The majority (80.4%) were single. Most (60.0%) had received further or higher education. Over half (57.1%) were no longer living with parents. In terms of employment status, the largest group (39.9%) were those unable to work due to illness or disability. Less than a third (30%) were in paid work, a further 8.6% were looking for work and 15.3% were students.

***Support Only (SO) group****:* the mean age was 26.5 years (range 17-55 years). The majority (62.5%) were male. The great majority (90.1%) were single. Most (58.6%) had received further or higher education. Over two thirds (70.5%) were still living with their parents. A third (33.3%) were students, just 13.8% were in paid work with a similar proportion (12.6%) looking for work. Just under a third were unable to work due to illness or disability.

Within the SAT cohort, there were statistically significant differences between the D&S and SO groups in terms of relationship status (chisq=4.740 (df 1), p=0.0295), whether or not living in the parental home (chisq=17.346 (df 1), p=0.000), and the proportion of the sample who were students (chisq=10.669 (df 1), p=0.001). There was also a statistically significant difference in age (p=0.0026, mean difference 4.64 years), with the D&S groupt, on average, older.

***Diagnosis Only (DO) cohort****:* the mean age was 35.23 (range 18-64 years). The majority (64.3%) were male and over two-thirds (67.9%) were single. Most (71.4%) had received further or higher education. Most (62.5%) had left the family home and almost half (45.5%) were in paid employment.

Differences between the D&S group and DO cohort were non-significant except for employment status and age. Here a higher proportion of the DO cohort were working (chisq=4.59 (df 1), p=0.0322) (as opposed to job-seeking/unable to work) compared to the D&S group. There was also a statistically significant difference in age (p=0.0033, mean difference 4.11 years), with the DO cohort, on average, older.

### Outcomes at baseline

Scores on standardised outcome measures at baseline are presented in Appendix 10 (Tables 32 (mental health outcomes) and 33 (other standardised measures)). The SO group WHOQOL-BREF Psychological Domain mean score was significantly higher than the D&S group and DO cohort. No other differences between groups in baseline outcome scores were observed.

### Discharge Status at T3

At T3 (12 months follow-up), SAT cohort study participants were asked to report if they had been discharged (and date of discharge) or were still in the service, see Figure 5. Quality of data was poor; 13.5% of responses was coded as missing data (highly unusual in this study and perhaps indicating uncertainty), and a further 20.1% coded as “study participant uncertain” (based on information provided under the “Other” response option). Just under 40% reported they were still using the service, and over a quarter (26.9%) had been discharged. From the data we have, it would appear that the D&S group were more likely to have been discharged at T3.

Figure 5: Status at T3 (12 months follow-up) (number (%))

When the study was designed, and in consultation with service leads, we had expected the majority of study participants to be discharged by T3.

### Concerns worked on: SAT cohort

At 12 months follow-up (T3), we used a checklist to ask about the concerns they had worked on with the SAT (see Figures 6 and 7). There was no difference between D&S and SO groups in the total number of concerns worked on. However, there were some differences in type of concern. For example, a smaller proportion of the SO group reported working on understanding of autism, living with autism and family members’ understanding of autism. In contrast, compared to the D&S group, greater proportion had worked on employment, financial and social network/relationship issues. Across both, around a third reported they had worked on managing anxiety and/or other emotional difficulties.

Figure 6: Concerns worked on with SAT: D&S versus SO groups

Figure 7: Distribution of D&S vs SO groups in terms of number of concerns worked on

## Results: SAT cohort outcomes

Tables presenting descriptive analysis of outcomes (standardised measures and categorical indicators) at each time-point are presented in Appendix 11 (Tables 34-39). This section focuses on presenting results on changes in outcomes between T0 and T3. At the outset, we note there were no significant differences in baseline (T0) scores on any outcome measures between those retained at T3 and those not retained. There were also no significant differences in socio-demographic characteristics, except men were more likely to drop out of the study compared to women. Overall, retention to the study was over 80%.

### *Mental health*

Table 9 describes changes in mental health outcomes for the D&S and SO groups between T0 and T3. For the both groups, differences in WHOQOL-BREF Psychological Domain and GHQ-12 mean scores at T3 compared to T0 were not significant. In terms of mental health caseness (assessed using movement around sample mean GHQ-12 score at T0, for the D&S group, the size of the proportion of the sample moving to below the GHQ-12 clinical threshold at T3 was statistically significant (p<0.01). This was not the case for the SO group.

Table 9: SAT cohort: change in mental health outcomes: T0 – T3

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **DIAGNOSIS AND SUPPORT (D&S) GROUP** | | | | | | | | | | | | |
| **Outcome** | | | **Sample size** | | **Mean Score** | | **Difference in mean score (95% CI)** | | | **p value** | | **Effect size\*** |
| **T0** | **T3** |
| **WHOQO-BREF Psychological domain** | | | 132 | | 38.43 | 40.09 | 1.65 (-4.11, 0.80) | | | 0.19 | | 0.12 |
| **GHQ-12** | | | 133 | | 18.24 | 17.14 | 1.11 (0.05, 2.26) | | | 0.06 | | 0.16 |
| **GHQ caseness: movement around cut-off point\*\*** | | | | | | | | | | | | |
|  | | | | **T3 (n)** | | | | | | | | |
| above cut-off | | | | below cut-off | | | *Total* | |
| **T0 (n)** | above cut-off | | | 32 | | | | 28 | | | *60* | |
| below cut-off | | | 10 | | | | 63 | | | *73* | |
| *Total* | | | | *42* | | | | *91* | | | *133* | |
| *McNemar’s chisq=8.53 (df 1), exact p=0.0051* | | | | | | | | | | | | |
| **SUPPORT ONLY (SO) GROUP** | | | | | | | | | | | | |
| **Outcome** | | | **Sample size** | | **Mean Score** | | **Difference in mean score (95% CI)** | | | **P value** | | **Effect size\*** |
| **T0** | **T3** |
| **WHOQOL-BREF Psychological Domain** | | | 75 | | 43.31 | 42.60 | 0.71 (-2.43, 3.85) | | | 0.65 | | 0.05 |
| **GHQ-12** | | | 74 | | 17.41 | 17.16 | 0.25 (-1.62, 2.13) | | | 0.79 | | 0.03 |
| **GHQ caseness: movement around cut-off point\*\*** | | | | | | | | | | | | |
|  | | | | **T3 (n)** | | | | | | | | |
|  |  | | | above cut-off | | | | | below cut-off | | *Total* | |
| **T0 (n)** | above cut-off | | | 16 | | | | | 17 | | *33* | |
| below cut-off | | | 18 | | | | | 24 | | *42* | |
| *Total* | | | | *34* | | | | | *41* | | *75* | |
|  | | *McNemar’s chisq=0.8658 (df 1), exact p= 1.0* | | | | | | | | | | |

\*Cohen’s d= (mean2 – mean1)/standard deviation, (d=0.2 small, d=0.5 medium, d=0.8 large effect).

\*\*Caseness: above or below sample mean GHQ-12 score @ T0

### Quality of life

For the D&S group, no statistically significant changes in scores from T0 to T3 were observed on measures of health-related quality of life (EQ-5D-5L), and the other WHOQOL-BREF domains (Social, Physical and Environmental) (see Table 10). This was also the case for the SO group, except for WHOQOL-BREF Social Domain scores where a statistically significant deterioration was observed (p<0.05), representing a small effect.

### Perception of social networks

In terms of perceptions of social networks (measured using the ‘Belonging’ sub-scale of the ISEL Support Evaluation List-Short Form (ISEL-SF)), changes in score between T0 and T3 were not significant for either D&S group or SO group, see Table 10.

Table 10: SAT cohort: changes in quality of life and perception of social network: T0-T3

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Outcome** | **Sample size** | **Mean Score** | | **Difference in mean score**  **(95% CI)** | **p value** | **Effect size\*** |
| **T0** | **T3** |
| **D&S GROUP** | | | | | | |
| **Quality of life domains** | | | | | | |
| Health-related QoL  (EQ-5D-5L) | 130 | 0.70 | 0.68 | 0.03 (-0.01, 0.06) | 0.13 | 0.13 |
| WHOQOL-BREF Social | 133 | 44.64 | 45.39 | 0.75 (-4.80, 3.29) | 0.71 | 0.03 |
| WHOQOL-BREF Physical Health | 131 | 52.52 | 52.91 | 0.40 (-3.00, 2.21) | 0.76 | 0.03 |
| WHOQOL-BREF Environment | 133 | 56.98 | 55.43 | 1.55 (-0.89, 3.99) | 0.21 | 0.11 |
| **Perception of social networks** | | | | | | |
| ISEL-SF: Belonging sub-scale | 132 | 6.84 | 6.79 | 0.05 (-0.42, 0.53) | 0.83 | 0.02 |
| **SO GROUP** | | | | | | |
| **Quality of life domains** | | | | | | |
| Health-related QoL  (EQ-5D-5L) | 74 | 0.73 | 0.72 | 0.01 (-0.04,0.06) | 0.74 | 0.04 |
| WHOQOL-BREF Social | 75 | 47.22 | 41.67 | 5.56 (0.63, 10.49) | 0.03 | 0.23 |
| WHOQOL-BREF Physical Health | 74 | 55.28 | 54.98 | 0.30 (-3.08, 3.68) | 0.86 | 0.20 |
| WHOQOL-BREF Environment | 75 | 57.09 | 55.54 | 1.55 (-1.77, 4.87) | 0.36 | 0.11 |
| **Perception of social networks** | | | | | | |
| ISEL-SF: Belonging sub-scale | 75 | 6.41 | 6.31 | 0.12 (-0.53, 0.75) | 0.74 | 0.04 |

\*Cohen’s d= (mean2 – mean1)/standard deviation, (d=0.2 small, d=0.5 medium, d=0.8 large effect).

### Daily living: occupations and activities

Five categorical indicators of daily living were used in the study:

* Perceived ability to manage the usual activities of daily living, captured using relevant item of ED-5D 5L)
* Perceived sufficiency of information needed for daily living, assessed using relevant item of WHOQOL-BREF
* Change in employment status of those in paid work, job-seeking or unable to work due to illness or disability at T0.
* Satisfaction with capacity for work, assessed using relevant item of WHOQOL-BREF
* Satisfaction with how spend free time, captured using an item designed for this study.

*Managing usual activities of daily living:* In the D&S group at T0, 57 study participants reported they were unable to manage, or had severe or moderate problems managing, the usual activities of daily living, see Table 11. At T3, 26 (45.6%) of these individuals reported no or slight problems in this domain of their life. This change was statistically significant (p<0.05). In the SO group at T0, 24/75 of study participants reported not being able, or having moderate to severe problems, to manage the usual activities of daily living. At T3, 12 of these individuals reported no or slight problems. This change was not statistically significant.

*Availability of information needed for daily living*: The changes in the proportion of the sample reporting having sufficient information for daily living between T0 and T3 was not significant for neither the D&S nor the SO group (see Table 11).

*Employment status*: amongst study participants at T0 in paid work, job-seeking or unable to work due to illness or disability, the proportion reporting a change in employment status (i.e. not working to working), or remaining in work, at T3 was non-significant for the D&S and SO group, see Table 12.

*Satisfaction with capacity for work*: the proportion of the sample reporting changes in their satisfaction with their capacity for work at T3 compared to T0 was non-significant for both D&S and SO groups, see Table 12.

*Satisfaction with how spend free time*: the proportion of the sample reporting changes in satisfaction with how they spend their free time at T3 compared to T0 was non-significant for both D&S and DO groups, see Table 13.

Table 11: SAT cohort: Perceived ability & sufficiency of information to manage daily living

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **MANAGING USUAL ACTIVITIES OF DAILY LIVING (EQ-5D-5L USUAL ACTIVITIES DOMAIN)a** | | | | | | | |
| **D&S group** | | | | | | | |
|  | | **T3 (n)** | | | | |  |
| unable/severe problems | moderate problems | | no/slight problems | | *Total* |
| **T0 (n)** | unable/severe problems | 6 | 3 | | 5 | | *14* |
| moderate problems | 8 | 14 | | 21 | | *43* |
| no/slight problems | 2 | 9 | | 64 | | *75* |
| *Total* | | *16* | *26* | | *90* | | *132* |
| *Symmetry Test: chisq=8.36 (df 3), p=0.0392\** | | | | | | | |
| **SO group** | | | | | | | |
|  | | **T3 (n)** | | | | |  |
| unable/severe problems | moderate problems | | no/slight problems | | *Total* |
| **T0 (n)** | unable/severe problems | 4 | 2 | | 4 | | *10* |
| moderate problems | 3 | 3 | | 8 | | *14* |
| no/slight problems | 3 | 11 | | 37 | | *51* |
| *Total* | | *10* | *16* | | *49* | | *75* |
| *Symmetry Test: Chisq = 0.82 (df3), p=0.846* | | | | | | | |
| **AVAILABILITY OF INFORMATION NEEDED FOR DAILY LIVING (WHOQOL-BREF Q13)a** | | | | | | | |
| **D&S group** | | | | | | | |
|  | | **T3 (n)** | | | | | |
| not at all / a little / moderately | | mostly/  completely | | *Total* | |
| **T0 (n)** | not at all / a little/ moderately | 44 | | 23 | | *67* | |
| mostly /completely | 19 | | 47 | | *66* | |
| *Total* | | *63* | | *70* | | *133* | |
| *Mcnemar’s Chisq Chisq=0.38 (df 1), exact p=0.537* | | | | | | | |
| **SO group** | | | | | | | |
|  | | **T3 (n)** | | | | | |
| not at all / a little / moderately | | mostly/  completely | | *Total* | |
| **T0 (n)** | not at all / a little/ moderately | 26 | | 8 | | *34* | |
| mostly /completely | 14 | | 27 | | *41* | |
| *Total* | | *40* | | *35* | | *75* | |
| *Mcnemar’s Chisq =1.64 (df1), exact p=0.2000* | | | | | | | |

Table 12: SAT cohort: change in employment status & capacity for work: T0-T3

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **EMPLOYMENT STATUSa** | | | | | | | |
| **D&S group** | | | | | | | |
|  | | **T3 (n)** | | | | |  |
| paid work | unable to work due to illness/disability or job-seeking | | | | *Total* |
| **T0 (n)** | paid work | 28 | 7 | | | | *35* |
| unable to work due to illness/ disability or job-seeking | 9 | 44 | | | | *53* |
| *Total* | | *37* | *51* | | | | *88* |
| *Mcnemar’s Chisq = 0.25 (df 1), exact p=0.617* | | | | | | | |
| **SO group** | | | | | | | |
|  | | **T3 (n)** | | | | |  |
| paid work | unable to work due to illness/disability or job-seeking | | | | *Total* |
| **T0 (n)** | paid work | 8 | 0 | | | | *8* |
| unable to work due to illness/ disability or job-seeking | 1 | 26 | | | | *27* |
| *Total* | | *9* | *26* | | | | *35* |
| **SATISFACTION WITH CAPACITY FOR WORK (WHOQOL-BREF Q13)b** | | | | | | | |
| **D&S group** | | | | | | | |
|  | | **T3 (n)** | | | | | |
| very dissat. /dissat. | | neither | very sat. / sat. | *Total* | |
| **T0 (n)** | very dissat. /dissat. | 44 | | 19 | 9 | *72* | |
| neither | 8 | | 11 | 8 | *27* | |
| very sat. / sat. | 58 | | 8 | 17 | *31* | |
| *Total* | | 44 | | 38 | 34 | 130 | |
| *Symmetry Test: Chisq=5.08 (df 3), p=0.1659* | | | | | | | |
| **SO group** | | | | | | | |
|  | | **T3 (n)** | | | | | |
| very dissat. /dissat. | | neither | very sat. / sat. | *Total* | |
| **T0 (n)** | very dissat. /dissat. | 25 | | 11 | 1 | *37* | |
| neither | 5 | | 3 | 4 | *12* | |
| very sat. / sat. | 3 | | 8 | 14 | *25* | |
| *Total* | | *33* | | *22* | *19* | *74* | |
| *Symmetry Test: Chisq= 4.58, (df 3), p=0.205* | | | | | | | |
| a Individuals reporting ‘Other’ (volunteering, student, maternity/paternity leave, parent/carer, retired) excluded from this analysis..  b Response categories collapsed as indicated. | | | | | | | |

Table 13: SAT cohort: change in satisfaction with how spend free time: T0-T3

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **D&S group** | | | | |
| I am satisfied with how I spend my free timee | | **T3 (n)** | | |
| true | false | *Total* |
| T0 (n) | true | 42 | 21 | *63* |
| false | 21 | 48 | *69* |
| *Total* | | *63* | *69* | *129* |
| *Mcnemar’s Chisq =0.00 (df 1), exact p=1.000* | | | | |
| **SO group** | | | | |
| I am satisfied with how I spend my free timee | | **T3 (n)** | | |
| true | false | *Total* |
| T0 (n) | true | 29 | 11 | *40* |
| false | 13 | 22 | *35* |
| *Total* | | *42* | *33* | *75* |
| *Mcnemar’s Chisq =0.17 (df 1), exact p=0.683* | | | | |
| a Response categories collapsed as indicated. | | | | |

### Access to autism specific networks and support

*Membership:* No significant changes in membership of local/regional/national autism-specific voluntary sector organisation and/or an on-line forum/community was observed in the D&S group or the SO group. In both groups, at T3 the great majority were not members of any such group or organisation (D&S=109/132 (82.6%); SO=62/74(83.8%) (see Table 14).

*Contacts:* In terms of contacts with any autism-specific third sector organisations, at T0, 113/133 (84.9%) of the D&S group had had no contact with any such organisations in the previous four weeks (see Table 14). By T3, 26 (23.0%) of the T0 ‘no-contact’ group had had some sort of contact with an autism-specific organisation in the previous four weeks. This change was statistically significant (p<0.01). This overall positive change in contacts with autism-specific third sector organisations was not observed in the SO group. However, at T0, a greater proportion of individuals had been in contact with such an organisation compared to the D&S group (D&S=20/133 (15.1%); SO: n=18/74 (24.4%)).

Table 14: SAT cohort: change in access to AS networks & support: T0-T3

|  |  |  |  |
| --- | --- | --- | --- |
| **MEMBERSHIP OF AUTISM-SPECIFIC VOLUNTARY ORGANISATIONS / ON-LINE COMMUNITY** | | | |
| **D&S group** | | | |
|  | **T3 (n)** | |  |
| **T0 (n)** | Member of org. and/or community | No membership | *Total* |
| Member of org.and/ community | 2 | 6 | *8* |
| No membership | 21 | 103 | *124* |
| *Total* | *23* | *109* | *132* |
| *Mcnemar’s Chisq =2.00 (df 1), exact p=0.1573* | | | |
| **SO group** | | | |
| **T0 (n)** | Member of org. and/or community | No membership | *Total* |
| Member of org.and/ community | 5 | 7 | *13* |
| No membership | 8 | 54 | *61* |
| *Total* | *12* | *62* | *74* |
| *Mcnemar’s Chisq =0.07 (df 1), exact p=0.7963* | | | |
| **ANY CONTACT WITH AUTISM-SPECIFIC VOLUNTARY ORGANISATIONS / COMMUNITIES?** | | | |
| **D&S group** | | | |
|  | **T3 (n)** | |  |
| **T0 (n)** | 1 + contact | No contact | *Total* |
| 1 + contact | 11 | 9 | *20* |
| No contact | 26 | 87 | *113* |
| *Total* | *37* | *98* | *133* |
| *Mcnemar’s Chisq =8.53 (df 1), exact p=0.0051\** | | | |
| **SO group** | | | |
|  | **T3 (n)** | |  |
| **T0 (n)** | 1 + contact | No contact | *Total* |
| 1 + contact | 8 | 10 | *18* |
| No contact | 7 | 49 | *56* |
| *Total* | *15* | *59* | *74* |
| *Mcnemar’s Chisq =0.4669 (df 1), exact p=0.6291* | | | |

### Longer-term outcomes

For individuals recruited early to the study, the opportunity was taken to collect longer-term follow-up data at 18 (T4) and 25 (T5) months (D&S group: T4, n=94/133; T5, n=62/133; SO group: T4, n=56/88); T5, n=42/88). Tables reporting our descriptive analyses are presented in Appendix 12. We offer a brief overview of findings here.

*Mental health*: For the D&S group, at T4 no statistically significant changes in mental health outcomes were observed (Appendix 12, Table 40). At T5, and not observed at T3, statistically significant improvements in scores on the WHOQOL-BREF Psychological Domain (p<0.01, small effect size) and GHQ-12 (p<0.05, small effect size) were observed (Appendix 12, Table 40). However, unlike at T3, movement of the sample from above to below the clinical threshold (using sample mean as the threshold) was non-significant.

For the SO group, a statistically significant deterioration in WHOQOL-BREF Psychological Domain score between T0 and T4 was observed (p<0.001, medium effect size) (Appendix 12, Table 41). However, by T5 this deterioration, while still observed, was non-significant (Appendix 12, Table 41). In terms of other mental health outcomes, no statistically significant changes were observed between T0 and T4 and T0 and T5. This pattern of results replicates T0 to T3 findings.

*Quality of life:* For the D&S group, no statistically significant changes in scores on quality of life measures (EQ-5D-5L, WHOQOL-BREF Social, Physical Health and Environment domains) were observed between T0 and T4 and T0 and T5 (Appendix 12, Table 42). These finding align with those observed for T0 to T3.

For the SO group, there were no statistically significant differences in scores on these measures between T0 and T4 scores or T0 and T5 scores (Appendix 12, Table 43). This aligns with T0 to T3 findings, except for that time period a significant deterioration in WHOQOL- BREF Social Domain scores was observed.

*Perception of social networks*: For the D&S group no statistically significant changes were observed between T0 and T4 and T0 and T5 (Appendix 12, Table 42) in study participants perceptions of the quality of their social networks (ISEL-SF, Belonging subscale). For the SO group, the findings were the same (Appendix 12, Table 43). All these findings align with those observed for T0 to T3.

*Daily living: occupations and activities:* For the D&S group, just under half (48.8%) of those reporting unable to/severe/moderate problems managing usual daily activities at T0, reported no or slight problems at T4 (Appendix 12, Table 44). This aligns with T0-T3 (statistically significant) findings. This proportion increases when comparing T0 and T5 (59.3%), with this increase being significant (p<0.05) (Appendix 12, Table 45). No other statistically significant changes in our indicators of daily living (i.e. perceived availability of information needed for daily living, employment status, satisfaction with capacity for work and how spend free time) between T0 and T4 and T0 and T5 were observed. This aligns with T0-T3 findings.

For the SO group, half (10/20) of study participants reporting unable to/severe/moderate problems managing activities of daily living at T0 reported no/slight problems at T4 (Appendix 12, Table 46). A similar proportion (9/18) also observed at the T5 timepoint (Appendix 12, Table 47). These proportions are similar to those observed T3 and, as for the T0- T3 analysis. Changes in the proportions of the T4 and T5 samples reporting a positive change in availability of information to manage daily life and satisfaction with leisure time compared to T0 were non-significant. The overall patterns of results appear to be similar to T0 – T3.

*Membership of autism-specific organisations/communities*: In the D&S group, at T4 the proportion of individuals who had become members of an autism-specific organisation since T0 (13.7%) was similar to that observed at T3 (Appendix 12, Table 48). By T5, however, the proportion of T0 non-members reporting to have become a member of an autism-specific organisation had increased to 20.6% (Appendix 12, Table 48). In terms of contact with such organisations in the previous four weeks, at T4 15.3% of those at T0 reporting ‘no contact’ had had at least one contact with such an organisation in the previous 4 weeks. At T5, this proportion rose to 24.5% - a figure similar to that observed at T3 (and which was statistically significant). At both time-points, cell counts preclude testing for clinical significance.

For the SO group, as at T3, very few individuals not members of autism-specific organisations at T0 had become members, either at T4 or T5 (Appendix 12, Table 49). Finally, in terms of contacts with autism-specific organisations in the previous four weeks, as at T3, only a small minority had had any contact with such groups in the four weeks prior to T4 and T5.

## Results: service & individual characteristics associated with SAT cohort outcomes.

A key objective of quantitative evaluation was to investigate whether particular service or individual characteristics are associated with outcomes. For these analyses, we focused only on mental health outcomes.

The selection of characteristics to explore in the quantitative evaluation was strongly informed by findings from the mapping study (*Chapter 2*) and our qualitative research with SAT practitioners (*Chapters 4 and 5*) and service users (*Chapters 7 and 9*). Individual characteristics are set out in Table 15, they include socio-demographic characteristics, diagnostic status at referral, health and functioning at referral, informal resources and support at 12 month follow-up (T3), input from the SAT on self-management, and status in the service at T3. Service characteristics (see Table 16) focused on high level organisational, structural and delivery features.

Table 15 Individual characteristics hypothesised to be associated with outcomes

|  |  |
| --- | --- |
| **Characteristic** | **Variable** |
| **Socio-demographics** |  |
| Age | Age in years |
| Gendera | Male; female |
| **Diagnostic status at referral** |  |
| Reason for referral | Diagnosis & Support vs Support Only |
| **Health and functioning @ T0** |  |
| Mental health at referral (T0) | T0 GHQ score (Likert scoring) |
| Functioning at referral (T0) | T0 EQ-5D-5L ‘Usual activities’ domain scorec |
| **Informal resources & support @ T3** |  |
| Social networks @ T3 | T3 Interpersonal Support Evaluation List (ISEL-SF): Belonging (BE) subscale score |
| Perceived availability of information to manage day to day life @ T3 | T3 WHOQOL-BREF Q13d (*Availability of information needed in day to day life*). |
| Contact with autism-specific groups/communities @ T3 | Contact vs no contact with AS-specific organisation/on-line community in previous 4 weeks |
| **Status in service** |  |
| Still under SAT @ T3 | In service vs discharged |
| a Insufficient number in the ‘neither’ gender category (n=9) to include in the analysis  b Response categories collapsed: very/dissatisfied vs neither dissat/satis vs very/satisfied  c Response categories collapsed: no / slight problems vs moderate / severe problems & unable  d Response categories collapsed: not at all/a little/moderately vs mostly/completely  e Responses to T3 question: what concerns did the service work on with you, focusing on ‘self-management’ concerns: *understanding of autism; managing anxiety/other emotions; living with autism, connecting with other autistic people/communities (0 vs 1/2 vs 2=3/4)* | |

Table 16 Service characteristics hypothesised to be associated with outcomes

|  |  |  |
| --- | --- | --- |
| **Service characteristic** | **Variable value (or label)** | **Allocation of research sites to characteristic** |
| **Organisational/structural characteristics** | | |
| LA involvement  *[Indicator of social care expertise and easier access to LA support]* | CCG | A, B, C, D, E, F |
| Joint CCG / LA | Ha, Hb, IA, J |
| Single vs multi-service team  *[D&S group only]* | Single service | A, B, CA, E, F, IA, J |
| Multi-service | D, Ha, |
| **Diagnostic assessment process [D&S group only]** | | |
| Autism only vs ND service | Autism only | A, B, F, J |
| ND | CA, D, E, Ha, IA |
| Dominant mode of delivering psychoeducation post-diagnosis | Group | A, B, F, Ha, IA |
| 1:1 | CA, D, E, J |
| **Delivery** | | |
| Skill mix (in addition to clinical psychology, number of professional disciplines represented on team) *[Indicator of degree to which SAT takes an holistic approach]* | 2-3 disciplines | A, B, Ca, D, Ha, Hb |
| 4+ disciplines | E, F, IA, J |
| Routinely do 1:1 work re MHPs | Yes | A, B, CA, D, F, IA, J |
| No | E, Ha, Hb |
| Delivery of care plan | Managed | A, B, Ca, D, Ha, Hb, IA, J |
| Episodic | E, F |
| Drop in provision and/or named contact whilst in service | Yes | A, Ca, D, Ha, Hb, J |
| No | B. E, F, IA |
| **Discharge practice (separate analysis: outcomes @ T4/T5)** | | |
| Type of discharge | Closed | E, F, IA, J |
| Stepped | A, B |
| Open | Ca, D, Hb |

Generalised linear regression modelling techniques were used. Characteristics were added one at a time to the model, with only those significant (p<0.05) retained for the final model. All analyses controlled for age, gender and outcome score at baseline, and accounted for clustering by site.

Modelling statistics (statistical significance, regression coefficients, and 95% CIs were used to allocate characteristics to one of four categories:

* **strong** evidence found of an association between the characteristic and the outcome measure
* **some** evidence found of an association between the characteristic and the outcome measure
* **weak** evidence found of an association between the characteristic and the outcome measure
* **no evidence** found of an association between the characteristic and the outcome measure.

### Characteristics with no evidence of association with T3 mental health outcomes

Regression analysis explored, one at a time, the association between individual and service characteristics and mental health outcomes (WHOQOL-BREF Psychological Domain, GHQ-12). Individual characteristics where no evidence was found of an association between the characteristic and T3 mental health outcomes were:

* diagnostic status at referral (i.e. SAT-D&S vs SAT-SO)
* functioning at referral (EQ5D-5L usual activities domain)
* contact with autism-specific groups/communities @ T3

Status in service (i.e. discharged vs still in service) was significantly associated with T3 mental health outcomes. However, it was not taken forward to modelling due to the high level of missing data (42/180, 23%).

Service characteristics where we found no evidence of an association between the characteristic and T3 mental health outcomes were:

* Local Authority involvement in commissioning/funding service (taken to indicates social care expertise & easier access to LA services)
* single vs multi-team service structure
* autism vs neurodevelopmental service
* mode of delivering psychoeducation post-diagnosis
* whether or not routinely do 1:1 work for (non-complex) mental health problems

### Characteristics with evidence of association with mental health outcomes

Tables 17 and 18 present outputs from the multiple regression modelling for T3 WHOQOL-BREF Psychological Domain and GHQ-12 respectively. Varying degrees of strength of evidence of association (almost always in the same direction) were observed for all individual and service characteristics with one or both the mental health outcomes.

#### Individual characteristics

* *Age*: there was moderate evidence of an association between age and WHOQOL-BREF Psychological Domain score at T3, but no evidence of association found between age and GHQ-12 scores.
* *Gender*: there was moderate evidence of an association between gender (women faring worse) and GHQ-12 score at T3, and a weak association between gender (women faring worse) for WHOQOL-BREF Psychological Domain score at T3.
* *Mental health at entry to service*: there was moderate evidence of an association between T0 GHQ-12 scores and WHOQOL-BREF Psychological Domain scores at T3.
* *Informal social networks*: there was strong evidence of an association between T3 ISEL-SF BE subscale scores (perceived availability of social network) and WHOQOL-BREF Psychological Domain and GHQ-12 (Likert) scores at T3.
* *Availability of information (WHOQOL-BREF, q13)*: there was strong evidence of an association between perceived availability of information to manage everyday life and WHOQOL-BREF Psychological Domain and GHQ-12 scores at T3, with greater sufficiency of information associated with better mental health outcomes.

#### Service characteristics

* *Skill mix*: there was strong evidence of an association between skill mix and both mental health outcomes, with greater skill mix (that is, four or more professional disciplines working in the service) associated with better outcomes.
* *Delivery of care plan*: evidence of a weak association between WHOQOL-BREF Psychological Domain and GHQ-12 scores at T3 and delivery of the care plan was found, with managed (as opposed to episodic) care associated with better outcomes.
* *Drop-in provision and/or named contact*: no evidence of an association was found between this characteristic and WHOQOL-BREF Psychological Domain outcome scores at T3. For GHQ-12 score at T3, there was moderate evidence that lack of drop-in/named contact was associated with better T3 scores.

Table 17 Multiple regression model: T3 WHOQOL-BREF (Psychological Domain) & individual and service characteristics

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Coefficient** | ***p*-value** | **95% CI** |
| T0 WHOQOL-BREF Psychological Domain score | 0.55 | 0.000 | (0.39, 0.72) |
| **Individual characteristics** | | | |
| Age (years) | 0.09 | 0.007 | (0.02, 0.15) |
| Gender (ref: male) | 1.00 |  |  |
| female | -2.37 | 0.077 | (-5.01, 0.26) |
| T0 GHQ-12 score | -0.49 | 0.023 | (-0.92, -0.07) |
| T3 ISEL-SF BE subscale score | -1.34 | 0.002 | (-2.18, -0.50) |
| T3: Availability of information  (ref: not/little/moderately) | 1.00 |  |  |
| mostly/completely | 5.52 | 0.032 | (0.47, 10.56) |
| **Service characteristics** | | | |
| Skill Mix (ref: 0-2 disciplines) | 1.00 |  |  |
| 4+ disciplines | 7.39 | 0.001 | (3.18, 11.61) |
| Delivery of care plan (ref: Episodic) | 1.00 |  |  |
| managed | 4.59 | 0.082 | (-0.58, 9.75) |
| Drop in provision and/or named contact whilst in service (ref: yes) | 1.00 |  |  |
| no | 0.34 | 0.684 | (-1.29, 1.97) |
| *Constant* | *26.15* | *0.000* | *(11.68, 40.61)* |

Table 18 Multiple regression model: T3 GHQ-12 & individual and service characteristics

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Coefficient** | ***p*-value** | **95% CI** |
| T0 GHQ-12 score | 0.37 | 0.000 | (0.25, 0.49) |
| **Individual characteristics** | | | |
| Age (years) | 0.03 | 0.531 | (-0.07, 0.13) |
| Gender (ref: male) | 100 |  |  |
| female | 1.44 | 0.033 | (0.12, 2.76) |
| T3 ISEL-SF BE subscale score | 0.60 | 0.000 | (0.30, 0.91) |
| T3: Availability of information  (ref: not/little/moderately) | 1.00 |  |  |
| mostly/completely | -2.86 | 0.009 | (-5.02, -0.70) |
| **Service characteristics** | | | |
| Skill Mix (ref: 0-2 disciplines) | 1.00 |  |  |
| 4+ disciplines | -2.14 | 0.000 | (-3.33, -0.96) |
| Delivery of care plan (ref: Episodic) | 1.00 |  |  |
| managed | -1.00 | 0.064 | (-2.05, 0.06) |
| Drop in provision and/or named contact whilst in service (ref: yes) | 1.00 |  |  |
| no | -1.58 | 0.005 | (-2.70, -0.47) |
| *Constant* | *8.51* | *0.000* | *(4.03, 12.99)* |

## Results: comparison of D&S group & DO cohort

The final component of our quantitative evaluation of Specialist Autism Teams was to compare outcomes of individuals not previously diagnosed with autism in terms of their care pathway. That is, either they had accessed a Specialist Autism Team (D&S group of the SAT cohort) or had accessed a regional/national diagnostic assessment service (DO cohort). We report findings from qualitative interviews with service users relevant to this element of the study in Chapter 9.

The opportunity to incorporate a DO cohort into the study emerged part way through the study and was carried out with the full support of the Study Steering Committee and funder. At the time this element of the study was conceived, there were very few existing studies from which to base power calculations. This affected the accuracy of our original power calculations and, as revealed by post-hoc power calculations, resulted in an underestimation of sample size requirements. Thus findings should be treated as preliminary.

### Changes in mental health around the point of diagnosis

A descriptive analysis of mean GHQ-12 scores at T0, T2 (post-diagnosis time-point) and T3 (12 month follow-up) was carried out and results for the D&S group and DO cohort compared, see Figure 8.

Figure 8: Mean GHQ-12 scores at baseline, post-diagnosis and 12 month follow-up: DO cohort and D&S group

 

The overall trajectory of mean GHQ-12 score for the D&S group was in a positive direction. This was not the case for the DO cohort, with evidence of a deterioration between T0 and T2.

### Outcomes at 12 months follow-up

No statistically significant changes in DO cohort mental health outcomes were at T3 compared to T0 (see Table 19).

Table 19: DO cohort: change in mental health outcomes: T0 – T3

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Outcome** | | **Sample size** | | **Mean Score** | | **Difference in mean score (95% CI)** | | **P value** | | **Effect size\*** |
| **T0** | **T3** |
| **WHOQOL-BREF Psychological Domain** | | 52 | | 34.47 | 38.54 | 4.071 (-9.25, 1.11) | | 0.12 | | 0.22 |
| **GHQ-12** | | 52 | | 19.60 | 18.40 | 1.192 (-1.39, 3.78) | | 0.36 | | 0.13 |
| **GHQ caseness: movement around cut-off point\*\*** | | | | | | | | | | |
|  | | | **T3 (n)** | | | | | | | |
| above cut-off | | | | below cut-off | | *Total* | |
| **T0 (n)** | above cut-off | | 12 | | | | 9 | | *21* | |
| below cut-off | | 10 | | | | 21 | | *31* | |
| *Total* | | | *22* | | | | *30* | | *52* | |
| *McNemar’s chisq= 0.05 (df 1), exact p= 1.00* | | | | | | | | | | |

\*Cohen’s d= (mean2 – mean1)/standard deviation, (d=0.2 small, d=0.5 medium, d=0.8 large effect).

\*\*Caseness: above or below GHQ-12 mean score at baseline.

Similarly, no statistically significant changes in outcomes were observed in terms of quality life (EQ-5D-5L, WHOQOL-BREF Social, Physical and Environment domains) and perceptions of social networks (ISEL-SF Belonging subscale) (Appendix 13, Table 50). Likewise, no changes were observed on indicators of daily living nor regarding access to autism-specific networks (Appendix 13, Tables 51 and 52).

### Comparing T3 mental health outcomes for DO cohort and D&S group

We then used ANCOVA to compare T3 mental health outcomes of the DO cohort and D&S group. This was repeated restricting the D&S group to those individuals who used SATs which also provided a regional diagnostic service and recruited to the DO cohort. Outputs presented in Appendix 14 (Table 53: WHOQOL-BREF Psychological Domain; Table 54: GHQ-12). No significant differences in mental health between the two groups were observed at T3.

## Summary

This chapter has reported findings from the quantitative elements of our observational study. First, we presented a descriptive account of outcomes, and changes in outcomes, of users of Specialist Autism Teams (SATs), separated into two groups according to the reason for their referral to the SAT (Diagnosis and Support (D&S) vs Support Only (SO)). Second, we reported our investigation into the association between certain service and individual characteristics and outcomes. Finally, we presented findings from an initial exploration of differences in outcome between individuals diagnosed and then supported by a Specialist Autism Team (D&S group) and individuals who used a diagnostic assessment only service (DO cohort).

A statistically significant, positive change in the proportion of study participants scoring below the GHQ-12 clinical threshold (sample mean) was observed in the D&S group but not the SO group. No other significant changes in mental health outcomes were observed. No statistically significant changes in perceived social support and other quality of life domains were observed in the D&S group. In the SO group, a deterioration social quality of life was observed.

With respect to daytime occupation/usual activities, in the D&S group, a statistically significant proportion of study participants reported no longer having severe or moderate problems managing the usual activities of daily living at T3. This was not observed in the SO group. No statistically significant changes in other indicators of daytime occupation/activities (that is, perceived availability of information required for daily living, employment, satisfaction with capacity for work and satisfaction with leisure time) were observed in either group.

In terms of access to autism-specific networks and support. For the D&S group, whilst the proportion in membership of an autism-specific organisation/community did not change, a statistically significant proportion who reported no contacts with such organisations at T0, reported at least one contact in the four weeks prior to T3 data collection. This was not observed in the SO group.

Our second set of analyses investigated the association between individual and service characteristics on mental health outcomes. We found no evidence of an association between T3 mental health outcomes and diagnostic status at referral (i.e. D&S vs SO), functioning at referral, or contact with autism-specific communities. We also found no evidence of an association between T3 mental health outcomes and the following service characteristics: Local Authority involvement, service structure (single vs multi-team), autism vs ND service, predominant mode of delivering psychoeducation (group vs 1:1), whether service routinely offers 1:1 work for (non-complex) mental health problems.

Multiple regression modelling work found moderate evidence of an association between at least one mental health outcome and age and gender. There was also strong evidence of an association (in a positive direction) between mental health outcomes and social support, and greater sufficiency of information to manage everyday life at T3. Furthermore, there was strong evidence that richer skill mix was associated with better mental health outcomes. In addition, weak evidence was found of an association between how the care plan was delivered (managed vs episodic) and mental health outcomes (favouring managed care). For the final service characteristic taken forward to the modelling work, the evidence regarding the association between access to drop-in provision and/or a named contact was equivocal.

Finally, we reported findings from an initial exploration of outcomes of individuals who used a regional diagnosis assessment service (DO cohort), comparing them to individuals diagnosed by a SAT (D&S group). First, we looked at the trajectory of mental health outcomes. This exploratory analysis indicates a potential differential impact of receiving a diagnosis of autism between the DO cohort and the D&S group. Second, we compared DO cohort outcomes at baseline (T0) with outcomes at the 12 month follow-up time point (T3); no statistically significant changes were observed. Finally, we compared T3 mental health outcomes of the DO cohort with our D&S group. No significant differences were observed. We would note these analyses were underpowered and therefore no conclusions can be drawn. However, the lack of improvement in outcomes of the DO cohort at 12 months follow-up, and deteriorations in mental health outcomes in the immediate post-diagnosis time period, do indicate areas of potential concern which require further research. The following chapter reports findings from a second, qualitative component of this work in which we describe and compare the experiences of individuals from the D&S group and DO cohort.

# Experiences of an autism diagnosis with and without post-diagnosis support

## Introduction

This chapter reports the experiences and impacts of receiving an autism diagnosis, comparing the accounts of those who received extended psychoeducation and access to other support (D&S group of SAT cohort) with those who only received a diagnostic assessment (our DO cohort). This chapter thus presents our second set of evidence on this topic, with the previous chapter reporting findings from an initial comparative exploration of outcomes.

## Methods

Given we report our qualitative research with service users over two non-consecutive chapters, we have chosen to report the methods in an appendix (see Appendix 6). To summarise, 37 autistic adults were interviewed and ten family members. The sample comprised 22 individuals from the SAT cohort’s D&S group (representing all research sites), and nine from the DO cohort (representing the main research site which recruited to the DO cohort plus one of the other two). In terms of family members, three were relatives (all parents) of individuals in the DO cohort, and eight were relatives of individuals in the SAT-D&S cohort.

Findings are organised around five topics:

* hopes and expectations on referral for diagnostic assessment;
* emotional responses to the diagnosis;
* experiences of follow-up session(s) and psychoeducation;
* several months on: the perceived impacts of the diagnosis.

We note there is, on occasion, a small overlap between the findings reported in this chapter and those of Chapter 7. This has been necessary in order to provide sufficient context to some of the findings.

## Hopes and expectations on referral

Many interviewees had suspected they were autistic for some time, often years, prior to the diagnostic assessment. A minority, however, did not think this was the case and only agreed to the assessment to satisfy the referring practitioner. Some interviewees reported that, at the time of referral, they were having one or more, sometimes quite substantial, difficulties in their lives for which they were seeking help and support (e.g. mental health problems, independent living, social isolation, adjustments at work or college). A few also recalled hoping that a diagnosis would help others (e.g. family, work colleagues) to understand them better.

## Emotional responses to the diagnosis

Although interviewees had typically been seeking a diagnosis, reactions were multi-faceted and often shifted over time. Most interviewees said that, at least initially, they had reacted positively to the diagnosis, referring to primarily to feelings of ‘relief’. This relief centred on having an explanation for, and validation of, the struggles they had experienced in their life. For some this put an end to years of not being believed or, in their experience, being perceived as ‘mad’, ‘crazy’, or ‘a pain’.

*Me and my mum sat and cried with relief, because my mum thought she was going barmy, and it was just more of a relief that somebody like professional actually had acknowledged what we’d said and finally agreed with us….. So it was just a lot of relief that somebody had actually listened and believed what I was saying*. (SU28)

Some further articulated a sense of hope that they would (finally) get the help they needed and be able to make changes to their life.

*I’m not mad, this is the way I’m made. Yay, I can get help. (SU30)*

However, it was common for initial feelings of relief to be combined with, or superseded by, feelings of shock, anxiety and confusion. The following extract is the same interviewee as the penultimate quote above.

*I think I found it quite difficult initially. I’d got the clarity and it was nice to have it recognised, but then at the same time it was like, well got this label now, right, what do I do with it? And then trying to come to terms with it and accepting it was difficult. (SU28)*

And another interviewee said:

*In the first couple of days it was quite a relief to understand that these problems that I was having, or I am having, should I say ….. it made me think, “Right, I can deal with that now”. So that was helpful. But then sort of from that, the next few weeks, months, it just kind of ate away at me every single day. I just kind of thought, “Oh my god, I’ve got this condition, I don’t know what it means, I don’t know how to deal with it, I don’t know how to live a normal life now.” (SU32)*

For a small minority of participants, the immediate reaction was entirely negative. They attributed this to not wanting to have ‘something wrong’ with them, particularly something that was not ‘curable’.

*After she’d given me the diagnosis, I was like “Right, so what can I do about it?”. And she said “You don’t sound very happy.” [And I said..] “No, well obviously I’m not very happy because someone’s just told me I can’t do certain things. Just by saying to me you’re autistic, that’s telling me you can’t do anything about it.” I’m a doer, I spend my life finding ways to deal with things, even if I can’t solve it I need to be able to do something. So I felt quite at a loss. (SU33)*

Whether or not interviewees described their initial reaction as positive or negative, feelings of frustration and loss featured in many interviewees’ accounts of their reaction to diagnosis. Interviewees of all ages had reflected on how life might have been different if they had been diagnosed earlier in life.

*Initially the Asperger's diagnosis upset me more than other mental health diagnoses I'd had in the past and I couldn't explain why. I was diagnosed at age 58 and I'd loved to have known much earlier than that because then I could have tried to moderate or control it and my life could have been different, relationships might have worked.* (SU1)

*I was grieving the fact that if I had been diagnosed when I was nine I might not have been suicidal ….. and I might never have been homeless and I might have received the support that I clearly so desperately needed (SU35)*

As the following quote demonstrates, for at least some people, grief and loss remained an experience a year after receiving the diagnosis.

*I’m grieving twenty lost years of my life. And I think perhaps there’s something there about adult diagnosis that is not necessarily taken seriously enough. Most of us have gone through hell and back. From speaking to others, a lot of us have gone through awful things as much because we were misdiagnosed or undiagnosed, as because of our autism itself. (SU35*)

Interviewees also described finding it difficult to understand how they could have struggled with life for so many years, coming into contact with a wide range and/or number of practitioners over that period, but without their autism being recognised. Some described feelings of frustration and anger towards practitioners and/or family members. Again, for some, this sense of frustration was still being experienced when we interviewed them several months after receiving the diagnosis.

*I was also a bit frustrating thinking, “I'm in my late 40's and nobody has noticed this. How can it have gone on for so long with all the problems at school and with other things and nobody noticed?” I feel a bit annoyed with my parents they didn't pick up on it. At school they knew I was having massive problems and stuff. That side of it frustrates me, because they've been living with it as well, and have difficulties with this and that. (SU15)*

### Family members’ accounts

Family members’ accounts of their partner or son/daughter’s reaction to learning their diagnosis fell quite evenly into one of three types. First, relief: indeed a parent recalled being surprised at the level of their son’s relief, and realising they had been unaware of how much the diagnosis meant to their child.

*He was thrilled to know why he’d been feeling the way he had for so long, and we didn’t know he was suffering like that. (F3)*

Others described their relative’s reaction as neutral or ambivalent. Interestingly these observations did not always tally with their partner or child’s account where, as well as providing a new understanding of themselves, feelings of shock, depression and anxiety were described.

Third, some reported a very negative reaction, with one describing high levels of distress:

*The diagnosis completely floored her. She was beside herself and because she suffers with other mental health issues she literally says, “Well that’s it, my life’s over, I may as well not even be here*”. (F9)

Another spoke of how, although she felt very positive about her son getting a diagnosis because it “opened doors all over the place”, her son’s response had been very different. She further explained that he still (approximately 12 months after diagnosis) got “depressed” if he thought about it.

## Experiences of follow-up session(s) and psychoeducation

For the DO cohort, the diagnostic assessment package purchased by the referring agencies included the offer of a single follow up meeting. Some also offered a single post-diagnosis/psychoeducational group session.

In contrast, those using a SAT were offered at least one follow up session, plus a psychoeducation intervention delivered either via group and/or a series of one-to-one sessions (see *Chapter 3*). The objective of psychoeducation is to increase understanding of autism, self-understanding and self-management skills (see *Chapters 2 & 4*).

It was at this point, therefore, that the experiences of care and support diverged significantly for DO and SAT (D&S group) cohorts. Furthermore, while many DO cohort interviewees said those providing the assessment had made it clear there would be no longer-term support after the diagnostic assessment, there was some evidence that at least some may not have fully appreciated the limits to what the service could offer.

## DO cohort interviewees

These interviewees consistently described the follow up session as including: a discussion of the written report of the diagnostic assessment; being provided with information leaflets about autism; being encouraged to seek further information from the internet; and being signposted to relevant services.

Two elements of this session were regarded as valuable and helpful: explanations as to which aspects of their difficulties were linked to autism (and which were not), and advice on living with autism (e.g. encouragement to develop daily routines, techniques for avoiding ‘meltdowns’).

However, shortcomings and concerns with regard to other aspects of the feedback session were described. First, some reported information leaflets were age inappropriate (e.g. targeted at young people) or included negative suggestions about what autism meant for people. Second, some who had followed the advice to use the internet as a source of information described coming across information and statistics that were highly negative about the implications of being autistic. This rendered interviewees feeling worried for the future.

Finally, signposting to other services (e.g. social services, employment advisors etc.) was typically regarded as ineffectual and even demoralising. All those advised to contact other services had not done so, pointing out that the very fact they were autistic made this difficult, even if they were ‘high-functioning’.

*They* [service] *say your diagnosis opens doors. What doors? I find that quite difficult, because somebody, for me, has to open the door else I can’t get through it. (SU33)*

Thus, a clear and strong theme in DO cohort interviewees’ accounts was the insufficiency of the input they had received after receiving the diagnosis. Indeed, for some, there was a sense of an experience of abandonment in their accounts.

*What I got was I got a diagnosis and then they gave me a few leaflets and said “There you go, good luck, you won’t be seeing us again, take care, bye.” And that was really frustrating. (SU27)*

*You shouldn’t be diagnosed and then left to your own devices.* *There was disappointingly little*…*I got something from them [the diagnosis].* *I suppose I should be grateful for that. Some people get nothing at all.* (SU10)

Among those interviewees who described being shocked or confused by their diagnosis, the limited nature of follow up support seemed to be particularly problematic, exacerbating negative emotional responses. For example, one participant, who had not expected to be diagnosed, said that discharge left her feeling like she had been in a *‘hit and run accident’*. Another participant said that if had not been for the support offered by people outside the service he would have felt like he had been ‘*hung out to dry’.*

### Family members’ accounts

Where the service user’s reaction was neutral or relieved, and/or it felt like there was little need for support, parents were satisfied with input received. In contrast to this, a parent whose daughter became very upset by the diagnosis describing contacting the service for advice and was dismayed that nothing could be offered other than a follow up session scheduled a number of weeks later, once reports had been completed.

## SAT cohort interviewees

SAT cohort interviewees who attended the psychoeducation intervention offered were, overall, very positive about this intervention.

*It ended a lifetimes worth of feeling inadequate and feeling worthless. (SU36)*

*It was valuable beyond words. It [the diagnosis] could have been life-changing in a way that left me stranded and in fact it has been life-changing in a way that’s given me enormous support and enormous hope, and a new capacity for thinking about myself and the world around me*. *(SU35)*

Aspects of the intervention identified as particularly helpful included:

* content which gave insight into how autism may affect them, including the positive aspects of the condition
* content on dealing with disclosure of diagnosis
* learning coping techniques for dealing with difficulties commonly experienced by autistic adults (i.e. sensory overload, anxiety, dealing with social situations etc.)
* being directed to other reliable sources of information
* listening to and/or sharing experiences (group delivery only);
* speakers with positive stories of living with autism (group-delivery only);

A dominant theme in these individuals’ accounts was the impact on how they viewed themselves. They spoke about feeling more accepting or forgiving of themselves. Some also described feeling less need to mask autistic behaviours, and/or the positive aspects of being autistic.

*It helped me gain a deeper understanding of my own struggles and why I have them, but it also emphasised that having autism has given me a lot of strengths which is not something I had considered before. (SU36)*

However, a small proportion had not accessed any psychoeducation input. For the majority this was because the SAT they used only offered a group-delivered intervention which they were unable, or unwilling, to attend. In addition, one interviewee had waited a year before receiving psychoeducational input. He described enduring months of sleep difficulties, regularly staying up into the early hours to re-read the lengthy assessment report (over 150 pages) in an attempt to understand the diagnosis and its potential impact over the course of his life.

### Family members’ accounts

Family members typically described the psychoeducation their partner/child had received as highly beneficial. However, in one instance there had been a very substantial delay in the follow-up sessions being offered of which the parent was highly critical.

## Perceived impacts of diagnosis

### Positive impacts

All participants said being diagnosed with autism had some positive impacts, though the nature and extent of this impact varied considerably.

The most commonly reported positive impact was an increased understanding of self, including why they found certain environments or situations difficult. Some believed this understanding had reduced their anxiety and/or led to improvements in self-esteem. Others reported it had enabled them to develop strategies to help them cope better with life (e.g. developing a better morning routine, making greater use of calendars and lists) and taking more care of themselves (e.g. allowing themselves more ‘downtime’, avoiding ‘meltdown’ triggers, ending difficult relationships). Having the diagnosis was also said to have helped family and friends to better understand their behaviour and the things they found difficult or challenging. In some cases, this resulted in improved relationships.

A second way in which being diagnosed with autism had achieved positive impacts in interviewees’ lives was that it had reduced interviewees’ sense of isolation. Comfort was drawn from simply knowing there were other people who had similar life experiences to their own. Very occasionally, interviewees reportedjoining a local autism group or had friends disclose that they were also autistic.

A third mechanism by which the diagnosis had a positive impact was the way it enabled access to practical assistance such as welfare benefits (Personal Independence Payments, Employment Support Allowance, Disabled Students Allowance), university/college/workplace assessments, adjustments and support.

Fourth, it had caused improvements in the quality of care and support received from other services, with practitioners using diagnostic assessment reports to help direct care, or responding more appropriately to an individual’s needs. Finally, and occasionally, it had triggered other family members to undergo an autism diagnostic assessment.

### Negative impacts

Set against these positive experiences, some interviewees reported long-standing, or unresolved, difficulties related to the diagnosis. The characteristics of this group are consistent. It comprised all interviewees from the DO cohort and those from the SAT cohort (3/20) who had received very limited or no psychoeducational input because, either, they had chosen not to or had been unable to access the psychoeducational intervention offered.

Among those in our sample from the DO cohort, more than half said they were still struggling to come to terms with and understand their diagnosis, and the implications it may have for their lives.

*….still quite overwhelming at times... the diagnosis in what it actually means. It’s very much a positive thing. However there isn't a day that goes by that the A word doesn't flit through my thoughts. It's everywhere, life changing. (SU29)*

*I just don’t understand it and I don’t get the condition, I don’t, and as much as I try and read about it, it just doesn’t make any sense to me. (SU32)*

*I want to understand what happens now. So it’s kind of like I’ve been given a diagnosis and a pile of paperwork and it’s like, well, what does this actually mean? Is this gonna hold me back at work, is it gonna hold me back in university, do I need to compensate for the way that I act socially? I don’t really know, I don’t really know what it means. (SU27)*

The vast majority of DO cohort interviewees said they wanted further help understanding and coming to terms with the diagnosis. Some described how they were still actively searching for information and sources of support. Even those who were initially relieved to be diagnosed and continued to view the diagnosis positively, spoke of struggling or feeling overwhelmed by it at times. As a result, they were keen to point out the importance of high quality psychoeducation and wider post-diagnostic support.

*It's a dedicated assessment centre so I believe it does well what it does. However… diagnosis is a traumatic experience, life changing. Some will handle it better than others. I guess I'm one of the lucky ones who is quite positive about the diagnosis and life in general and have found ways to self-manage quite well... others are not. (SU29)*

A few DO cohort interviewees believed receiving the diagnosis had caused a significant detrimental effect on their mental health:

*I spent a year thinking I needed to die because of what someone had told me, because there's nothing for you if you're autistic, because you can't change the way you are (SU33)*

*Even a year down the line I’m still seeing it as kind of a death sentence like, right, that’s it, my life’s over, I don’t know how to deal with this condition and everything, and you end up looking at everything differently, and it triggers loads of stuff off that you might not necessarily have thought of before, and I think that can then get you quite stressed and quite anxious. (SU32)*

In all these cases interviewees attributed the severity of their mental health difficulties on the fact that psychoeducation and other post-diagnostic support had not been available to them. Two explained they had eventually sought out help from a “therapist” (unclear if this is an NHS referral or private practitioner) when their feelings of anxiety, depression and suicidal thoughts spiralled to an unmanageable level.

### Family members’ accounts: impacts on the individual

Family members of individuals from both cohorts described positive impacts. These included their relative seeming more “comfortable” with themselves and that it had enabled access to practical support related to participating in everyday life and supporting achievement of things they had hoped for (e.g. travelling overseas).

Family members of SAT cohort interviewees also typically regarded the diagnosis as opening access to additional care and support (including that directly provided by or accessed through the SAT). This had brought a range of, sometimes very significant, benefits. These included improvements in mental health, greater independence and an improved ability to manage everyday life and assistance with disclosure of diagnosis to work colleagues.

*Since he’s had the assessment he’s not talked of killing himself. …* *he’s not actually said, since then, that, I might as well hang myself or I wish I could just cut my head off. He hasn’t said anything horrible like that, since this has been going on with these, you know, weekly meetings, etc. So they must be doing something, mustn’t they? (F4)*

In contrast, some family members of DO cohort interviewees saw no positives coming from the diagnosis *per se*. Furthermore, when the diagnosis did not then lead to additional support (and potentially positive impacts for the individual), this could be a source of frustration.

*It was time consuming to do and where did it get us? Although they’ve said you now have an official diagnosis, it’s like so what? Because it doesn’t help, it doesn’t do anything for her, she can’t access any services. (F7)*

One parent (DO cohort) firmly believed the diagnosis had had a negative impact on her child’s life.

*She’ll say…. “I can’t help it. I’ve got Asperger’s. I’m on the autistic spectrum. There’s nothing I can do about it. It’s not changed her behaviour as such because she’s always had meltdowns, but it’s as if she thinks it is her lot now and how life has to be. (F9)*

### Family members’ accounts: impacts on themselves

Parents closely involved in their child’s life also reported impacts on their own lives. For the couple of other family members we interviewed, impacts were minor or much less significant.

Across both cohorts, parents reported that the diagnosis, in itself, had been sufficient to have a positive impact on family relationships. This was for two reasons. First, having some understanding of the condition meant that situations which might trigger upset or arguments could be avoided. Second, it prevented family members misinterpreting behaviour as deliberately difficult.

However, where individuals had reacted negatively to the diagnosis, support from the service appeared to play a major role in determining whether, and how, this affected parents.

*She constantly tells us “you’re rubbish, you’re a bad parent, you don’t do this, you don’t support me, you’re not getting me any help, you’re not getting me this, you’re not getting me that”. You do feel.. well yeah, I am a rubbish person. (F9)*

This contrasts sharply with another family’s experience where the individual received a one- toone psychoeducation intervention. This parent reported a marked improvement in her son’s mental health, which in turn led to significant improvements in their own levels of stress.

Finally, few family members said that they wanted help for themselves. Instead, they explained that, by helping the individual, services would also be helping the family. A minority, however, did express a desire for support. Suggestions included, for emotional support, having access to a parent/carer support group and information about other possible sources of support.

## Summary

This chapter has reported the experiences and impacts of receiving an autism diagnosis. We compared the accounts of those who, post-diagnosis, received extended psychoeducation and access to other support (sampled from the SAT cohort, D&S group) with those of individuals who had been diagnosed by a regional/national autism diagnosis service where no psychoeducation is available (sampled from our DO cohort). A small number of family members were also interviewed.

Many, but not all, interviewees said they expected to be diagnosed with autism. Some described quite significant issues or difficulties which they hoped an autism diagnosis would (help to) resolve. The initial response to the diagnosis was typically one of relief and a sense of explanation. For a minority of our sample, however, the reaction was one of wanting to reject the diagnosis and the loss of hope and control they believed it brought. Among those whose initial reaction was positive, emotions typically became more mixed. Notions of frustration that they were not diagnosed earlier and grief over ‘lost years’ were common themes. For some these feelings were still present at the time we interviewed them, several months after the diagnosis. Family members’ observations of their relative’s reaction are reasonably aligned but also revealed evidence of emotional experiences hidden from them.

DO and SAT cohort interviews varied in the quality, duration and intensity of psychoeducational support accessed post-diagnosis. This led to very different experiences and impacts. Almost all SAT cohort interviewees had accessed and spoke very highly of the psychoeducational support they had received in terms of its content and the influence and impacts it had on them. Those who attended group-delivered psychoeducation noted the value of hearing positive stories from peers, and the opportunity to be exposed to shared experiences. A small number, however, had not accessed the psychoeducation intervention offered by their SAT. This was usually because it was a group-delivered intervention and they had felt unable to attend. (Some SATS did not offer 1:1 sessions as an alternative). A couple had experienced significant delays in it being provided.

DO cohort interviewees, whilst valuing the opportunity for explanations and advice that a follow-up session offered, also described the insufficiency of input. For some, this, in itself, had been a very difficult experience, with notions of abandonment emerging from their accounts. In addition, there was a consensus among these interviewees that provision of written information was of limited value and advice to use the internet to locate further information carried risks. Finally, none had pursued services to which they had been signposted.

We carried out our interviews around twelve months after the start of the diagnostic assessment process, with diagnosis typically having taken place around six to nine months previously. By this stage all participants could identify a positive impact of being diagnosed with autism. However, the nature and extent of this varied considerably.

An increased understanding of self was frequently described, and some believed this had directly led to improvements in their well-being. It also enabled them to develop more effective coping strategies. A reduced sense of isolation – brought about by simply knowing others had the same experience – and improvements in relationships with family and friends were also reported. In addition, among those using other (mainstream) services, diagnostic assessment reports had been used by these practitioners to improve care provided.

However, some DO cohort interviewees reported long-standing or unresolved difficulties associated with the diagnosis. Some described difficulties with acceptance and/or understanding of autism. Almost all DO cohort interviewees, including those who had been relieved on receiving the diagnosis, said they wanted further help understanding and coming to terms with the diagnosis. A few believed receiving the diagnosis had caused a deterioration in their mental health. In all instances, they attributed this to the lack of psychoeducation and other post-diagnostic support.

Family members’ accounts broadly align with those of their relatives. Again, among those drawn from the DO cohort, there was a frustration with the lack of support. We also asked family members about the impact on themselves of their relative being diagnosed. Positive impacts on family relationships were often described. However, they also noted the impact that deteriorations in the well-being of their relative had on them, with increased levels of stress and hopelessness described. The majority of family members did not want support for themselves, rather they pointed to the benefits to them of their relative receiving the care and support they needed.

# The economic analysis

## Introduction

The economic analysis comprised a number of components and concerned only the SAT cohort. Specialist Autism Teams (SATs) were costed, based upon financial information provided by each service or its managing organisation. Service utilisation patterns were costed and compared between the ‘Support Only’ (SO) and ‘Diagnosis and Support’ (D&S) groups. Inter-individual variations in service utilisation were examined by reference to differences in participant and SAT characteristics. Links between service utilisation costs in the 12-month period after baseline and the primary outcome score at the 12-month follow-up point were explored, again adjusting for differences in individual and SAT characteristics. We looked at how costs differed by service characteristics. We examined the cost-effectiveness of different service arrangements by bringing together the cost findings and both the primary outcome (WHOQOL-BREF Psychological Domain) and the QALY gain. We used regression analyses of variations in both costs up to 12-month point and these two outcome at 12 months to generate parameters that allow examination of cost-effectiveness of different service characteristics As with almost any study, there are limitations to the data available and, for some analyses, sample sizes are low.

## Methods

### Setting

The setting was the same as for the outcomes evaluation (see *Chapter 8*).

### Study participants

Inclusion criteria for the SAT cohort and characteristics of sample members are described in Chapter 8.

### Costs of SATs

SAT costs (measured in £ sterling) were calculated using financial information (overall annual budget for 2017-18) obtained by the research team from each SAT or its managing organisation, combined with data on the total number of clients supported in each site (also obtained from SATs themselves) to give an overall average cost per study participant for each SAT. It was not possible to carry out micro-costing of activities within the SATs because of the considerable time that any such exercise would have taken, nor did those services hold information in a way that would allow separate costing of their various diagnostic and post-diagnostic activities. The advantage of a top-down costing is that it is easier to operationalise than micro-costing, considerably less time-consuming for the researcher, and also considerably less intrusive for services. The exploration of cost variations (see below) can partially compensate for this disadvantage by including regressors that reflect key service and individual components in the analyses.

Some but not all SATs provided us with high-level budgetary information. Where financial information was missing, costs were imputed, taking into account differences between SATs in the proportion of D&S and SO service users on caseloads as this potentially has an effect on average per-person costs. This was estimated from the proportions in our study sample. When we later analysed cost variations and cost-outcome links we used both SAT cost and (other) service costs.

### Service utilisation and associated costs

Service utilisation patterns (health, social care, other statutory sectors) for individuals were collected with an adapted version of the Client Service Receipt Inventory (CSRI) created specifically for this study. It was completed at each time-point, covering a retrospective period of 4 weeks.

Services provided within the SAT were assumed to be covered by the SAT budget. However, contacts with professionals and services reported in the CSRI are likely to represent some double-counting, as we know generally that study participants can find it hard to attribute professionals to specific roles and/or services. We therefore conducted additional analyses to test how sensitive key findings were to the possibility of some degree of double-counting. We did this, for example, in the cost variations analyses by setting each of the largest cost components to zero (to represent no contact with that particular service outside the SAT) and examine whether it affected comparisons between different types of SATs/SAT characteristics.

The CSRI also collected information on employment status (allowing calculation of productivity costs associated with days off due to sickness absence) and privately borne costs. It was not possible to collect data from family members or others on the amount or nature of unpaid care and support. If a participant was categorised as in full-time paid employment the number of days taken off work in the last 3 months was multiplied by the number of hours worked per day (assumed to be 7) multiplied by the minimum wage (£7.83 for adults). If an individual worked part-time, the number of hours worked per week was divided by 5 working days to obtain the number of hours per day. This was multiplied by the minimum hourly rate at that time of £7.83. If someone was self-employed, the costs for lost productivity were treated in the same way as for a full-time worker. For other work status responses such as trainee, voluntary worker, job-seeking, not working due to sickness/disability, student, maternity/ paternity leave, carer and retired, we did not attach monetary values to them and cost was assumed to be zero.

The focus of the economic evaluation, as set out in the pre-specified analysis plan, was costs between baseline and 12 months, computed from data collected for 4-week retrospective periods at 3 months (T1), 6 months (T2) and 12 months (T3), and interpolating between time-points to get a full 52-week costing. Sample sizes at 18 and 24 months were insufficient to conduct robust analyses, and analysis beyond 12 months was not part of the original design for the study. Unit costs utilised in our analyses are given in Table 20.

Table 20: Unit costs utilised in analyses

|  |  |  |
| --- | --- | --- |
| **Category** | **Unit costs** | **Source** |
| GP consultation | £31 per 9.22 min. including direct care | Health and Social care costs 2017-18 (PSSRU, 2018) |
| Psychologist | £43 per hour, £0.72 per min. | Health and Social care costs 2017-18 (PSSRU, 2018) |
| Occupational therapist | £43 per hour, community OT | Health and Social care costs 2017-18 (PSSRU, 2018) |
| Nurse | £59 per face to face consultation | Health and Social care costs 2017-18 (PSSRU, 2018) |
| Speech & language therapist | £34 per hour | Health and Social care costs 2017-18 (PSSRU, 2018) |
| Social worker | £44 per hour | Health and Social care costs 2017-18 (PSSRU, 2018) |
| Support worker | £23 per hour | Health and Social care costs 2017-18 (PSSRU, 2018) |
| Police officer | £48 per hour | Health and Social care costs 2017-18 (PSSRU, 2018) |
| Private cost | £74 Other therapist, adults, one to one | NHS reference cost 2017-2018 (2018) |
| Fixed group | £16 delivery by a non-specialist | Health and Social care costs 2017-18 (PSSRU, 2018) |
| Support group | £16 delivery by a non-specialist | Health and Social care costs 2017-18 (PSSRU, 2018) |
| Social group | £16 delivery by a non-specialist | Health and Social care costs 2017-18 (PSSRU, 2018) |
| Outpatient | £140 per visit | NHS reference cost 2017-2018 (2018) |
| Accidents & Emergency | £160 per visit | NHS reference cost 2017-2018 (2018) |
| Walk in Centre | £160 per visit | NHS reference cost 2017-2018 (2018) |
| Day case | £742 for day case | NHS reference cost 2017-2018 (2018) |
| Inpatient care | £6161 for non-elective short stay | NHS reference cost 2017-2018 (2018) |
| Minimum hourly rate | £7.83 minimum wage rate per hour for adults (25+) | UK government website (2019)  https://www.gov.uk/national-minimum-wage-rates |

### Statistical tests

Independent t-tests compared means for the annual health and social care costs and societal costs by different cost components. Bootstrapping was used (bias-corrected) due to skewed costs.

#### Cost variations

In analyses of variations in cost, the dependent variable was cost over the 12-month period between T0 and T3, calculated as above. Multivariate statistical analyses were conducted to explore to what extent the observed variations in some cost measures between individuals in the sample were associated with characteristics of those individuals and of the SATs that provided their support and/or diagnosis. Given the absence of previous research on SATs to guide selection of variables, the analyses examined associations with potentially all individual characteristics measured at baseline (using measures described in previous chapters), and particularly the effects of different SAT characteristics (again, described earlier; see Table 16), although we were parsimonious in inclusion of independent variables given the sample size.

Generalised linear modelling (GLM) was used for these analyses to allow flexibility to address probable skewness in the dependent variables. We tested for the best fitting distributional form. Site-specific variance clustering was considered in the regression equations with robust standard errors. All baseline variables for the individual and SAT service characteristics were tested for statistical significance using p-value of 0.05 and explored for potential inclusion in the model. They were added one at a time to the cost model given statistical significance and theoretical importance. Variables considered for potential inclusion were the following:

* *Individual characteristics at baseline*: age, gender, ethnicity, marital status, highest educational qualification, living arrangements (living alone, living with others), accommodation type (rented, student halls, own/mortgaged), work situation, time-off employment/education, EQ-5D five domains individually (mobility, self-care, usual activities, pain/discomfort, anxiety/depression), membership of autism-specific organisations or online, met with voluntary support worker, attended local group meeting, helpline, email contacts with autism organisation, WHOQOL-BREF physical, psychological, social, and environmental domains, and GHQ scores.
* *Service characteristics*: local authority involvement, multi-service team vs. single service, neurodevelopmental vs. autism only, dominant mode of delivering psychoeducation post-diagnosis, skill mix, routinely do one-to-one work regarding mental health problems, delivery of care plan, drop-in provision and/or named contact while in service. (We did not include discharge practice (closed, stepped, open) as this information was not available at T3.)

#### Cost-outcome links

The analysis of cost-outcome links focused on the primary outcome, WHOQOL-BREFPsychological Domain, as dependent variable, measured at 12 months, regressed on study participant characteristics at T0, SAT characteristics, and costs at both T0 *and* over the 12-month period that followed. Again, GLM modelling was used for these analyses, adjusting for clustering by site, and again both D&S and SO groups were identified and included in the same multiple regressions. Individual cost components for each service cost separately were included in the cost-outcome link regression to explore whether differences in costs may be driving differences in outcome.

The seventeen cost components included were: GP, psychologist, occupational therapist, nurse, speech & language therapist, social worker, support worker, group activities lasting fixed number of sessions, support group, social group, outpatient care, accident & emergency, walk-in centre, day case, inpatient care, police officer, and private appointment with other therapists.

These were included in the regressions along with age, gender, WHOQOL-BREF Psychological Domain at T0, diagnostic status at referral (SO vs D&S) and baseline health and social care costs.

#### Cost-effectiveness analysis

We examined cost-effectiveness in this observational design by estimating a number of regression equations: one with cost measured over 12 months as dependent variable (first for health and social care costs and then for societal costs); one with the primary outcome at 12 months (WHOQOL-BREF Psychological Domain score) as dependent variable (again separately from health and social care and societal perspectives, given that we needed to adjust for baseline costs); and one with QALYs measured over the period from baseline to 12 months as dependent variable (from health and social care and societal perspectives in turn). QALYs were calculated from EQ-5D scores and UK societal weights, using ‘area-under-the-curve’ calculations. Generalised linear modelling was used, adjusting for clustering by site.

We examined estimated coefficients on each of the service characteristics (local authority involvement, multi-service team vs. single service, and so on) in each equation to see whether these characteristics were significantly associated with cost or outcome variations. In principle, we could interpret these coefficients as measures of incremental changes in cost and effectiveness, and then compute incremental cost-effectiveness ratios (ICER) between two variants of a particular service characteristic. We have generally not done so below, as this adds little to our narrative summary of the results.

#### Statistics package

The statistical software Stata® 14.2 (StataCorp, College Station, TX, USA) and SPSS version 24 were used.

## Results

### SAT costs

Cost information was obtained from four of the nine SATs. One SAT (multi-service delivery model) provided partial information. Of the remainder, two declined to provide cost information, whilst the other two agreed to provide cost information but did not deliver it, despite reminders. For the SATs with cost information, average costs (AC) per client were estimated based on the method described earlier. This costing did not take account of other functions/services included in commissioning arrangements (e.g. training/support to staff in mainstream services; public awareness raising; provision on low-level support post-discharge). Average cost per client for the four SATs from which we could obtain budget data and information on total number of service users per year were £360, £768, £781 and £2951. Differences between SATs may be linked to operational scale (the lowest-cost SAT supported more than four times as many autistic people than the highest-cost SAT, for example), location (influencing some input prices), characteristics of people being supported, and the range of services delivered (e.g. some SATs did not accept referrals from those already diagnosed; extent of direct work). We can examine the latter two potential sources of variation with data collected in this study. For SATs that did *not* provide financial information, we imputed from these observed cost data as described earlier.

### Comprehensive support costs

Service utilisation data and costs for services provided by SATs (captured by SAT budgets) were summed to give the health and social care costs subtotal. In addition, costs were calculated for employment-related and other ‘formal’ sectors (police officer contacts) as described above (Appendix 15, Tables 55 and 56).

Significant differences in costs between D&S and SO groups over the 12-month period were found in relation to accessing three professions/interventions: psychologist (p=0.05), nurse (p=0.05), and fixed session, group-delivered interventions (p=0.05) (Appendix 15, Table 57). These are key features of SAT provision. Sensitivity analyses to address the possibility that there was double-counting between the SAT budgets and the service utilisation reported by study participants were therefore conducted.

Aggregating costs across the different service components revealed that the D&S group had service-related costs totalling £2546 over the 12-month period, compared to £1699 for the SO group. Societal costs (again excluding SAT costs for the moment) summed to £2733 for D&S and £1931 for SO (Appendix 15, Table 55).

Aggregated costs for each 4-week period of data collection by time-point and group (D&S v S0) are shown in Table 21. At baseline, total health and social costs were £125 for D&S (n=164) and £151 for SO (n=88). Costs increased over time, probably due to SAT involvement, although comparisons between time-points should be made cautiously because of sample attrition: individuals for whom costs were available are not identical between time-points. There were no significant differences in costs between the D&S and SO at any individual time-point.

Table 21: Costs (£, over 4-week retrospective periods) by time point and group

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Time point** | **Cost measure** | **D&S group** | | | **SO group** | | | **Test of difference in mean costs** | |
|  | **N** | **Mean** | **SD** | **N** | **Mean** | **SD** | **T** | **Sig** |
| T0 | Health & social care | 164 | 125.07 | 213.83 | 88 | 151.26 | 238.57 | -0.89 | 0.37 |
|  | Societal | 164 | 210.52 | 493.13 | 88 | 179.22 | 321.65 | 0.54 | 0.59 |
| T1 | Health & social care | 99 | 170.58 | 601.93 | 58 | 225.95 | 359.18 | -0.64 | 0.53 |
|  | Societal | 138 | 194.41 | 354.93 | 77 | 200.86 | 345.90 | -0.13 | 0.90 |
| T2 | Health & social care | 87 | 168.92 | 202.84 | 44 | 183.91 | 216.58 | -0.39 | 0.70 |
|  | Societal | 137 | 149.26 | 268.42 | 70 | 166.03 | 264.61 | -0.43 | 0.67 |
| T3 | Health & social care | 90 | 272.27 | 594.05 | 45 | 192.33 | 255.91 | 0.86 | 0.39 |
|  | Societal | 133 | 240.09 | 603.19 | 75 | 141.05 | 242.69 | 1.36 | 0.18 |

### Cost variations

As noted earlier, analyses of cost variations took each measure of cost over the 12-month period between T0 and T3 as dependent variable, regressed on individual characteristics at baseline and SAT characteristics, adjusting for clustering by site. Generalised linear modelling (GLM) with gamma distribution and identity link was used for these analyses as the best fitting model with lowest Akaike Information Criterion (AIC) values among other GLM model specifications. As noted above, two series of regression analyses were conducted: for health and social care costs, and for societal costs.

#### Health and social care costs

Some *individual characteristics* at baseline were significantly associated with health and social care costs over the 12-month period to T3, see Table 22:

* The SO group had lower costs than the D&S group (difference of £1107).
* Women had higher costs than men, the average difference being £534.
* People living with parents, foster carers or guardians at the start of the study tended to have lower costs than those who did not (difference of £770).
* A one-point higher WHOQOL-BREF Psychological Domain score at baseline was associated with a £17 lower cost.
* People who had higher baseline costs were more likely to have higher 12-month costs.

Other individual characteristics were not associated with health and social care cost differences.

Table 22: Factors associated with health and social care cost (£) variations

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Characteristic** | **Coefficient** | **Robust std error** | **z** | **P>z** | **95% Confidence**  **Interval** | |
| Diagnostic status on referral (1=already diagnosed (SO); 0=not yet diagnosed (D&S)) | -1107.21 | 116.30 | -9.520 | 0.000 | -1335.14 | -879.27 |
| Baseline health & social care cost (£) | 4.65 | 1.11 | 4.190 | 0.000 | 2.48 | 6.83 |
| Age | -7.35 | 17.60 | -0.420 | 0.676 | -41.84 | 27.15 |
| Gender (1=female; 0=male | 533.58 | 145.72 | 3.660 | 0.000 | 247.97 | 819.18 |
| Living with parents at T0 (1=yes; 0=no) | -770.23 | 328.53 | -2.340 | 0.019 | -1414.14 | -126.31 |
| Time off work/education due to illness (1=yes; 0=no) | 594.23 | 388.99 | 1.530 | 0.127 | -168.19 | 1356.64 |
| WHOQOL-BREF Psychological Domain score at T0 | -17.33 | 3.51 | -4.940 | 0.000 | -24.20 | -10.45 |
| LA involvement1 | -1251.46 | 991.27 | -1.260 | 0.207 | -3194.31 | 691.38 |
| Team structure2 | -197.13 | 434.78 | -0.450 | 0.650 | -1049.29 | 655.03 |
| Autism vs ND3 | -348.57 | 87.57 | -3.980 | 0.000 | -520.20 | -176.95 |
| Psychoeducation4 | 404.49 | 267.16 | 1.510 | 0.130 | -119.12 | 928.11 |
| Skill mix5 | 2481.10 | 551.29 | 4.500 | 0.000 | 1400.59 | 3561.60 |
| One-to-one work6 | -114.57 | 389.18 | -0.290 | 0.768 | -877.37 | 648.20 |
| Delivery of care plan7 | 3107.13 | 644.48 | 4.820 | 0.000 | 1843.96 | 4370.30 |
| Constant term | -30.69 | 744.21 | -0.040 | 0.967 | -1489.31 | 1427.94 |
| 1 LA involvement is joint local authority and clinical commissioning group (CCG) (coded as 1) or just CCG (coded as 0)  2 Team structure is multi-service team (= 1) or single service (= 0)  3 Autism vs ND: service is neurodevelopmental service (ND) (= 1) or autism only (= 0)  4 Psychoeducation: whether dominant mode of delivering psychoeducation post-diagnosis is one-to-one (= 1) or group (= 0)  5 Skill mix: in addition to clinical psychology, the number of professional disciplines represented on team (an indicator of degree to which SAT takes a holistic approach) is 4 or more disciplines (= 1) or 2 or 3 disciplines (= 0)  6 One-to-one work: routinely do 1:1 work for (non-complex) mental health problems (1 = yes; 0 = no)  7 Delivery of care plan is managed (= 1) or episodic (= 0) | | | | | | |

Looking at the *service characteristics* (see also Table 22), those significantly associated with T3 health and social care costs were:

* Autism vs ND: Individuals in SATs with a neurodevelopmental service had lower costs than individuals in SATs with an autism-only service (difference of £349).
* Skill mix: Individuals in SATs that involved 4 or more professional disciplines had higher costs than individuals in SATS that involved only 2 or 3 disciplines (difference of £2481).
* Delivery of care plan: Individuals in SATs with a managed approach to care plan delivery had higher costs than individuals in SATs that used an episodic approach (difference of £3107).

The service characteristic drop-in provision and/or named contact whilst in service (1 = no; 0 = yes) does not appear in the regression results because of multicollinearity.

We noted earlier the possibility of double counting of some costs if sample members reported contacts with professionals whose costs were, in fact, already accounted for in our estimates of SAT delivery costs. Professions/services where double counting was judged most likely to have occurred were, as follows: consultations with nurses, psychologists or support workers. Analysis of these profession/service costs found they differed according to service characteristic (see Appendix 15, Table 58). We conducted sensitivity analyses by re-running the health and social care cost regression after removing costs for the two largest cost components (nurses and psychologists) singly and in combination. The significance of some service characteristics was sensitive to measurement of costs: when psychologist costs were set to zero, psychoeducation became statistically significant; when nurse costs were set to zero, and when both nurse and psychologist costs were set to zero, both psychoeducation and one-to-one working became statistically significant. (Full details available on request.)

#### Societal costs

A second series of analyses focused on societal cost variations. Total societal costs included costs for police officer, private out-of-pocket payments for private appointments with other therapists and costs associated with productivity losses due to sickness absence, in addition to the total annual health and social care costs analysed above. The same set of individual and service characteristics was explored for their associations with costs as for the health and social care costs analyses, with variables retained or excluded depending on statistical significance, taking into account correlations with other variables. Analyses were adjusted for clustering.

A number of *individual characteristics* at baseline were significantly associated with societal costs over the 12-month period to T3, see Table 23. The SO group had lower costs than the D&S group (difference of £1020).

* Women had higher costs than men, the average difference being £599.
* A one-point higher WHOQOL-BREF Psychological Domain score at baseline was associated with a £20 lower cost.
* People who had higher baseline costs were more likely to have higher 12-month costs.

Other individual characteristics were not associated with health and social care cost differences.

Table 23: Factors associated with societal cost variations (£)

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Coefficient** | **Robust std error** | **z** | **P>z** | **95% Confidence**  **Interval** | |
| Referral (1=SO; 0=D&S) | -1020.21 | 113.14 | -9.020 | 0.000 | -1241.96 | -798.47 |
| Baseline societal cost (£) | 3.59 | 1.47 | 2.450 | 0.014 | 0.71 | 6.46 |
| Age | 17.78 | 10.40 | 1.710 | 0.087 | -2.60 | 38.16 |
| Gender (1=female; 0=male | 599.12 | 192.93 | 3.110 | 0.002 | 220.99 | 977.26 |
| Time off work/education due to illness (1=yes; 0=no) | 829.07 | 501.41 | 1.650 | 0.098 | -153.68 | 1811.83 |
| WHOQOL-BREF Psychological Domain score at T0 | -20.07 | 4.26 | -4.720 | 0.000 | -28.42 | -11.73 |
| LA involvement1 | -388.92 | 683.62 | -0.570 | 0.569 | -1728.80 | 950.95 |
| Team structure2 | -679.16 | 200.38 | -3.390 | 0.001 | -1071.90 | -286.43 |
| Autism vs ND3 | -113.17 | 154.94 | -0.730 | 0.465 | -416.84 | 190.50 |
| Psychoeducation4 | 827.23 | 91.82 | 9.010 | 0.000 | 647.27 | 1007.18 |
| Skill mix5 | 2495.06 | 411.13 | 6.070 | 0.000 | 1689.25 | 3300.86 |
| One-to-one work6 | -873.47 | 229.93 | -3.800 | 0.000 | -1324.13 | -422.81 |
| Delivery of care plan7 | 2976.92 | 556.50 | 5.350 | 0.000 | 1886.20 | 4067.65 |
| Constant term | -30.69 | 744.21 | -0.040 | 0.967 | -1489.31 | 1427.94 |
| 1 LA involvement is joint local authority and clinical commissioning group (CCG) (coded as 1) or just CCG (coded as 0)  2 Team structure is multi-service team (= 1) or single service (= 0)  3 Autism vs ND: service is neurodevelopmental service (ND) (= 1) or autism only (= 0)  4 Psychoeducation: whether dominant mode of delivering psychoeducation post-diagnosis is one-to-one (= 1) or group (= 0)  5 Skill mix: in addition to clinical psychology, the number of professional disciplines represented on team (an indicator of degree to which SAT takes a holistic approach) is 4 or more disciplines (= 1) or 2 or 3 disciplines (= 0)  6 One-to-one work: routinely do 1:1 work for (non-complex) mental health problems (1 = yes; 0 = no)  7 Delivery of care plan is managed (= 1) or episodic (= 0) | | | | | | |

Looking at the *service characteristics*, five were significantly associated with T3 societal cost variations:

* Team structure: Individuals in SATs with multiservice teams had costs that were on average £679 lower than for individuals in SATS with a single team structure.
* Psychoeducation: Individuals in SATs where the dominant mode of delivering psychoeducation post-diagnosis was one-to-one had £827 higher costs than individuals in SATs that used group delivery.
* Skill-mix: Individuals in SATs that involved 4 or more professional disciplines had higher costs than individuals in SATS that involved only 2 or 3 disciplines (difference of £2495).
* One-to-one work: Individuals in SATs that routinely providing one-to-one work regarding (non-complex) mental health problems had lower costs than individuals in SATs without such an approach (difference of £873).
* Delivery of care plan: Individuals in SATs with a managed approach to care plan delivery had higher costs than individuals in SATs that used an episodic approach (difference of £2977).

We conducted equivalent sensitivity analyses for societal cost variations as reported above for health and social care cost variations. In this instance, the analyses showed that the pattern of the service characteristics was *not* sensitive to the measurement of psychologist or nurse costs. (Again, details are available on request.)

### Cost-outcome links

Examination of the cost-outcome links focused on the primary outcome, WHOQOL-BREF Psychological Domain. Seventeen cost components (over the 12-month period to T3) were included (GP, psychologist, occupational therapist, nurse, speech & language therapist, social worker, support worker, group activities lasting fixed number of sessions, support group, social group, outpatient care, accident & emergency, walk-in centre, day case, inpatient care, police officer, and private appointment with other therapists), along with referral group, age, gender, WHOQOL-BREF Psychological Domain at T0, and baseline societal costs.

The regression equation is presented in Table 59 in Appendix 15. Some individual and SAT characteristics were found to be associated with inter-individual differences in outcome (consistent broadly with the analyses reported in Chapter 8), but there was no significant association between the WHOQOL-BREF Psychological Domain at 12 months and total annual societal costs. Significant predictors were baseline WHOQOL-BREF Psychological Domain scores and GP costs. In other words, differences in GP costs and WHOQOL-BREF Psychological Domain scores at baseline were driving some differences in the WHOQOL-BREF Psychological Domain scores at T3.

### Cost-effectiveness analysis

The cost-effectiveness of different service characteristics was examined by looking at the estimated coefficients on service characteristic indicators in the cost and outcome regressions. The cost regressions (one for health and social care costs; one for societal costs) have been reported in Section 10.3.3. In this section we report the outcome regressions, first for WHOQOL-BREF Psychological Domain, and then for QALYs. Again we used generalised linear modelling (GLM), in this case finding that a Gaussian family distribution and identity link had the best fit (lowest Akaike Information Criterion values).

In the first regression (WHOWOL-BREF Psychological domain, health and social care perspective) (Table 60, Appendix 15), three of the service characteristics indicators were significantly associated with T3 outcome variations:

* Team structure: Individuals in SATs with multiservice teams had on average a 5-point higher score on the WHOQOL-BREF Psychological Domain than individuals in SATS with a single team structure, taking into account other covariates.
* Autism vs ND: Individuals in SATs with a neurodevelopmental service had on average a 10-point lower score on the WHOQOL-BREF Psychological Domain than individuals in SATs with an autism-only service.
* One-to-one work: Individuals in SATs that routinely providing one-to-one work regarding (non-complex) mental health problems had on average a 17-point higher score on the WHOQOL-BREF Psychological Domain than individuals in SATS with a single team structure.

In the second regression (WHOWOL-BREF, Psychological domain), this time from a societal perspective) (Table 61, Appendix 15), four of the service characteristics indicators were significantly associated with T3 outcome variations:

* LA involvement: Individuals in SATs with joint local authority and CCG arrangements had on average a 9-point lower score on the WHOQOL-BREF Psychological Domain than individuals in SATS with just CCG arrangements, taking into account other covariates.
* Team structure: Individuals in SATs with multiservice teams had on average a 4-point higher score on the WHOQOL-BREF Psychological Domain than individuals in SATS with a single team structure.
* Autism vs ND: Individuals in SATs with a neurodevelopmental service had on average a 10-point lower score on the WHOQOL-BREF Psychological Domain than individuals in SATs with an autism-only service.
* One-to-one work: Individuals in SATs that routinely providing one-to-one work regarding (non-complex) mental health problems had on average a 20-point higher score on the WHOQOL-BREF Psychological Domain indicator than individuals in SATS where this was not routinely offered.

The third and fourth regressions took QALYs over the 12-month period as dependent variable, and analysed variations from, first, a health and social care perspective, and then a societal perspective (in the adjustment for baseline cost). We also adjusted for baseline utility score (computed from EQ-5D), outputs are presented in Tables 62 and 63 (Appendix 15.)

In the first regression, three *service characteristics* were significantly associated with QALY variations:

* LA involvement: Individuals in SATs with joint local authority and CCG arrangements had on average a 0.683 higher QALY score than individuals in SATS with CCG arrangement only, taking into account other covariates.
* Autism vs ND: Individuals in SATs with a neurodevelopmental service had on average a 0.182 lower QALY score than individuals in SATs with an autism-only service.
* One-to-one work: Individuals in SATs that routinely providing one-to-one work regarding (non-complex) mental health problems had on average a 0.395 lower QALY score than individuals in SATS with a single team structure.

From a societal perspective, the same three *service characteristics* were significantly associated with QALY variations over the 12-month period:

* LA involvement: Individuals in SATs with joint local authority and CCG arrangements had on average a 0.585-point higher QALY score than individuals in SATS with just CCG arrangements, taking into account other covariates.
* Autism vs ND: Individuals in SATs with a neurodevelopmental service had on average a 0.194-point lower QALY score than individuals in SATs with an autism-only service.
* One-to-one work: Individuals in SATs that routinely providing one-to-one work regarding (non-complex) mental health problems had on average a 0.381-point lower QALY score than individuals in SATS with a single team structure.

Bringing these analyses together, the findings in relation to the effects of service characteristics on costs, self-reported psychological quality of life (QoL) and QALYs can be summarised as follows, see also Table 24.

* LA involvement: From a health and social care perspective there are no cost or psychological QoL differences between SATs with joint local authority/CCG arrangements or just CCG-led. From a societal perspective, there is no cost difference but psychological QoL is slightly worse (9 points on a scale that runs from 0 to 100) for joint LA/CCG SATs. However, local authority involvement was associated with higher QALY scores over the 12-month period. Overall, the cost-effectiveness case joint local authority/CCG arrangements rests on the credibility of the QALY results.
* Team structure: Psychological QoL outcomes are slightly better for SATs with multiservice teams compared to single team structures, but the difference is only 4 or 5 points on the 100-point scale. Health and social care costs do not vary with this service arrangement, but societal costs are slightly lower for multiservice team SATs. QALYs do not vary with team structure. Overall, these findings do not suggest major differences from a cost-effectiveness standpoint between team structures.
* Autism vs ND: Psychological QoL outcomes are 10 points lower for individuals in SATs with a neurodevelopmental service rather than an autism service, which is marked on a scale running from 0 to 100. QALYs were also lower. Health and social care costs are slightly lower for neurodevelopmental service SATs and there is no difference in societal costs. Overall, these findings point to a cost-effectiveness advantage for autism-only services.
* Psychoeducation: There was only one significant difference between SATs whose dominant mode of delivery of psychoeducation post-diagnosis was one-to-one compared to SATs where there was group delivery: societal costs were slightly higher for the former. Sensitivity analyses suggest that one-to-one delivery of psychoeducation might be slightly less costly (health and social care costs only) if our measurement of psychologist costs included some double-counting. Overall, however, there is no strong cost-effectiveness case for either one-to-one or group delivery.
* Skill-mix: In the case of skill mix, there are no observable differences in psychological QoL according to the richness of skill mix in the SAT being used, nor any differences in QALYs, but individuals supported by SATs that involved 4 or more professional disciplines had substantially higher costs than individuals in SATS that involved only 2 or 3 disciplines. On cost-effectiveness grounds, and in terms of psychological QoL and QALY outcomes, arrangements in which fewer professions are included appear to be preferred.
* One-to-one work: Individuals in SATs that routinely provide one-to-one work for people with (non-complex) mental health problems have substantially better psychological QoL outcomes at either no higher cost (health and social care perspective) or at reduced costs (societal perspective) compared to not using one-to-one approaches. On the other hand, QALYs were lower with one-to-one work. Sensitivity analyses suggest that one-to-one work might be slightly more costly (health and social care costs only) if both psychologist and nurse had been double-counted, although the difference was not great. Overall, given that psychological QoL was the primary outcome and that the validity of QALYs generated from EQ-5D has not been established for autistic people, we conclude that one-to-one work by SATs is a cost-effective way to deliver support for people experiencing with mental health problems as indicated by changes in self-reported psychological QoL.
* Delivery of care plan: Individuals in SATs with a managed approach to delivering care plans had significantly higher costs but psychological QoL outcomes and QALYs were unaffected. Overall we would conclude that an episodic approach appears to be more cost-effective than a managed approach with respect to this particular outcome.

Table 24: Summary of cost and outcome differences by SAT service characteristics

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Health and social care perspective | | Societal perspective | |
|  | Cost | Outcome | Cost | Outcome |
| LA involvement | No difference | No difference in WHOQOL-BREF PD1; QALYs higher | No difference | WHOQOL 9 points lower; QALYs higher |
| SATstructure | No difference | WHOQOL-BREF PD1 5 points higher | £679 lower | WHOQOL 4 points higher |
| Autism vs ND | £349 lower | WHOQOL-BREF PD1 10 points lower  QALYs lower | No difference | WHOQOL 10 points lower  QALYs lower |
| Mode of delivering psychoeducation | No difference | No difference | £827 higher | No difference |
| Skill mix | £2481 higher | No difference | £2495 higher | No difference |
| One-to-one work for presenting mental health problems | No difference | WHOQOL-BREF PD1 17 points higher  QALYs lower | £873 lower | WHOQOL 20 points higher  QALYs lower |
| Approach to delivering care plan | £3107 higher | No difference | £2977 higher | No difference |

1 PD = Psychological Domain

## Summary

Our economic evaluation had a number of elements. We calculated the cost of each SAT from locally provided data. We calculated other service-related costs, but also noted that double-counting of some components is possible, although our exploration via sensitivity analyses did not suggest that this would have had little impact on our overall findings. We observed cost variations across the sample, and explored these in a series of multiple regression analyses. We similarly explored variations in the primary outcome measure (WHOQOL-BREF Psychological Domain) and QALYs measured over a 12-month period to explore the relative cost-effectiveness of different service arrangements.

Mean service-related costs of supporting this sample of autistic adults in contact with SATs were £2240 (health and social care) and £2453 (societal). Numerous individual and service characteristics appeared to be linked to cost variations. Annual *health and social care costs* were *lower* for:

* people already diagnosed with autism (SO group) compared to those not previously diagnosed (D&S group);
* males;
* people living with parents, foster carers or guardians;
* people with higher WHOQOL-BREF Psychological Domain scores at baseline;
* people with lower baseline costs.

Annual *societal costs* were *lower* for exactly the same groups of people except there was no societal cost difference associated with living arrangement (with parents etc.).

In addition, we found both cost measures were associated with some of the service characteristics identified as distinguishing between SATs. For health and social care costs, significant associations were found with: autism vs neurodevelopmental services, skill mix (number of professional disciplines involved) and delivery of care plan (managed vs episodic). For societal costs, significant associations were found with team structure (multi-service vs single team), psychoeducation (one-to-one vs group), skill-mix, one-to-one work for people with mental health problems, and delivery of care plan.

When we looked at cost-effectiveness, and in terms of psychological QoL outcomes, the strongest evidence found suggested: autism-only services were more cost-effective than neurodevelopmental services; arrangements involving a smaller number of professionals appear more cost-effective; one-to-one work with people experiencing with mental health problems was cost-effective; and an episodic approach is more cost-effective than a managed approach to delivering care plans. When we measured effectiveness with QALYs, the pattern of cost-effectiveness was slightly different. However, it has not been established that the EQ-5D is a suitable instrument for generating QALYs for autistic adults, and we would suggest caution in interpreting these particular findings.

# Discussion

## Introduction

In this chapter we consider the strengths and limitations of this study before moving on to discuss and synthesise the study findings, placing them, where possible, within the context of existing evidence.

## Strengths and limitations

### Strengths

This is the first study to investigate Specialist Autism Team (SAT) provision in England – a model of care consistently set out in government strategy since 2011 and recommended by NICE. The study has identified and described the approaches taken by localities to setting up such provision and explored practitioners’ experiences of implementing and delivering SATs. In the main study phase, and using a mixed method approach, we evaluated such provision, seeking to investigate and understand SATs from the perspectives of practitioners, service users and family members as well as tracking service users’ outcomes and their use of a wide range of specialist and generic services. A key objective of this chapter is to synthesise and integrate findings from these various elements of the study. Hopefully, we have achieved this and, in doing so, demonstrate the benefits afforded by the mixed methods design.

Overall, the services recruited to the study as research sites represented well the range of approaches taken to SAT provision. Retention to the study, and data completeness, were excellent. All outcome measures performed well, including those had previously used with this population. We believe this indicates the outcomes evaluated and standardised measures chosen – in consultation with our Project Advisory Group (PAG) – were appropriate and meaningful. In addition, we worked with the PAG on the design and layout of the study questionnaire booklet. Thus the hard copy was printed on pale yellow paper with a dark blue print, layout was uncluttered and, where required, shading used to distinguish between rows/items. Furthermore, at 12 month follow-up – our primary time-point and where highest retention was observed (>85%) - we included a question about the specific impact of the SAT on participants’ lives, with the option of using a free text response format to describe experiences. Over half of study participants took the opportunity to briefly share their experiences (reported in *Chapter 6*). As well as generating data, we believe this also supported retention. Levels of retention also lend support to other strategies used. These included: hard and on-line versions of questionnaires, the use of personalised/non-automated text and email alerts immediately prior to a data collection time-point, and a three-stage reminder process, using both electronic (email, text) formats and letters. At the same time, it is vital to acknowledge the commitment of study participants to this research.

In England, the care and support of autistic people remains a policy priority and there is a long-term commitment to improve provision.32, 41 Thus, the findings from this study (which commenced in 2014) remain highly relevant. Furthermore, whilst its focus has been on a model of care and service delivery in England - given the limitations in provision and service development in other countries, and a desire on their part to address this issue - the findings have a wider use and application.28

The study was designed and carried out in the absence of a broader evidence base on autistic adults without LD. There was, for example, a very limited literature to draw on to inform selection of outcome measures when the study was being designed in 2013. Since then, however, there has been a burgeoning awareness of the need for a robust evidence base to inform the care and support of autistic adults without LD.28, 36, 42 Whilst the last couple of years have seen the publication of some studies on outcome measurement or service design and delivery, the evidence base remains very limited. Thus, this study comprises a significant contribution, not only with respect to models of providing care and support to autistic adults without LD, but only methodogically. For example, learning about recruitment and retention, data collection and outcomes measurement. With respect to the latter, members of the research team (EM, BB) have conducted an evaluation of the psychometric properties of the GHQ-12 using Rasch analysis (available from the authors).

### Limitations

There are a number of limitations which are important to detail given their implications for the extent to which, conclusions can be drawn.

Stage 1 sought to identify services which fulfilled NICE’s description of multi-disciplinary, community-based provision for autistic adults – referred to by NICE as ‘Specialist Autism Teams’. We did not identify any service which fully aligned with NICE’s descriptive criteria of SAT provision. The key deviation was that all the services identified worked exclusively with autistic adults without LD, though some provided consultancy to other services with regard to all autistic adults. As such, this is not a study limitation, but rather a ‘limitation’ of implementation of the SAT provision model. However, it does mean that the findings and conclusions drawn cannot inform service development for autistic adults with LD.

Other variations in the integrity of NICE’s vision for SATs were also observed between SATs. For example, differences in provision for carers, engagement in upskilling practitioners in mainstream services, extent of multi-disciplinarity (and, by implication, holistic approach to care and support), and the provision, or not, of longer-term, low intensity support. We have explored why services differed in the extent to which they have, or could, fully implement SAT provision and this has generated useful and important evidence.

Evaluating the impact of different structural arrangements and approaches to care and service delivery on service user outcomes and resource use was a core study objective. A key finding from Stage 1 was that each SAT was idiosyncratic. This meant we could not cluster SATs into different ‘types’, or service models, and then go on to evaluate and compare the different models using one or two exemplar services per model. Thus, as specified in the study protocol, we moved on to investigate how service characteristics (e.g. structural features, delivery approaches, ways of working) may affect user outcomes and resource use.

It is important here to note that in the quantitative component of this investigation, for each characteristic, the research sites clustered together differently. This was exacerbated by needing to have nine research sites to fulfil sample size recruitments within the study timeline. (The study had more research sites than originally planned due to withdrawal of a large SAT early in study set-up, slower than expected throughput (and hence recruitment) in some sites, and significant delays in recruitment opening in two sites due to delays in re-commissioning processes). These issues can, to some extent, be managed in the analytical process. However, it remains that we need to be careful in the interpretation of some findings, and the weight given them.

Finally, for the economic evaluation, data regarding SATs funding, budgets and caseloads were secured from fewer than half the research sites. Perceived vulnerabilities with respect to funding and commissioning arrangements may have inhibited sharing of budgetary and costs information with the research team. Imputation was used to derive estimated costs for each site; however, the wide variation between sites means findings should be treated with caution. Taking a top-down approach to understanding service costs meant a break-down of staff costs/resource by the different SAT functions (e.g. diagnostic assessment, mental health interventions, drop-in provision and work with other groups such as training and consultancy) was not possible. The very different approaches taken by SATs to, for example, the diagnostic assessment process (as reported in Chapter 3, Section 3.2.5) illustrate the limitations of the top-down approach. They also serve to demonstrate the need for caution when interpreting findings. Certainly, to carry out micro-costings would have required a substantial additional research resource. However, on reflection and in hindsight, given the novelty of the delivery model and the lack of existing research, this may have been a worthwhile investment.

In terms of the qualitative elements, one site was under-represented in the sample of service users interviewed for the study. This was because, unexpectedly, it closed recruitment quite early in the study timeline and there were, therefore, limited numbers of study participants eligible for interview (i.e. had used a service ~ 12 months) when these took place towards the end of the study. However, this site was well represented in the sample who provided written accounts of their experiences within the T3 study questionnaire (reported in *Chapter 6*). In addition, whilst we used a sampling frame to ensure representation of range of characteristics and experiences, the sample recruited to interview was self-selecting, though we note that over seventy per cent of those invited were interviewed.

Furthermore, we did not recruit as many family members to the qualitative evaluation as had been planned. Given the topic of the interview, it was essential that the autistic adults chose whether a family member was also invited to take part in the study. Fourteen (out of 38) agreed to this and, of these, nine family members were recruited. This means the conclusions we can draw regarding family members’ views of the impacts of using a Specialist Autism Team on their relative (e.g. child, partner) are limited. In addition, our understanding of family members’ needs – and the actual or potential role SATs played in meeting those needs – is partial. It is important to note here that many of the interviews we did conduct with family members revealed significant concerns and difficulties – both for themselves and the autistic person. This accords with findings from existing research which has looked at family members of autistic adults.25, 43

Once the study was underway a small additional element was introduced which offered an exploratory comparison of the outcomes and experiences of those on a diagnostic pathway provided by a SAT (D&S group of the SAT cohort) and those diagnosed by a regional/national diagnostic assessment service (DO cohort) where no post-diagnosis support was available. It is important to highlight the initial nature of these findings. The quantitative evaluation was underpowered, and the number recruited to our qualitative study limited. Furthermore, we do not know if and how the quality of the diagnostic assessment process from which the DO cohort was recruited compares to other diagnostic services in England. The particular challenges associated with discriminating autism from co-occurring mental health problems is well-documented,44 and indicates the need for a high level of expertise. Senior practitioners in our research sites believed they offered high quality diagnostic assessments (including at least one feedback session). However, they noted this was not necessarily the case either for other diagnostic assessment pathways operating across the country. Thus, these findings cannot be generalised and certainly more research is required in this area.

Finally, all sites reported higher than expected levels of demand on their service that had not been matched by an increase in resources. In addition, in two of our sites there were extended periods during which a key post (e.g. specialist practitioner, clinical psychology) was unfilled. The consequence for all services was longer wait times between intake and full assessment and, potentially, wait times for interventions set out in the care plan. Findings from our qualitative data collected from service users *(see Chapters 6 and 7*) indicates this may affect both the service user experience and impact.

## The implementation of specialist autism team provision in England

Stage 1 of the study (see *Chapter 2*) sought to identify localities in England which had a Specialist Autism Team (SAT). The key findings from Stage 1 of this study are:

* SAT provision in England has been developed specifically for autistic adults without autism;
* in 2015, (just) eighteen localities in England were identified as having a SAT;
* SATs differ according to a number of service characteristics.

The rationale for specifically developing provision for autistic adults without LD was consistent across SATs. Namely, the lack of any specialist services for this group, concerns about unmet need, and evidence about increased risk of poor outcomes: a deficit identified by national audits of autism provision.45 None of the SATs were fully ‘compliant’ with the NICE guidance on roles, function and skill mix. Resource and/or commissioners’ service specifications constrained the scope of services. For example, direct provision of care and support for carers and autistic adults in the community not currently ‘in the service’ was often very limited.

Our findings suggest that the 2010 Autism Act and NICE guidance stimulated the development of SATs across England with two-thirds of SATS established from 2010 onwards. However, access to such provision remains very limited, with just eighteen SATs identified. Representing this statistic in terms of numbers of LAs, this indicates that individuals living in less than a sixth (25/152, 16%) of LAs in England have access to a SAT. Differences in the data collected mean we cannot directly compare our findings with the fourth (2016) national review of progress in implementing in the Autism Act.45 However, they do report just 16% of LAs report access to autism-specialist post-diagnostic needs assessments for autistic people without learning disabilities (e.g. mental health) which, given this is a clear SAT function, indicates that our mapping work is likely to have identified all, if not the great majority of SATs in England.

Clearly, the extent to which Specialist Autism Teams have been implemented has, to date, been very limited. On the other hand, this mapping study has generated strong evidence that it *is* possible to implement such provision, and there are different ways of setting up such a service (e.g. the single vs multi-team model, models of Local Authority involvement).

The NICE guidance made clear statements about the functions of a SAT and the need for a multi-disciplinary approach. However, no evidence-informed guidance could be offered on service characteristics such as models of organisation and delivery and ways of working. As a result, differences in the implementation and operationalisation of this guidance were anticipated. Our findings confirm this is the case, with SATs varying in terms of a number of characteristics. These included: organisational features, staffing and skill mix, diagnostic assessment protocols, interventions used to address presenting needs, priority given to supporting self-management, and the extent to which they engaged with supporting family members and upskilling professionals in mainstream services, and the approaches taken to delivering such support. The specific interventions being provided also varied; for example, many provided group sessions on living with autism, but each was unique. The funding available, the extent of statutory social care involvement (i.e. Local Authorities) and clinical opinion strongly influenced the specific characteristics and practices of services.

The absence of an evidence-base had the potential to affect a number of different decision-making processes related to the establishment of SATs. This included the content of service specifications developed commissioners, and the funding allocated. Furthermore, whilst the resources available impacted decisions made by professionals involved in designing and delivering SATs, their own clinical opinions and cumulative clinical experience sometimes strongly influenced service characteristics. This is also the case for the specific interventions provided where, again, evidence on effectiveness and user experience is extremely limited.34, 46-48

Such observations are, by no means, unexpected. Statutory provision is unavoidably influenced and constrained by available resources, and clinical experience is an inevitable but valuable contributor to clinical decision-making and, more recently, service design.49, 50 However, as with other studies, these findings highlight the need for investment in developing an evidence-base that can support and inform issues of the design and delivery of services for autistic adults. 35, 37

## Delivering Specialist Autism Teams

A nested qualitative study of the experiences of senior practitioners within Specialist Autism Teams provided another layer of understanding of SATs and built on the findings from the mapping study. Reported in Chapter 4, this piece of work revealed the range of challenges senior staff encounter as they lead and deliver SATs. In addition, throughout the chapter, the learning accrued through cumulative clinical experience is a strong theme. This is not surprising. We should remember that the majority of services we evaluated were relatively ‘young’. All had been developed in the absence of any research evidence to guide service design and delivery and there were very few SATS already in existence on which to model service design. (Indeed, prior to acting as research sites for this study, none of our research sites were aware of the existence of many of the other research sites).

The learning revealed during interviews and focus group discussions concerned both a refinement of specific aspects of practice and ways of working with autistic adults without LD and a growing understanding about models of working and service delivery for SATs that are feasible and sustainable. To some extent, the external and internal pressures of constrained resources, experienced relatively more acutely in mental health and Local Authorities,41, 51 meant services had (rapidly) become critically reflective and solution-focussed.

All services were extremely concerned about the volume of referrals. Both well-established services (where a decline in demand – at least via the diagnostic assessment pathway – might be expected) and those more recently opened reported a year on year increase. The volume, and its increasing nature, had not been anticipated. Importantly, none had received additional commensurate funding, a few had seen a reduction in funding. Furthermore, none believed the level of demand would fall. Certainly it is likely that increased awareness of autism among professionals and the public has contributed to increased demand for diagnostic assessment in adulthood.52 SAT practitioners also believed the lack of any other non-LD autism-specific provision in the locality and mainstream services’ reluctance to work with autistic adults (with their own resource constraints increasing that resistance) were the key drivers to growing numbers of referrals into the SAT. Furthermore, these factors also made for difficulties for SATs trying to refer to other services (e.g. IAPT, CMHT) and, for some service users, discharging them from the service.

In response to these pressures, all the services in our study had revised their service offer or ways of working. These changes had in some way, it was felt, compromised the quality of care including wait time (both for assessment and interventions), the intensity of support provided or a lack of flexibility in how care was provided; for example, only offered group-delivered interventions. However, there were also examples of innovations had been implemented in response to these constraints that senior practitioners felt had been particularly successful.

### Supporting sustainability

An important component of this nested study concerned distilling learning and opinions about whether and how SAT provision should further develop. All services were convinced of the importance and value of SATs having a core role in the care and support of autistic adults without LD, both those needing/newly diagnosed and those diagnosed as children or earlier in adulthood. However, to ensure there are sustainable improvements in support for autistic adults without LD, senior practitioners believed some shifts in the role of Specialist Autism Teams, and the emphasis and priority given to certain functions by such services, was required. They were as follows:

* whilst maintaining the availability to provide autism-specialist interventions and support, placing greater emphasis and resource on consultation and supervision of practitioners working in mainstream/generic services;
* ensuring practice, and interventions offered, supported self-management rather than fostered dependency;
* developing, and investing in, low-intensity support available post-discharge; ideally, but not only, this would incorporate collaborative working with local peer-led networks.

Such suggestions are not to say that senior practitioners believed the vision of SATs set out by NICE needed modification. The Guideline clearly specifies SATs as being responsible for providing *and/or* coordinating care and support (our emphases). And the Autism Strategy identified autistic adults without LD as being likely to particularly benefit from preventive support. Rather, they believed that service specifications may need revising. Based on their experiences to date, senior practitioners emphasised that such changes require ‘buy-in’ and commitment from commissioners. They noted, however, it had proved very challenging, or indeed impossible, to secure funding for, for example, drop-in services or other preventive type provision. The absence of an evidence base on the impacts and effectiveness on low-intensity support was a barrier to making a case for incorporating such provision in the SAT offer.

With respect to increasing the emphasis given to the consultative role, it is important to note that senior practitioners were very clear it would not remove the need and demand for autism-specialist interventions provided by practitioners with extensive expertise in autism, and for those with complex needs. They also noted the potential risks associated with under-trained professionals assuming a level of autism-expertise or competence.

Furthermore, adopting a consultative/supervision model was dependent on mainstream services being willing, and allowed, to work in this way. Whilst ‘consultative’ models of healthcare delivery have been implemented in other fields of health care, it is not a familiar approach in community adult mental health. The recently published NHS Long Term Plan,41 however, points in that direction, noting the requirement for healthcare providers to ‘make reasonable adjustments’ so that autistic people can access and use their services.

Supporting self-management, making available long-term low-intensity support from SATs (e.g. telephone ‘clinics’, drop-in services), and supporting autistic adults to connect with peer-led groups and communities all point to building resilience and preventing future difficulties, even crises. We noted earlier the challenge of making the case for investing in such provision, although some modelling work published by the National Audit Office demonstrated such provision for autistic adults without LD may be cost-saving, or at least cost neutral.53 Wider evidence indicates a potential benefit of supporting self-management and for its integration within the care of people with long-term conditions.54, 55 However, robust evidence to their impact and effectiveness for autistic adults without LD is required. 35, 56

However, and particularly with respect to the notion of promoting community and peer-led support, it is important to also draw attention to findings from Stage 2 concerning the membership and contact with autism-specific third sector organisations and peer-led groups and communities (see *Chapter 8*). We found that less than a quarter of study participants were members of an autism-specific voluntary organisation with a similar proportion having had any contact with such an organisation in the four weeks prior to each data collection time point. Whilst an increase in contacts with such organisations was observed at 12 months follow-up, and appeared to be sustained into the longer-term, it is important to remember that, for the majority no change was observed. This finding highlights that some people may be unable, even with support, to use peer support. Equally, and as we report in Chapter 8, others may be dis-interested or unwilling to do so.

## The evaluation of the Specialist Autism Teams

### Domains of impact

Chapter 6 reported findings from our analysis of free text data collected at T3 on the ways SATs had impacted on study participants’ lives (or not). Over half of T3 respondents responded to this question. The impacts described were wide-ranging and serve to illustrate the range of needs of an autistic adult without LD may have. We organised them into seven broad categories: understanding of autism, acceptance of self, improved mental health, reduced sense of isolation, improved relationships and social networks, help with employment and education, supporting access to other services. In addition, the positive impact of contact with supportive and autism-expert practitioners was reported. Together, these provide evidence that some degree of holistic care was being achieved by the SATS we evaluated. Our data on service users’ reports of the number and range of concerns they had worked on with their SAT (see *Chapter 8*) corroborate this as do findings from our in-depth semi-structured interviews with service users (see *Chapter 7*).

Thus, in these interviews a similarly wide range of needs was described. In addition, it was clear that interviewees varied considerably in the severity and complexity of their needs. For example, some of those referred via the diagnostic assessment pathway (and including post-diagnostic psychoeducation) identified no further needs for which they required the support of the SAT. Others, however, had multiple and/or long-standing needs and difficulties. In terms of perceived outcomes of using a SAT, we heard a range of experiences. Some described their needs being fully, or predominantly, met and this included those who, on referral to the service, had significant difficulties. Others had a more mixed experience, with some needs being met and others remaining unmet. The accounts of a third group indicated that their needs remained predominantly unmet. In a subsequent section (*Factors affecting outcomes of using a SAT*) we report our findings as to why there were these different experiences.

### Outcomes

Overall, and in line with other studies,25, 57 on all domains of the WHOQOL-BREF, mean scores were lower for sample members than UK norms.58, 59 With respect to the GHQ-12, compared to other studies which have used this measure, a greater proportion of our sample were scoring above the population mean clinical threshold (>80% vs 40%).60, 61 Using EQ-5D to generate utility scores, the sample had markedly worse generic health-related quality of life than population norms (e.g. 0.696 for those aged 23-34 compared to an England norm of 0.919).62

A number of changes in outcomes were observed between baseline and 12 months follow-up (T3) (see *Chapter 8*). For the D&S group, a statistically significant improvement in the proportion of study participants scoring below the GHQ-12 clinical threshold was observed. Whilst the WHOQOL-BREF Psychological Domain mean score also improved, this was not a statistically significant change. The picture for the SO group is different with no statistically significant improvements mental health observed.

With respect to our secondary outcome measures (EQ-5D-5L, WHOQOL-BREF Social, Physical, Environmental domains, ISEL-BE subscale), for the D&S group, changes in mean score between T0 and T3 were slight and non-significant. The same pattern of findings was observed for the SO group, except for the WHOQOL-BREF Social Domain where a statistically significant (p<0.05) deterioration was observed at T3.

We also investigated changes in outcomes using a set of categorical indicators that assessed two broad domains: day-time occupation/usual activities and access to autism networks and support. For the D&S group, a statistically significant increase (p<0.05) in the proportion reporting no/slight problems with managing daily living was observed. However, there was no evidence of positive change in terms of perceived availability of information needed for everyday living, employment status, satisfaction with capacity for work and satisfaction with leisure time. For the SO group, any changes were non-significant.

In terms of access to autism networks and support, for the D&S group, there was no significant change in levels of membership of autism-specific local/regional/national groups and/or on-line only communities. Indeed, at T3 less than a fifth were members of such an organisation/community. However, there was a significant increase (p<0.01) in the proportion of the sample who had had some contact with such an organisation/community in the four weeks prior to T3. That said, it is important to note that the majority (73.9%) had had no contact. For the SO group, membership levels also remained low at T3 (16.1%). Unlike the D&S group, no significant change in levels of contact was observed.

To summarise, for the D&S group there was some evidence of improvement in mental health, ability to manage everyday living and use of autism-specific third sector/peer led organisations at T3. Findings for the SO group differed with the only statistically significant change observed being a deterioration in social quality of life (as measured by WHOQOL-BREF’s Social Domain). We would note that the size of the SO group is relatively small and therefore detecting changes in outcomes may be compromised.

There are a number of possible explanations for the differences observed between the D&S and SO groups. Thus, the groups differed in their sociodemographic characteristics. Overall, the SO group was younger and more likely, therefore to have been diagnosed in childhood. This also meant they were more likely to be students and to be living with their parents. Thus, the potential support networks of the two groups may differ and this may have affected outcomes. In addition, at baseline, the SO group reported a better mental health quality of life. This may indicate, for at least some, needs were less severe or less pervasive in their impact.

An alternative, or additional, explanation is that some in the SO group may have unresolved difficulties regarding the autism diagnosis which meant they were unable to (fully) benefit from the interventions provided by the SAT. SATs do not routinely offer a psychoeducational intervention to those referred to their service already diagnosed (i.e. the SO group). However, recent studies report young adults diagnosed as children may hold incorrect beliefs about autism.63 64 Furthermore, evidence is starting to emerge on the potential role of psychoeducation in preventing poor mental health outcomes because it seeks to support understanding, personal acceptance and a positive view of autism. 65, 66

It may also be the case at the expectations and needs of the D&S group and SO group differed. In our interviews with service users, those sampled from the SO group interviewees reported a wide range of, sometimes quite specific, needs associated with managing everyday life and social relationships. In contrast, and aligning with other research,67, 68 the expectations of the D&S group were strongly centred on the diagnostic assessment, particularly as a means to offering sense or validation of their lives. That is not to say, however, that some also had quite significant mental health and/or social needs. However, these needs tended to be expressed in more global terms. It is possible, therefore, that the ‘lack of fit’ between users’ needs (and expectations) and the care and support SATs offered was greater for the SO group compared to the D&S group. Other findings lend some support to this argument. First, there was a difference between groups in the proportion reporting the SAT did not work on any of their concerns (12.3% vs 6.8%) (see *Chapter 8*). In addition, the SO group was more likely to report little, no or a negative impact of using a SAT, with the lack of positive impact attributed to no, or unsuitable or insufficient, support being offered (see *Chapter 6*). Finally, and not possible for us to investigate, we do not know whether there are routine differences in the quality or intensity of support offered by SATs to these two groups.

### Factors affecting outcomes of using a SAT

A key objective of the study was to generate evidence on what a SAT should ‘look like’ in terms of its characteristics and ways of working. Our quantitative and qualitative data both contributed to addressing this objective.

#### Service characteristics

We found no evidence of an association between outcomes and any organisational or structural features investigated, namely: **Local Authority involvement** in commissioning/funding, the structure of the SAT (**single vs multi-team**), and whether the service was **autism-specific or a wider neurodevelopmental service**. Findings from the economic evaluation align with this except for the autism-specific vs neurodevelopmental service characteristic, where (after adjusting for other baseline covariates) an advantage in favour of autism-specific SATs was observed. These indicate, in a very preliminary way, different in approaches to the broad organisational set-up of SATs may be acceptable. However, we would stress these are initial findings and evidence of no association should not interpreted as an absence of association. We have no evidence from our qualitative data that contradicts these findings with respect to single vs multi-team structure and autism-specific vs neurodevelopmental provision.

However, our finding of no evidence that Local Authority involvement is associated with user outcomes does require further discussion. Services we classified as having LA involvement varied in how this was operationalised (e.g. LA seconded social work post vs LS part-funding AS specialist support workers or drop-in provision), though for all it supported access to Community Care Assessments. Cell counts meant these different models of LA involvement had to be collapsed into a single characteristic and this does mean we have to be careful how we interpret this finding. In our analysis of service user interviews, active support with accessing other services was identified as being associated with needs being met (see *Chapter 7*). Senior practitioners believed that LA involvement could be an important and valuable feature of SATs (see *Chapter 5*), offering the ability to carry out, or smooth access to, social care assessments, and promoting collaborative working between the SAT and adult social care teams more widely. However, they also noted very long waiting lists for LA social care assessments, and this may offer further explanation for our findings. Finally, the proportion of SAT users needing and eligible for LA social care is likely to be relatively small (see Table 64, Appendix 16). This means any impacts on outcomes may not have been discernible given the size and nature of the sample recruited to this study.

We did, however, find strong evidence of an association between **skill mix** and outcomes, with greater skill mix associated with better mental health outcomes. These findings align with wider evidence on positive impact of richer skill mix in mental health services.69 Our qualitative evidence consistently supports, and offers explanations for, this. The ‘fit’ between service users’ needs and what a SAT was able to provide – at least partly determined by skill mix – was identified by service users and SAT practitioners as key to the impacts SATs could achieve (see *Chapters 5-7*). Richness of skill mix can be taken as an indicator of the extent to which a truly holistic approach can be achieved. This emerged as one of the core explanations for differences in service users’ experiences and the degree to which they felt their needs were met by the SAT (see *Chapter 7*). This perspective also provides an explanation for seemingly contradictory findings from the economic evaluation which did not find richer skill mix was more cost-effective in terms of psychological quality of life. We also note the tentative nature of conclusions drawn from the economic evaluation.

With respect to the overall model of care delivery, we applied the broad classification of **managed vs episodic care**. Managed care was defined as the active, on-going review and monitoring the care plan and its impacts. SATS allocated to ‘managed care’ included those where the service user was actively involved in review and forward planning. ‘Episodic care’ describes a model where there is minimal review and oversight of progress through a set of interventions determined at needs assessment. Episodic care should not, however, be regarded as necessarily less holistic in the range of care and support offered. We found weak evidence that managed care was associated with better mental health outcomes at 12 months follow-up. Again, findings from our qualitative research accord with this. It appeared that it facilitated a responsive approach, meaning the needs emerging during the time in the service could be responded to, something that was highly valued. It also supports goals-focussed approaches to care and support. However, episodic care is associated with lower costs, and so may be seen as more cost-effective.

In some SATs, the managed care model included service users having a ‘named contact’ within the service whom they could get in touch with between appointments or group sessions. Many of these SATs also offered some form of informal drop-in service (see *Chapter 3*). Another, whilst not offering a named contact did provide a ‘drop-in’ service, though not necessarily at the outset of joining the service. Findings from our qualitative research with senior SAT practitioners and service users (see *Chapters 5 and 6*) indicated that having a named contact was an important feature of service delivery in terms of the potential to affect outcomes (and service user experience). We also knew from our interviews with service users that, for some, the opportunity for low-intensity, reactive contact with the service – such as that afforded by a drop-in service, was valued. We therefore decided to group these two features into a single service characteristic (**drop in provision and/or named contact**) and tested for an association with outcomes at 12 months follow-up. Findings were mixed. There was no evidence of an association between this characteristic and psychological quality of life (WHOQOL-BREF Psychological Domain). However, there was moderate evidence of an association between not offering drop in provision and/or a named contact and more positive mental health outcomes. This is unexpected and, as already described, runs firmly counter to shared view of service users and practitioners.

In terms of features of service delivery, there was no evidence that the mode by which SATs typically delivered **psychoeducation (group vs individual)** was associated with outcomes. Findings from the economic evaluation similarly conclude that, in terms of cost effectiveness, there is no strong case for either mode of delivery. Our interviews with service users revealed the different benefits of both modes of delivery (see Chapter 7). For those who found attending groups very difficult, this could act as a significant barrier to take-up, an issue perhaps more acute though not unique to autistic adults.70 At the same time, certain aspects of group delivery were identified by service users as extremely helpful. These included the opportunity to hear others’ experiences (including positive ‘peer role models’) and a reduced sense of isolation. Indeed, these benefits were the rationale given by senior practitioners to use group delivery, but they also noted the importance of having resources available to support, where required, attendance of a group. Finally, we note here that all senior SAT practitioners believed their psychoeducation was of high quality, a position re-iterated by our qualitative data (see *Chapters 6, 7, 9)*. It is important to stress, therefore, that this finding should not be generalised to other models of diagnostic provision.

We also found no evidence that **routinely offering 1:1 work for (non-complex) mental health problems** (as opposed to group-delivered interventions or supported referrals) was associated with mental health outcomes. However, in terms of psychological quality of life, findings from our economic evaluation provide preliminary evidence of the value of SATs providing 1:1 work for non-complex mental health problems. A number of factors may be at play here. First, all SATs sought to refer on to mainstream community mental health services (e.g. IAPT) and 1:1 work with non-complex cases was typically limited in its duration and intensity. Second, all SATs routinely offered at least one (typically) group intervention to improve managing anxiety and psychological resilience. The lack of evidence on their effectiveness, and the effectiveness of generic IAPT interventions for autistic adults without LD, make it difficult to further specify possible explanations for this finding. Also pertinent here may be the positive emotional impact of simply feeling understood (because of the service’s autism expertise) which service users described (see *Chapter 7*).

#### Individual characteristics

We found no evidence that **referral pathway** (D&S vs SO) was associated with mental health outcomes. In terms of associations between individual characteristics and mental health outcomes at T3, we found moderate evidence of an association between **age** and mental health quality of life (WHOQOL-BREF Psychological Domain) at T3, but this was not the case for GHQ-12 scores at T3. In terms of **gender**, there was moderate evidence that gender (favouring men) was associated with mental health quality of life at T3, with a similar pattern of findings (weak) for GHQ-12 scores. There was also moderate evidence that **mental health at T0** (GHQ-12 score) was associated with mental health outcomes at T3.

Three further person-centred factors (all assessed using a categorical indicator) were investigated as predictors of T3 mental health outcomes.

* contact with autism-specific communities,
* having the information needed to manage everyday life,
* social networks/support.

These factors are all, we would argue, amenable to intervention.

No evidence was found of an association between **contact with autism-specific communities** (in the previous four weeks) and mental health outcomes. We note this is a very crude indicator of the extent to which individuals were using autism-specific communities as a source of support: small cell counts meant we could not look at the intensity or nature of those contacts, and we only asked about the previous four weeks. These limitations may offer some explanation for our finding. At the same time, it is important to refer to observed levels of membership and contacts with autism-specific group/community (see *Chapter 8*). At T3, fewer than one in five were members of an autism-specific group/community, and less than a quarter had had any contact with such an organisation in the previous four weeks. Furthermore, our evidence on longer term outcomes (18- and 24-month follow-up) does not indicate that such support is taken up post-discharge (see *Chapter 8; Appendix 12 (Tables 48 & 49)*). At the same time, it is important to note that SAT staff regarded such groups/communities as an important contributor to providing long-term, low intensity support to autistic adults without LD (see *Chapter 4*). This accords with other research,67, 71-73 and the NICE guideline recommends SATs work in partnership with such organisations. To our knowledge, however, there have been no studies of their effectiveness, neither could we find any literature on reach and take-up of such provision. 34, 56

We found strong evidence of an association (in a positive direction) between **perceived availability of information to manage everyday life** and T3 mental health outcomes. A recent qualitative review of autistic adults’ experiences of self-determination and quality of life describes the role of information plays in supporting self-determination, and the literature on self-management of long-term conditions also points to its importance.74, 75 However, we do note this finding should be regarded as a ‘first look’ at this issue. We used a single question from the WHOQOL-BREF as our indicator of satisfaction with availability of information to manage every life. This reveals nothing about the type of information and the purposes for which it may be used. However, our descriptive analysis suggests around half of the study participants reported inadequacies in the availability of information they needed for daily life (see *Chapter 8*).

Finally, we found strong evidence of an association between **perceived availability of social support** at mental health outcomes at T3. This is not unexpected: the association between social support/social isolation and depression is well established, though evidence regarding its association with anxiety more preliminary.76 Two items on our measure of perceived social support (BE subscale of ISEL-SF) refer to support from the family whilst the other refer more to friendship groups. We have already discussed the role of SATs in supporting autistic adults without LD to make connections with peers. A further role is supporting family understanding of autism and, indeed, a quarter of our sample reported the SAT had worked on this concern (see *Chapter 8*). Our qualitative research with service users revealed that addressing family members’ understanding of autism was a valued element of SAT service provision (see *Chapter 6*). It was, however, sometimes reported as an unmet need. Findings from our mapping study revealed that care and support of family members was one aspect of provision set out in the NICE guideline which services did not prioritise, often due to resource constraints (see *Chapters 3 and 4*). However, we know from other research that family members may struggle to accept the diagnosis, with this having a significant negative impact on autistic adults themselves.68

## Comparing outcomes & experiences of the DO cohort and D&S group

Finally, we compared experiences and outcomes of individuals diagnosed and receiving post-diagnosis support from a SAT ( D&S group) with those diagnosed via a national/regional diagnostic assessment service (the DO cohort). We collected two sets of evidence. First, we collected the same outcomes data from the DO cohort as for the SAT cohort (reported in *Chapter 8*). Second, we interviewed a sub-sample of the DO cohort and, for some of these, a member of their family (see *Chapter 9*). We remind the reader here that the DO cohort sample was small, thus findings are initial and exploratory.

We found evidence of a potential difference between the DO cohort and D&S group in the trajectory of mental health outcomes from baseline to 12 months follow-up. Evidence of a potential deterioration in mental health (GHQ-12 score) in the immediate post-diagnosis period observed in the DO cohort was not seen in the D&S group. No statistically significant change on any of the study’s outcome measures and indicators was observed in the DO cohort between T0 and T3. This contrasts with observed improvements in mental health, ability to manage everyday life and contacts with autism-specific groups/communities found for the D&S group. Our analyses comparing T3 mental health outcomes of the DO cohort and D&S group were underpowered.

The interviews with individuals representing the DO cohort and D&S group revealed, to start, a commonality of experience of the diagnostic assessment process. The majority expected to be diagnosed and experiences of the actual process were typically positive. However, learning the diagnosis triggered a range of emotions. Relief was the typical first response; however, a minority despaired the life-long nature of the condition. Among those whose initial response had been positive, this soon shifted to a more mixed set of emotions. There was talk of frustration about not being diagnosed earlier and grief for the ‘lost years’. For some, these feelings were still being experienced when our interviews took place (around six to nine months post-diagnosis). Family members’ accounts suggest that such negative emotional experiences, and the investment individuals may place in the diagnostic assessment process, may be hidden from them.

The accounts of D&S group and DO cohort interviewees diverged substantially when experiences of post-diagnosis support were discussed. This was clearly located in the significant differences in the quality, duration and intensity of psychoeducational support they could access post-diagnosis. D&S group interviewees spoke highly of post-assessment feedback session(s) and psychoeducation interventions (typically group-delivered), and described the impact this had on them in terms of understanding, (self-) acceptance and a sense of being supported. In contrast, DO cohort interviewees – who within the diagnostic assessment package had a single feedback session and, sometimes, a single group psychoeducation session – described such support as insufficient. The experience of inadequate support, was itself, a negative experience with notions of abandonment an evident theme in their accounts.

At the time of our interviews, around six to nine months after diagnosis, all interviewees said being diagnosed had brought some positive impacts, particularly in terms of self-understanding (something we observed more widely among study participants, see *Chapter 6*). However, some DO cohort interviewees reported long-standing or unresolved difficulties associated with the diagnosis, and almost all expressed the need for further support with understanding and coming to terms with the diagnosis. A few believed receiving the diagnosis had subsequently caused a deterioration in their mental health. In all instances, this was attributed to the lack of psychoeducation and other post-diagnostic support.

Previous qualitative and quantitative studies of adults’ experiences of being diagnosed with autism also report relief as a predominant emotional response, and that the diagnosis offered an explanation for their experiences of life.72, 77-80 They too describe the potential range of emotions – both positive and negative – which may be experienced.67, 79, 81, 82 Similarly, they also report how the diagnosis may facilitate improvements in family relationships and the support received from other services or educational establishments/the workplace.67, 79 Studies which specifically explored immediate post-diagnosis support describe experiences of inadequate support which resulted in unanswered questions and a sense of isolation and dismay.68, 77, 78

We believe our findings make an important, new contribution to the existing, small evidence base. First, by interviewing individuals around six to nine months after diagnosis, it has been possible to explore medium-term impacts and experiences. Second, we have compared the impact of different post-diagnosis provision on individuals’ and family members’ experiences. This has revealed the negative impacts – potentially longstanding – that may occur as a result of inadequate psychoeducation support after diagnosis. It also offers evidence of the wider impacts and benefits associated with being diagnosed within the context of a Specialist Autism Team which has the potential to address, at least in the short to medium term, (some of) the needs of autistic adults without LD.

# Conclusions

## Summary of findings and implications

Eighteen services in England that fulfilled NICE’s description of a Specialist Autism Team were identified. All had been developed specifically for autistic adults without LD. Whilst some had existed before the Autism Act and subsequent NICE Guideline, most had been established in response to these. All had been commissioned due to concerns about the lack of access of specialist diagnostic assessments for adults, concerns about the well-being and outcomes of autistic adults without LD and the absence of any specialist provision for this group. It would appear, however, that the majority of localities in England do not offer this type of provision. That said, the findings from this study suggest that it *is* possible to develop and provide a service which aligns to the NICE guideline and government’s Autism Strategy for a multi-disciplinary, community-based service for autistic adults (without LD) and their families and which also supports other services involved in the care and support of this group. The services identified varied according to a number of service characteristics, and these did not cluster sufficiently for it to be possible to develop a service typology.

Senior practitioners working in SATs strongly believed in the value and unique contribution of their services. The multi-disciplinary nature of the service, staffed by practitioners specialist in autism, were seen as critical features. However, sustaining high quality care was challenging due to unanticipated levels of demand (not matched by increased funding), and the lack of other services being willing and available to share in the care and support of autistic adults without LD. Given SATs are a new type of provision, and with very little evidence and relatively limited clinical experience to draw on, it was, perhaps, unsurprising to find that many services had developed and evolved their provision and ways of working.

Looking forward, and to ensure sustainable care and support for autistic adults without LD, senior practitioners believed it would be necessary for their ‘consultative and supervision’ role to mainstream services to be expanded, though this was dependent on the collaboration of mainstream services and with the support of commissioners. In addition, investment was required to allow them to provide specialist, low intensity, on-going support (e.g. drop-in services) thus offering long-term continuity of care. There was strong agreement in the value and importance of involving and collaborating with the local autistic community to achieve such provision. Finally, and connected to the notion of low intensity and long term support, senior practitioners wanted to be able to invest more in interventions and ways of working which nurtured self-management and self-resilience.

The study collected quantitative and qualitative evaluation data. Findings from the quantitative evaluation demonstrate the wide range of need, health and functioning among those referred to SATs, and this was also observed in the qualitative data. Some people are referred with quite specific needs that are amendable to relatively straightforward interventions. Others are more complex. Evidence from our qualitative study indicates that both can benefit from a SAT, and our quantitative data demonstrates the range of needs and concerns SATs may address. Findings from our quantitative evaluation indicate that using a SAT may be associated with improved mental health (as indicated by movement from above to below clinical threshold), perceived ability to manage everyday and, for a minority, increased use of autism-specific groups/communities for support and advice. There was some evidence these benefits may be sustained into the longer term. However, significant improvements were not observed on our global and health-related quality of life measures, and these potential benefits were only observed in those accessing the SAT through the diagnostic assessment pathway (though we note small sample sizes for the support-only pathway). Overall, deteriorations in scores on standardised measures were not observed, this may indicate that, for some at least, use of a SAT prevented deteriorations in health and well-being.

The accounts of service users recruited to our qualitative study revealed a range of experience in terms of the needs they had when entering the service. For some, the diagnostic assessment and subsequent psychoeducation was sufficient, others had substantial and wide-ranging difficulties. Included in our sample were individuals who believed that using a SAT had achieved very considerable improvements in their lives. For those where needs remained un-, or under-, met, this was attributed to deficiencies in the duration, intensity, scope and flexibility of the support the SAT was able to offer. The ability of services to offer, where required, 1:1 work rather than group-delivered interventions, longer-term involvement, and less holistic provision were key barriers to meeting need. Taken together, these findings indicate that, as model of care, SATs have the potential to deliver expert, holistic care and support. However, insufficiencies in resource and lack of collaborative working with other services, sometimes reluctant to share involvement in the care of autistic adults without LD, hinders what can be achieved.

An initial exploration of our quantitative data on the effects of individual and service characteristics on outcomes found strong evidence that richer skill mix was associated with better mental health outcomes and, though evidence is weaker, managed care approaches were more favourable than episodic involvement in delivering care plans. These findings accord evidence from our interviews with service users, who also stressed the importance of a named contact within the service: something which often co-occurs with managed care. Findings from our economic evaluation show that some of these outcome improvements are only achieved at higher costs, which may prove a challenge to wider implementation; the economic evaluation also suggested that 1:1 work with SAT users with mental health problems could be cost-effective. There was also strong or moderate evidence that different structural models are acceptable for SATs, for example, single or multiple teams involved in service delivery, and locating the provision in autism-specific or neurodevelopmental services. Such evidence is useful to those seeking to develop, or re-design, such provision.

We found strong evidence of an association between mental health outcomes and quality of social networks and perceived availability of information to manage everyday life. These are both domains where SATs have the potential to intervene and, to some extent, point to providing social inclusion interventions and drop-in type provision, something for which many SATS had little designated resource. Two further findings from the study are relevant here. First is the relatively minimal engagement of the study sample, even post-discharge, with autism-specific third sector or peer-led groups or organisations, including on-line communities and forums. Second, among those who took part in our interview study, none had successfully pursued and used services (including autism specific groups/communities) which had been ‘signposted’ to them. Indeed, for the majority, no attempts had been made. It is clear that simply providing information, with the expectation that the service user will act on it, is ineffective or insufficient for many individuals. It may be the case that, compared to non-autistic people, autistic people without LD face additional challenges in pursuing signposts. The presence of mental health difficulties may be a further barrier. Overall, however, very little is understood about what is often a core feature of service provision.

The final element of our evaluation was a small scale comparison of individuals living outside of commissioning boundaries of a SAT, but referred to the SAT for diagnostic assessment only (the DO cohort), with those who had accessed SATs via the diagnostic assessment pathway (the D&S group of our SAT cohort). The very different post-diagnosis experiences and perceived outcomes reported by the two groups point to the fundamental importance of high quality and extended psychoeducation following diagnosis. It appeared to be the linchpin in the trajectories of the two groups, and serves to illustrate the significance and implications of diagnosing someone with autism.

### Implications

The notion of a Specialist Autism Team was developed by the Guideline Development Group convened by NICE in order to develop guidance on the diagnosis and management of autism in adults. This was a novel service model and the GDG acknowledged that research evidence available to support and inform the way this recommendation was operationalised and implemented was very limited. It called for research which would help to define those aspects of service organisation and delivery which best support positive outcomes. This was the primary objective of this study.

This study has shown it is possible to set up such a service. However, very few localities have been able to achieve this. Findings support the notion of Specialist Autism Teams and have demonstrated the benefits and positive impacts they can achieve. However, they need to be sufficiently resourced. Importantly, our findings suggest that different organisational structures are possible, including different approaches to integrating health and social care into a single provision (for example, jointly commissioned vs separate teams with joint working arrangements).

NICE called for evidence on what a Specialist Autism Teams should look like in terms of staffing and the interventions it should provide. Autism-specific expertise, interventions, and adjustments to service provision were identified as critical to the achievement of positive changes in people’s lives. With respect to staffing, overall our finding support a diversity of professions (or rich skill mix) within the service and an holistic, individualised approach to care and support. In terms of interventions, we believe the findings make a strong case for extended post-diagnosis psychoeducation, and interventions and practice that nurture self-management with respect to mental health, managing day-to-day life, and strengthening social networks. This should include the provision of low-intensity, drop-in type advice and support after discharge. There is some, limited evidence indicating it may be cost-effective for SATs to deliver 1:1 mental health interventions in-service, rather than supporting referrals to, for example, IAPT.

The great majority of those referred to SATs have mental health needs and addressing these is fundamental to achieving positive changes in other life domains. Some SATs operated on a model whereby non-complex mental health problems (or those not directly arising from autism diagnosis) were managed by referring on to generic community mental health services. However, such referrals (i.e. handover, assessment and intervention) need to supported by the SAT – with that support being available both to the individual and the receiving service. To make this work, commissioning arrangements need to include sufficient resource for SATs to be able to do this and for mainstream services to be required (and sufficiently resourced) to accept such referrals. The same argument applies to other statutory services.

Findings from this study do not support the use of signposting (i.e. simply providing information about another statutory or third sector service, or community support group/network). Given autistic adults may encounter additional barriers when initiating an approach to a new organisation, any service working with autistic people should consider reviewing their use of signposting. In addition, services should not assume that peer-led/autism-community organisations and networks, or support groups/networks run by autism charities, are widely used or replace autism-specialist services providing, or being available for, advice and support on a longer-term basis to autistic adults living in their locality.

Finally, and aligning with existing evidence, findings from this study raise significant concerns about the insufficiency or lack of post-diagnosis psychoeducation provided by services which only offer diagnostic assessment.

## Research recommendations

Research concerning the lives, and care and support of autistic adults without LD is one that is newly emerging but burgeoning. As has been noted elsewhere,83 investment at this early stage in the development of a core outcome set, in partnership with autistic adults without LD, would help to ensure the best return on that investment. This may require the development of new measures or adaptation of existing ones.84

Based on the findings of this study, and to further develop the evidence-base required by commissioners and professionals with responsibility for the care and support of autistic adults, we make the following recommendations for future research:

* informed by, and drawing on the findings of this study, a large-scale, mixed methods observational study comparing the effectiveness and cost-effectiveness of Specialist Autism Team provision with diagnostic assessment only provision, and including) family members’ outcomes. This would generate further, and more definitive, evaluation evidence and allow further, more complex, exploration into service design/delivery characteristics associated with outcomes;
* identification and evaluation of approaches to Specialist Autism Teams providing a ‘consultation and supervision’ function to mainstream services involved in the care and support of autistic adults without LD;
* identification, description and evaluation of approaches to provide low intensity, long-term autism-specialist support to autistic adults without LD;
* studies which develop the evidence base on existing ‘manualised’ interventions being delivered by SATs such as psychoeducational and self-management interventions; these should be designed to answer the questions: what works for whom and under what circumstances?;
* work to identify and describe the information needs which enable autistic adults without LD to manage everyday life, and how these needs can be best met;
* research which furthers our understanding of how autistic people without LD respond to and use signposting, and ways to improve the impact of signposting.

Acknowledgements

Dr Tom Berney was a co-applicant and provided clinical supervision to the research team. We are grateful for his input and insights.

The National Autistic Society was a co-applicant and supported the PPI work, and development and execution of the dissemination and impact strategy. In particular, we acknowledge the support and contributions of Carol Povey, Tom Madders and Tim Nicholls.

The research would like to thank the Project Advisory Group for their support and commitment to this project. Their insights and contributions were invaluable.

We also thank the Study Steering Committee, chaired by Professor Richard Hastings, for their advice, input and support.

We also thank Teresa Frank for the administrative support she provided across the course of the project, and for the administrative support provided by Emily Dunn and Karen Overend.

We also acknowledge the work and contribution of Dr Wendy Mitchell to Stage 1 of the project and establishing the Project Advisory Group.

Contributions of authors

**Bryony Beresford (Professor, Health and Social Care Services Research)**: lead applicant and Principal Investigator. Oversaw delivery of the project, led all aspects of the work except the economic evaluation. Supervised the research team, except health economist team.

**Suzanne Mukherjee (Research Fellow)**: contributed to: Stage 1 data collection and analysis, recruitment of Stage 2 research sites and study set-up, qualitative research with SAT practitioners. Led the second iteration of qualitative data analysis and write-up of all qualitative elements. Supported work with Project Advisory Group.

**Emese Mayhew (Research Fellow)**: responsible for research administration databases and support to study administrators, oversaw data management and conducted quantitative analyses.

**Emily Heavy (Research Fellow)**: carried out all qualitative data collection (service users, family members), developed analytical framework and coded all data, contribution to write-up of qualitative data.

**A-La Park (Assistant Professorial Research Fellow)**: worked on data collection and analysis for economic evaluation.

**Lucy Stuttard (Research Fellow)**: contributed to Stage 1 data collection and analysis, recruitment of Stage 2 research sites and study set-up, oversaw early stages of outcomes data collection and data management processes. Supported work with Project Advisory Group.

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**Martin Knapp (Professor, Health and Social Care Policy)**: co-applicant. Led all aspects of the economic evaluation and supervised the researchers working on the economic evaluation.

Data sharing statement

Available data have been included in appendices. Any queries or data requests should be submitted to the corresponding author for consideration. Access to available anonymised data may be granted following review.

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Appendix 1: Chapter 3 tables

Table 25 Socio-demographic and population characteristics of research sites

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Socio-demographic and population characteristics** | | | |  |
| **Site ID** | Approximate adult population in locality served by SAT | Number of LAs co-terminus with CCG | Relative deprivation\* | Rural Urban Classification85 | Size:  Area mile2 |
| A | 377,500 | 1 | 4/152 | Urban with major conurbation | 44 |
| B | 219,500 | 1 | 60/152 | Urban with major conurbation | 59 |
| CA | 243,000 | 1 | 8/152 | Urban with minor conurbation | 29 |
| D | 212, 000 | 1 | 40/152 | Urban with major conurbation | 54 |
| E | 175,000 | 1 | 120/152 | Urban with major conurbation | 41 |
| F | 605,000 | 3 | 78/152  121/152  128/152 | Includes: mainly rural with hub towns, urban with significant rural, urban with city & town, | 832 |
| H | 126,500 | 1 | 144/152 | Urban with major conurbation | 15 |
| IA | 439,500 | 1 | 48/152 | Urban with minor conurbation | 142 |
| J | 199,000 | 1 | 9/152 | Urban with major conurbation | 8 |
| \* Indices of Multiple Deprivation – Rank of Average Score (Upper Tier Local Authorities (n=152, 2015. Lower rank indicates greater deprivation.86 | | | | | |

Table 26 Service lead and skill mix represented in the research sites

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Site ID** | **Clinical lead** | **Clin psy.** | **Psychiat.** | **Social worker** | **OT** | **SaLT** | **Nurse consult.** | **MH Nurse** | **AS Support Workera** | **AS Clinical**  **Specialistb** | **Assist.**  **psy.** |
| A | Clinical psychologist | 8 | 0 | 0 | 0 | 0 | 0 | 20 | 26 | 10 | 0 |
| B | Clinical psychologist | 2 | 0 | 0 | 0 | 0 | 0 | 10 | 0 | 0 | 10 |
| CA | Autism nurse consultant | 16 | 2 | 0 | 0 | 12 | 10 | 2 | 6 | 0 | 10 |
| D | Clinical psychologist | 4 | 2 | 0 | 10 | 0 | 0 | 0 | 10 | 0 | 6 |
| E | Clinical psychologist | Yesc | Yesc | 0 | 0 | Yesc | 0 | Yesc | Yesc | 0 | Yesc |
| F | Clinical psychologist | 19 | .25 | 5d | 5e | 0 | 0 | 4d | 0 | 0 | 12 |
| H\* | Ha: Clinical Psychologist | Yesc | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Hb: Autism Clinical  Specialist | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 8 | 15 | 0 |
| IA | Clinical psychologist | Yesc | Yesc | 10 | 4 | 8 | 0 | 4 | 0 | 0 | 0 |
| J | Psychiatrist | 4 | 7 | 5 | 10 | 3 | 0 | 0 | As requiredf | 0 | 0 |
| a Support worker: includes ‘assistant practitioner’, ‘social inclusion worker’  b ASC clinical specialist: includes ‘senior practitioner’.  c Service unable to specify because SAT function only one aspect of service and staff delivering care to wider population. In Site E, excluding clinical  psychology and psychiatry, involvement of some staff with SAT typically restricted to complex cases only.  d One (of three) Local Authority only  e Two (of three) Local Authorities only  f Commissions specialist employment support service (includes support workers) as required | | | | | | | | | | | |

Table 27 Provision for carers by research site

|  |  |  |
| --- | --- | --- |
| **Site ID** | **Description of provision for carers** | **Partnerships with third sector organisations** |
| A | Signpost to carers’ organisations. | Able to signpost to active local autism carers group(s). |
| B | Signpost to carers’ organisations | Able to signpost to active local autism carers group(s). |
| CAa | Described as ‘integral to the service’; may attend 1:1 sessions with service user (joint interventions). | Able to signpost to active local and regional autism carers group(s). |
| Db | Two psychoeducation sessions post-diagnosis. | Able to signpost to active local and regional autism carers groups. |
| E | Two psychoeducation sessions post-diagnosis. | Able to signpost to active local and regional autism carers groups. |
| F | Able to contact service for requests with signposting and advice, if appropriate, contacts are discussed by the team. | Able to signpost to active local autism carers group(s). |
| H(a & b)c | Ha: offer 3 psychoeducational sessions for families/carers post-diagnosis.  Hb: Don’t formally offer support but will provide informal support/advice if appropriate and service user agrees. | Able to signpost to active local autism carers group(s). |
| IAa | Offer a support group led by psychologist for a fixed number of sessions. Predominantly attended by parents. | Able to signpost to active local autism carers group(s). |
| J | 6 weekly carers event. Have speakers plus time to chat/raise isues. Predominantly attended by parents. | No active local autism carers group(s). |
|  | **All sites supported referrals to LA for Carer Assessments** | |

Table 28 Training and consultancy by research site

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Site ID** | Training for specific services | Joint working | Routine advisory service | Public awareness activities |
| A | Monthly awareness training sessions across Trust | Advise services/professionals on a case by case basis re autism specific adjustments | No | Not reported |
| B | Monthly awareness training sessions across Trust | Advise services/professionals on a case by case basis re autism specific adjustments | No | Not reported |
| CAa | One off and rolling training programmes to statutory agencies (NHS, LA, police, prison service) & private sector organisations. | Advise services/professionals on a case by case basis re autism specific adjustments | No | Contribute to community awareness raising activities |
| Db | Runs training for CMHT | Not a routine part of service does. | No | Not reported |
| E | One off and rolling training programmes to statutory agencies (e.g. NHS, LA, police, prison service) | Advise services/professionals on a case by case basis re autism specific adjustments | No | Not reported |
| F | Deliver training to psychiatrists on diagnosing autism. | Advise services/professionals on a case by case basis re autism specific adjustments. | Each week, two 30 minute consultation appointments available for booking by teams/ professionals in statutory services | Not reported |
| H(a & b)c | Run training workshops on request. Wide range of agencies (e.g. police, adult education, CMHT, social care) | Advise services/professionals on a case by case basis re autism specific adjustments. | No | Not reported |
| IAa | Rolling programme of 1 day’s introduction to autism training open to all LA and Trust staff. Provide be-spoke training to statutory and private organisations. | Advise to services/professionals on a case by case basis re autism specific adjustments. | No | Monthly public seminar for autistic people & family members. |
| J | One off and rolling training programmes to statutory agencies (NHS, LA, police, prison service) and other organisations (e.g. businesses) | Advise services/professionals on a case by case basis re autism specific adjustments. | No | Run awareness-raising events. |

Appendix 2: The nested qualitative study with senior practitioners

**Study objectives**

The objectives of the nested qualitative study of senior practitioners’ views and experiences was as follows:

* To understand and describe the implementation and delivery of Specialist Autism Team type provision;
* To identify and describe the external and within-service factors which support or hinder the operation of the service and the quality of care and support provided;
* To explore and report senior practitioners’ cumulative experiences of providing care and support to autistic adults without LD;
* To secure senior practitioners’ views on the factors which affect the impact of their services on individuals’ lives
* To explore views regarding aspects of service organisation and delivery (within SATs and across the wider service context) which support the development of sustainable long-term care for autistic adults without LD, and experiences of implementing such approaches.

Findings from this nested study are reported in Chapters 3, 4 and 5

**Methods**

Data were collecting using:

* individual telephone interviews with one practitioner (or a joint interview with up to 3 senior practitioners) in each research site. This was followed up, where required, with email conversation to address missing information or points of clarification.
* an overnight workshop to which all sites were invited. The workshop schedule is presented in Box 3, and participant details in Box 4.

Interviews and workshop discussions were audio-recorded and verbatim transcripts created. Qualitative content analysis and thematic analysis were used to analyse the data. Thematic frameworks are set out in Box 5 with data coded using this framework. Analytical writing and mind map were used to map and explore interconnections between themes and structuring of the presentation of the data.

Box 3: Workshop schedule

|  |  |
| --- | --- |
| 8:45 | Taxis from hotel |
| 9:00 | **ARRIVE: TEA/COFFEE AVAILABLE** |
| 9:15 | Introductions, housekeeping, plan for the day |
| 9:25 | Overview of the SHAPE project: objectives, impact and current progress  *(Presentation by research team)* |
| 9:45 | Overview of findings from national mapping exercise  *(Presentation by research team)* |
| 10:05 | Introducing each service: the speed dating way  *(Each service gives a 4 minute presentation about their service)* |
| 10:45 | Reflection on current approaches to delivering ‘Specialist Autism Team’ provision  *(Whole group discussion)* |
| 11:00 | **COFFEE and CAKES** |
| 11:30 | Experiences of delivering a ‘Specialist Autism Team’ service: what helps and hinders you meeting your objectives?  *(Small group work and feedback)* |
| 12:15 | What works, and for whom?  *(Small group work and whole group discussion)* |
| 1:00 | **LUNCH** |
| 1:45 | Do’s and don’ts: learnings about autism-specific practice  *(Individual tasks and whole group discussion)* |
| 2:30 | Involving adults with autism in research: learnings from the SHAPE project  *(Presentation by research team)* |
| 3:00 | **COMFORT BREAK** |
| 3:15 | The issue of sustainability: what service features/ways of working need to be present, both within the Specialist Autism Team and the wider service context?  *(Small group work and feedback)* |
| 4:00 | Aspirations for the future  *(Service representatives work together followed by feedback)* |
| 4:15 | “Take aways” |
| 4:25 | Closing comments |
| 4:30 | **DEPART** |

Box 4: Workshop participants

|  |  |  |
| --- | --- | --- |
| **Site ID** | **Role [profession]** | |
| **Attended** | **Registered to attend, gave late apologies** |
| A | Service lead1 *[Clinical psychology]* |  |
| B | Acting service lead *[Clinical psychology]*  Senior team member *[Clinical psychology*] | Senior team member *[ASD Nurse Consultant]* |
| C | Service lead *[ASD Nurse Consultant]* | Senior team member [*SLT*] |
| D | Service lead *[Occupational therapy]* |  |
| E | Service lead *[ASD Nurse Consultant]* |  |
| F | Declined invitation to attend workshop due to capacity issues | |
| H | Service lead2 [*Senior ASD practitioner]*  Support worker | Service lead3 [*Clinical psychology*] |
| I | Service lead [*Speech & Language Therapy*]  Senior team member [*Clinical psychology*] |  |
| J | Senior practitioner [*Occupational therapy*] |  |
|  | Representatives from an additional SAT (service manager *[Clinical psychology]* Senior team member *[Psychiatry])* also attended the workshop. The service was unable to take part in the outcomes evaluation but the research team was keen for their inclusion in this element of the study due to experiences in providing drop-in provision and implementing strategies to support sustainable models of care and support for autistic adults without LD, and ‘upskilling’ mainstream services. | |
| 1 Across sites various terms used to denote this role including clinical lead, team manager, service manager.  2 Service lead for support service. Site comprised two services joint working to deliver SAT provision in locality.  3 Service lead for diagnostic service. Site comprised two services joint working to deliver SAT provision in locality. | | |

Box 5: Thematic analysis: thematic frameworks

|  |
| --- |
| * **Commissioning issues**   + commissioning cycle     - instability     - planning   + resource / resource constraints     - changes     - impacts on provision / quality     - private providers   + wider context of cost improvement |
| * **Volume**   + number of referrals     - changes     - wait lists   + sources of referrals     - CAMHS     - lack of other autism-specific services     - support needs trajectory   + caseload     - complexity     - barriers to discharge     - support needs trajectory   + commissioner / resource response |
| * **Response to increased demand**   + impact on provision   + impact on mode of delivery     - group vs 1:1     - home vs clinic     - limiting offer   + concerns   + managing expectations |
| * **Maintaining quality**    + managing /supporting group delivery   + information and communication to service users |
| * **Consultation / supervision role**   + potential impacts/benefits   + concerns   + barriers     - SAT time/resource     - short-termism     - changing old habits     - lack of engagement       * understanding       * interest     - pressure on mainstream service     - stability/churn of staff   + Trust responsibilities   + innovative practice |
| * **Self-management vs dependency**   + rationale for prioritisation   + practices and interventions to support self-management / reduce dependency   + managing discharge   + barriers to resourcing / delivering |
| * **Low-level on-going support**   + models of practice   + experiences of providing   + factors supporting / hindering approach |
| * **Wider context: local autism and carer communities**   + models of joint working   + involvement in service design/development   + service user evaluation |
| * **Factors affecting outcomes**   + individual - positive     - ‘theory of impact’   + individual – negative     - ‘theory of impact’   + family-level factors     - ‘theory of impact’   + service characteristics     - ‘theory of impact’   + other |

Appendix 3: Analysis of free text responses

Qualitative content analysis is a technique used to describe and interpret textual data using a systematic process of coding in order to identify categories, themes and patterns within the data.38 The analytical process was as follows:

1. Participants’ responses to the Time 3 question open question on ways in which the service had impacted (or not) on their life was entered into an Excel spreadsheet by Researcher A, alongside their rating of the impact (positive, little/no, negative). Guided by results emerging from other elements of the research as to the factors that affected experiences, data on the type of service received (‘diagnostic assessment only’, ‘diagnostic assessment and support’, or ‘support only’) was also entered into the spreadsheet.
2. Researcher A then reviewed the whole data set in order to: (1) remove any respondents whose response did not relate to the open question (For example, commenting on the usefulness of the research study rather than the service) and (2) checking whether there was concordance between the impact rating and qualitative data. This revealed that some of those who reported who rated the impact as positive reported that while the impact was positive the support provided was not sufficient to deal with their needs. It was therefore decided to create a fourth impact (‘positive impact but insufficient support’) to capture these nuances within the data.
3. Next the qualitative data was re-read, this time with a focus on ways in which the service had positively impacted participants’ lives, as well as reasons given for the service having little/no or a negative impact. Based on this review an initial list of codes was created.
4. The initial list of codes was added to the Excel spreadsheet so that the final table included the qualitative response alongside the list of potential codes. All qualitative responses were then read again and a note made on the spreadsheet of any codes that appeared within the qualitative response. Where data did not correspond to an existing code, an additional code was created and added to the spreadsheet. The focus was on creating a comprehensive list of codes so that no data was left uncoded.
5. Next a count of the number of times a code was endorsed by participants was carried out and a short summary report compiled. The results of this initial content analysis were shared with the Researcher B to allow for discussion of whether the codes made conceptual sense, and whether any codes should be removed or collapsed. This resulted in a final coding framework which included 18 ways in which services have a ‘positive impact’, four reasons for services having ‘little or no impact’, and two reasons for a ‘negative impact’.
6. After updating the database in line with the final list of agreed codes, the frequency count of the number of times codes appeared in the data was carried out, with comparisons made between participants in the different study groups (i.e. DO cohort, SAT cohort (D&S and SO groups).
7. Finally, Researcher A examined the qualitative data linked to each code in order to develop a deeper understanding of the meaning and significance of each code, and to check for any links between codes.

Appendix 4: T3 impact question: respondent characteristics

Table 29 Characteristics of service users who responded to T3 impact questions

|  |  |  |  |
| --- | --- | --- | --- |
| **Characteristic** | **Baseline measure**  **Numbers (%)** | | |
|  | **DO cohort** | **SAT cohort:**  **D&S group** | **SAT cohort:**  **SO group** |
| **Age (years)** |  |  |  |
| Mean (SD) | 38.3 (13.2) | 34.5 (13.1) | 28.7 (11.9) |
| Median (range) | 40.5 (18-64) | 31.0 (18-69) | 23.0 (17-55) |
| **Gender** |  |  |  |
| Male | 18 (56.3) | 37 (50.0) | 14 (43.8) |
| Female | 14 (43.8) | 35 (47.3) | 17 (53.1) |
| Neither | 0 (0) | 2 (2.7) | 1 (3.1) |
| *Total* | *32 (100)* | *74(100)* | *32 (100)* |
| **Relationship status** |  |  |  |
| Single | 20 (62.5) | 60 (81.1) | 28 (87.5) |
| Long-term partnership | 12 (37.5) | 14 (18.9) | 4 (12.5) |
| *Total* | *32 (100)* | *74 (100)* | *32 (100)* |
| **Educational Qualifications** |  |  |  |
| No qualifications | 2 (6.3) | 5 (6.8) | 1 (3.1) |
| GCSE/O Levels | 5 (15.6) | 20 (27.0) | 10 (31.3) |
| Further Education | 8 (25.0) | 19 (25.7) | 12 (37.5) |
| Higher Education | 17 (53.1) | 30 (40.5) | 9 (28.1) |
| *Total* | *32 (100)* | *74 (100)* | *32 (100)* |
| **Independent living** |  |  |  |
| lives with parents | 12 (37.5) | 26 (35.1) | 20 (62.5) |
| independent | 20 (62.5) | 48 (64.9) | 12 (37.5) |
| *Total* | *32 (100)* | *74 (100)* | *32 (100)* |
| **Employment status** |  |  |  |
| Paid work | 16 (50) | 27 (36.5) | 3 (9.4) |
| Student | 3 (9.4) | 6 (8.1) | 12 (37.5) |
| Job seeking | 0 (0) | 6 (8.1) | 1 (3.1) |
| Disabled | 7 (21.9) | 28 (37.87) | 12 (37.5) |
| Other | 6 (18.8) | 7 (9.5) | 4 (12.5) |
| *Total* | *32 (100)* | *74 (100)* | *32 (100)* |

Appendix 5: Types of positive impact

Table 30 Types of positive impact described by respondents @ T3

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **DO cohort**  **(n=24)** | | **SAT cohort:**  **D&S group**  **(n=50)** | | **SAT cohort: SO group (n=10)** | |
| Freq. | *Rank* | Freq. | *Rank* | Freq. | *Rank* |
| ***Understanding and acceptance of diagnosis and self*** | | | | | | |
| Increased understanding and acceptance of self | 15 | *1* | 26 | *1* | 4 | *1* |
| Help with coming to terms with diagnosis/seeing strengths of autism | 0 | *-* | 6 | *5* | 1 | *4* |
| Increasing others understanding of diagnosis (e.g. family, friends, colleagues) | 3 | *4* | 5 | *6* | 0 | *-* |
| ***Improved mental health and coping*** | | | | | | |
| Improved mental health/self-esteem | 4 | *3* | 12 | *2* | 1 | *4* |
| Development of coping strategies | 2 | *5* | 4 | *7* | 2 | *3* |
| Adjustments to medication | 0 | *-* | 3 | *8* | 0 | *-* |
| ***Help with employment & education*** | | | | | | |
| Access to adjustments/support at work/college/university | 5 | *2* | 3 | *8* | 0 | *-* |
| ***Access to/improved support from other services*** | | | | | | |
| Support from other services (e.g. housing, employment, social care etc.) | 1 | *6* | 4 | *7* | 3 | *2* |
| Signposting to other services | 0 | *-* | 4 | *7* | 0 | *-* |
| Provided other practitioners with information on needs | 0 | *-* | 1 | *10* | 0 | - |
| ***Improved social skills, relationships and networks*** | | | | | | |
| Improved social skills and/or relationships | 1 | *6* | 3 | *8* | 0 | *-* |
| Meeting others similar to myself | 0 | *-* | 7 | *4* | 2 | *3* |
| Attendance of social/hobby groups | 0 | *-* | 1 |  | 2 | *3* |
| ***Contact with supportive practitioners*** | | | | | | |
| Staff were understanding / respectful / supportive | 0 | *-* | 9 | *3* | 2 | *3* |
| Access to staff with expertise in autism | 0 | *-* | 2 | *9* | 1 | *4* |
| Practitioners easy to contact / responsive to needs | 0 | *-* | 3 | *8* | 2 | *3* |
| ***Reduced sense of isolation*** | | | | | | |
| Reassurance of knowing there is a service that can help if needed | 0 | - | 3 | 8 | 0 | - |
| Feeling less alone knowing others have the same condition | 0 | - | 1 | 10 | 0 | - |
| *Note: Total frequencies do not tally with the total number of people reporting a positive impact because some respondents attributed positive impact to more than one reason.* | | | | | | |

Appendix 6: Qualitative study of service users & family interviews: design & methods

**Objectives**

The qualitative component of the study addressed or contributed to addressing the following of the study’s overall objectives:

* identify and explore features of service organisation, delivery and practice, and individual characteristics, which are associated in user outcomes;
* describe the experiences of using a SAT;
* conduct an initial comparison of outcomes for individuals diagnosed and then supported by a SAT with a cohort of individuals who received a diagnostic assessment only.

**Design**

Single, in-depth semi-structured interviews with a sub-sample of study participants and, with their permission, a member of their family. Interviews took place at around the 12- month follow-up time point. In the original design (based on anticipating identifying distinct types of service model, and evaluating one or two exemplar services per model), it was proposed we would interview 40 study participants and 20 family members. These remained our target sample sizes.

We purposively sampled to represent the following characteristics:

* research site
* the different groups: D&S and SO groups within the SAT cohort and DO cohort
  + and within each group,
    - perceived impact of service at 12 months follow-up (using impact rating question in T3 questionnaire with the following response options: positive impact; little or no impact, or ‘negative impact
    - age
    - gender

Recruitment took place over a four month period and the profile of the recruited sample was reviewed on an on-going basis against the sampling framework. Service users were offered a range of ways of participating in an interview: face-to-face, telephone, and instant messenger. Telephone interviews were used with family members. Interviews took place between March and August 2018.

**Methods**

Our Project Advisory Group developed a ‘checklist of practice’ for the research team to support autism-friendly practices throughout process involved in taking part in an interview (see Box 6). Members of the Project Advisory Group (PAG) provided orientation and training on living with autism, and adjusting communication/interview techniques and facilitation strategies. We consulted with the PAG about the content of the topic guide, with drafts iteratively piloted with three members of the PAG.

Box 6: Doing qualitative research with autistic adults without LD: checklist of practice developed by the Project Advisory Group

|  |
| --- |
| **Planning interview work**   * Duration should generally not last more than an hour, but be prepared for flexibility. * Remember some people will be quite talkative, others will be more reticent. * Interviewers will need to be softly spoken and able to speak clearly. Avoid strong accents. * Consider using visual tools/cues within the interview as something to look at/work on – reducing need for eye-to-eye contact. * Consider where would be good places to do interviews. Do you need to offer choice over place interview? * Consider using a visual/physical cue which interviewee can use to signal does not want to answer a question, or wants interview to close (e.g. red and yellow cards) * Consider offering choice over gender of interviewer.   **When approaching people about taking part in an interview**   * Don’t try to recruit too far in advance. * Be clear when interviews need to be completed by. * Explain the purpose of the interview and provide information about timings, structure etc. It is better to over-estimate how long the interview will take when providing information about how long the interview will be. * Highlight value and importance of people’s own views and experiences. * Explain people they can bring someone along to support them and/or a calming object   **When confirming arrangements / providing final information**   * Consider if appropriate to check if any sensory impairments, dyslexia – and to ask if there any modifications to the way the interview happens that would help? * Provide information about the questions/sorts of topics to be covered in advance of the interview. Leave a space between each question or topic in case the person wants to write a few notes. If the interview may not necessarily follow a particular order, explain this. * Make it clear that they can choose not to answer some questions. * Remind re having someone with them to support and/or a calming object * Provide a photograph of the researcher. * Provide contact info, including mobile/text. * If aware have a support worker, explain fine to let them know or offer to do so. * Call the day before to remind/confirm arrangements and remind re contact details. Let the person know if there are times when you won’t be contactable (e.g. no phone signal)   **Arriving**   * Don’t wear perfume or use strongly scented products that day. * Be punctual. Consider calling: “*I’m on time, I’ll be there in 5 five minutes*.” * If delayed on way to interview, get in touch and, if possible, give a new arrival time. This should be precise rather than vague.   **Introductions**   * Let the interviewee instigate hand-shaking (or not) * Check name – how they would like to be called * Ask how they are. And how they feel about having the interview that day. Check happy to continue. If feeling anxious etc., check if there’s anything you can do. Remind person about having someone with them and/or a calming object.   **Some general principles re interviewing**   * Remind about the structure of the interview at the beginning, and keep doing this throughout, noting when moving on to a new topic. Within this, remind don’t have to answer questions and can close interview at any time. * Offer the chance for a break(s), and re-offer this during interview if feel appropriate/needed. * Offer thanks during interview when ending one topic and moving on to another topic. Reassure people that they are providing important and valuable information. * Keep to the timings described (for example, how long the interview will last), and make sure the interviewee knows you are taking responsibility for how long the interview will last, and all the questions are covered. If would like to extend duration, check rather than just press on.   **Asking questions**   * If appropriate, tailor questions specifically to individual’s experiences and reduce demand for accurate recall. (For example,… our research record says you started using the Asperger team in June 2017….). * Avoid using questions which demand them to recall information if we have the information already. * Ask one question at a time. Avoid multiple questions within a single utterance. * Use short, clear questions (for example, Instead of saying ‘I would like you to think back….’; just say ‘Think back….’ ) * Ask about specific things, rather than asking vague, general questions * Try to make sure the questions are relevant, and the individual will feel able to answer them.   **Waiting for/listening to answers**   * Silence is OK – remember the 8 second rule! * Do not automatically rephrase questions; give the person time to think about their answer. * Consider offering alternative of writing answers down   **At the end of an interview**   * Make clear statement that interview is finished, and clear that recorder switched off. * Check if any questions / concerns about the interview. * Reassure re value of contribution. Repeat thanks for contribution etc. * Be clear about what happens after the interview; for example how the researcher will use the information gathered during the interview. * Provide a mechanism for people to get in touch if they want to clarify something they said, or want to add further comments. * If the interview does not take place in the person’s home, check if they would like some quiet time before leaving the place where the interview happened. |

**Recruitment: service users**

Queries were run on the study dataset to identify participants eligible for interview (in terms of their time point in the study) and generate relevant sampling information.

An invitation letter, information sheet and response form were posted to 53 study participants. Individuals notified their interest in taking part in an interview either via returning the response form (indicating interested or not interested), or via email or text message. Thirty-nine individuals responded and agreed to take part in an interview with 38 completed. After two failed arrangements to conduct an instant messenger interview with the final interviewee, we did not pursue further. Of those who did not take part (n=14), six responded indicating they were not interested in taking part, and eight did not return a response form.

The sample comprised 19 men, 17 women and 2 people choosing to identify neither male or female. The majority (30/38) described themselves as White British, three as White Other, two as Mixed ethnicity and the remainder either described themselves as Asian/Asian British or ‘other’. Most (33/38) were single/separated or divorced. They ranged in age from 17 to 62 years. Nine were from the DO cohort, 22 from the D&S group of the SAT cohort and 8 from the SO group.

**Recruitment: family members**

At the end of interviews with service users, they were asked if there was someone in their family who might have a perspective on their (i.e.service user) outcomes and experiences. If this was the case, we sought agreement to approach about taking part in the study. However, we did not pose this request where it was clear from the interview that no family members had been involved with, or observed their use of, the service, or where asking this question might cause discomfort (e.g. where evidence of no current contact with family or significant discord). Fourteen service user interviewees provided contact details of a family member whom they were happy for us to approach about taking part in an interview.

These individuals were contacted by the method suggested by the participant (email, post, or phone) with nine agreeing to be interviewed. All except one were parents. Of these, the majority were parents of young adults (<25 years). All study groups (SAT cohort (DS and SO groups), DO cohort) were represented.

Following the interview, all individuals taking part in an interview were sent a multi-store shopping voucher (high street and on-line) with the thank you letter.

**Data collection**

For the service user interviews, all modes of data collection were used. Those choosing face-to-face also chose where the interview took place. Type and location of interviews were as follows:

* telephone interview: 19/38
* face-to-face: 15/38
  + chose interview at home: 6/15
  + chose interview in ‘public place’: 9/15
    - café: 8
    - library 9
* instant messenger: 3/38

In addition, one study participant requested an email interview. Here, a simplified version of the topic guide was devised and reviewed by a member of the PAG. The interview was administered as a number of blocks of questions, with each block being sent after receipt of the previous. Where clarification was required, specific, additional questions were added to the subsequent block of questions.

All verbal interviews were audio-recorded. On a couple of occasions where interviewees had requested interviews in a ‘public place’, the researcher had concerns about the quality of the recording because of ambient noise levels and/or the interviewee being very softly spoken, notes were also taken during the interview.

Family member interviews were conducted over the telephone.

The interviews with service users covered the following topics:

* services / interventions received from the service
* history of/reasons for referral
* expectations
* experiences of the assessment process and perceived outputs and outcomes
* experiences of services/interventions received and perceived outputs and outcomes
* impacts of service on life domains
* extent to which needs met
* factors supporting or hindering outcomes, impacts, needs met
* experiences of discharge
* suggested improvements to provision

The interviews with family members covered the following topics.

* nature of involvement with service
* expectations of service for the service user
* views on service user’s experience and perceived impacts
* family member’s own experience of the service
* suggested improvements to provision

Topic guides are available (Supplementary Material 3).

**Data analysis**

Two members of the research team (EH, SM) led on the analysis of the qualitative data with analysis supported by NVivo. Verbatim transcripts were created. The broad approach was thematic87, 88, and the constant comparative method89 used to support the analytical process. Following data immersion by one members of the research team and discussions within the team an initial thematic framework organised around key themes/topics covered in the topic guide was developed. High level themes are set out in Box 7. Transcripts were indexed in NVivo using this framework. EH carried out all data extraction. This was independently checked by SM. Alongside this work, short summaries of interviews were prepared to support the analytical process. Iterations of analytical writing were used to build and test descriptive and explanatory analyses. SM led on the analytical and writing phase, with on-going discussions and reviews of writing by the two other members of the research team (SM, BB).

Box 7: Service user interviews: broad thematic framework

|  |
| --- |
| * expectations and overall opinions   + expectations and reasons for going   + recommendations   + overall impression * services used, offered and declined   + diagnostic assessment   + reaction to diagnosis   + assessment of needs   + drop in centre   + information   + group work   + social or hobby group   + one to one sessions   + named contact   + referrals to other services   + other * areas worked on or not worked on with the service   + understanding of autism   + living with autism   + managing anxiety and other emotional difficulties   + social life / social networks   + connecting with others with autism   + job situation / employment   + finance issues/welfare benefits   + help from local council   + housing   + family relationships   + family understanding of autism * how the service is run   + waiting times and pre-discharge follow-up   + environment and set-up   + staff   + discharge and post-discharge follow-up |

Appendix 7: Description of outcome measures

*World Health Organisation Quality of Life Instrument, Abbreviated Version (WHOQOL-BREF)90*

The WHOQOL-BREF comprises 26 items comprising two global questions and 24 items capturing the following domains: physical health (7 items); psychological health (6 items); social relationships (3 items); environment (8 items). Respondents complete the measure with respect to the previous two weeks. The response format is a five-point scale. Raw scores are transformed into standardised scores. A higher score indicates better subjective quality of life. The WHOQOL-BREF Psychological health Domain was our primary outcome. The other domains were secondary outcomes. It has been used to explore quality of life among populations of adults with HFA and AS19, 91 and a recent UK psychometric evaluation of the measure reports good psychometric properties.84

*General Health Questionnaire (twelve item version) (GHQ 12)92*

The twelve-item version of the General Health Questionnaire (GHQ 12) was used to measure mental health. It focuses on two major areas – the inability to carry out normal functions and the appearance of new and distressing experiences. It comprises 12 items with each item rated on a four-point scale: less than usual, no more than usual, rather more than usual and much more than usual. The Likert scoring method (0,1,2,3) was used alongside a categorisation of ‘caseness’, or clinical threshold defined as scoring above the mean for the study sample. 60, 61

*EuroQol-5 Dimensions, five-level version (EQ-5D-5L)93 94*

This standardised measure of health status provides a descriptive profile of health-related quality of life with respect to five domains (mobility, self-care, usual activities, pain/discomfort and anxiety/depression) and a single index value of health status. It is a self-report measure comprising five items. Respondents report difficulty with each domain in terms of one of five levels: no problems, some problems, moderate problems, severe problems and extreme problems (coded 1 to 5, respectively). The five-digit figure generated is then converted into a single weighted index score.

*Interpersonal Support Evaluation List – Short Form: Belonging Support (BE) subscale95*

The Interpersonal Support Evaluation List – Short Form is a measure of perceived social support. A more recent large-scale psychometric evaluation has confirmed the four-factor structure of the measure. 96 It comprises four, 4-item subscales one of which is the Belonging Support (BE subscale which captures the perceived availability of others to interact with socially. Respondents indicate on a four-point scale (definitely true, probably true, probably false, definitely false) the extent to which each statement (or item) is true for them. It is scored 0 to 3, positive are reversed scored thus a lower score indicates greater perceived availability of others to interact with socially. This measure replaced the one originally proposed in our funding application (The Inventory of Socially Supportive Behaviours (Short Form)) following feedback from our User Advisory Panel.

Appendix 8: Quantitative evaluation: recruitment procedure & data collection processes

Recruitment materials and processes were developed in consultation with our User Advisory Group (UAG) and practitioners working in Specialist Autism Teams. Core features and stages of the recruitment process were:

* Introduction to the study by the SAT – either via letter or at intake or first full assessment appointment.
* Individual consents to contact by Clinical Studies Officer (CSO), either a face-to-face meeting in clinic, home visit or post
* According to preferred mode of contact, Clinical Studies Officer (CSO) establishes contact, shares Participant Information Sheet and consents to study.
* Respondent consents and completes T0 questionnaire.

Local modifications of the process were devised in order to align to individual service’s usual processes and practices and therefore minimise disruption and resource demand on services. In terms of subsequent data collection time points, at T0, study participants indicated their preference: postal, on-line/electronic survey (using Qualtrics software: http://www.qualtrics.com), or home visit by a local CSO to assist with completion. The research team administered data collection from T1 onwards, directly managing administration of postal and electronic surveys and liaising with local CSOs when a home visit was required.

To support retention, for postal and electronic survey administration, the following process was used at each follow-up data collection time point:

* text message alerting study participant to expect to receive study questionnaire booklet (via post or email)
* study questionnaires sent to participant
* if questionnaire not returned, after 9 days from initial administration, text reminder
* if questionnaire not returned after 16 days from initial administrations, questionnaire booklet re-sent in preferred format
* if questionnaire not returned after 25 days from initial administration, final text reminder.

In addition, at each data collection time point study participants were sent a £20 shopping voucher (multiple stores, high street and on-line) on receipt of a completed study questionnaire booklet.

Appendix 9: Characteristics of study participants:

Table 31 Characteristics of study participants

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **SAT cohort**  **(n=252)** | **SAT cohort:**  **D&S group (n=164a)** | **SAT cohort:**  **S0 group (n=88)** | **DO cohort**  **(n=56)** |
| **Age (years)** | | | | |
| Mean (SD) | 29.51 (11.7) | 31.1 (12.03) | 26.5 (10.45) | 35.23 (13.28) |
| Median (range) | 25 (17-69) | 27 (18-69) | 21 (17-55) | 31.5 (18-64) |
|  | **n (%)** | **n (%)** | **n (%)** | **n (%)** |
| **Gender** | | | | |
| Male | 148 (60.1) | 93 (57.1) | 55 (62.5) | 36 (64.3) |
| Female | 94 (37.4) | 64 (39.3) | 30 (34.1) | 20 (35.7) |
| Neither | 9 (3.5) | 6 (3.7) | 3 (3.4) | 0 (0.0) |
| **Relationship status** | | | | |
| Single | 211 (84.1) | 131 (80.4) | 80 (90.9) | 38 (67.9) |
| Long-term partnership | 40 (15.9) | 32 (19.6) | 8 (9.1) | 18 (32.1) |
| **Educational Qualifications** | | | | |
| None | 24 (9.6) | 15 (9.2) | 9 (10.3) | 7 (12.5) |
| GCSE/O Levels | 70 (27.9) | 43 (26.4) | 27 (31.0) | 9 (16.1) |
| Further Educ. | 92 (37.0) | 56 (34.4) | 36 (41.4) | 19 (33.9) |
| Higher Educ. | 64 (25.5) | 49 (30.1) | 15 (17.2) | 21 (37.5) |
| **Independent living** | | | | |
| With parents | 132 (52.6) | 70 (42.9) | 62 (70.5) | 21 (37.5) |
| Left family home | 119 (47.4) | 93 (57.1) | 26 (29.5) | 35 (62.5) |
| **Employment status** | | | | |
| Paid workb | 61 (24.5) | 49 (30.1) | 12 (13.8) | 25 (45.5) |
| Student | 54 (21.6) | 25 (15.3) | 29 (33.3) | 4 (7.3) |
| Job seeking | 25 (10.5) | 14 (8.6) | 11 (12.6) | 3 (5.5) |
| Unable to work due to illness/ disability | 92 (37.0) | 65 (39.9) | 27 (31.0) | 16 (29.1) |
| Other | 16 (6.4) | 10 (6.1) | 8 (9.2) | 7 (12.7) |
| *a Sample size: n=163/164 for gender, relationship status, educational qualifications, independent living and employment status*  *b Includes full and part-time employment, self-employed, apprenticeship* | | | | |

Appendix 10: SAT & DO cohorts - baseline scores: standardised outcome measures

Table 32: Mental health outcome measures: baseline (T0) scores: SAT and DO cohorts

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Sample size** | **Mean (SD)** | **Median (Range)** | **T-test** | | |
| **WHOQOL-BREF Psychological Domain** | | | | **Difference in mean score (95% CI)** | | **P-value** |
| SAT cohort: SO group | 88 | 44.2 (18.8) | 45.83 (0, 87.5) | SO vs D&S | -5.39 (-10.42, -0.36) | 0.04 |
| SAT cohort: D&S group | 164 | 38.81 (19.61) | 33.33 (0, 95.83) |  | | |
| DO cohort | 56 | 34.61 (19.93) | 33.33 (0, 80) | D&S vs DO | 4.20 (-1.81, 10.20) | 0.17 |
| **General Health Questionnaire (GHQ-12)** | | | | **Difference in mean score (95% CI)** | | **P-value** |
| SAT cohort: SO group | 88 | 17.17 (7.31) | 16 (0, 36) | SO vs D&S | 1.16 (-0.74, 3.05) | 0.23 |
| SAT cohort: D&S group | 164 | 18.33 (7.27) | 18 (3, 36) |  | | |
| DO cohort | 56 | 19.54 (7.61) | 17.5 (8, 36) | D&S vs DO | -1.21(-3.45, 1.04) | 0.29 |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **GHQ-12 caseness: under vs at or above whole sample mean score at baseline** | | | | **Chi -square Test** | |
|  | **Sample size** | **Under mean**  **n (%)** | **At or above mean**  **n (%)** | **Pearson’s Chi (df)** | **P-value** |
| SAT cohort: SO group | 88 | 55 (62.5) | 33 (37.5) | 0.991 (2) | 0.61 |
| SAT cohort: D&S group | 164 | 92 (56.1) | 72 (43.9) |
| Diagnosis only Cohort | 56 | 32 (57.1) | 24 (42.9) |

Table 33: Other standardised outcome measures: baseline (T0) scores: SAT & DO cohorts

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Sample size** | **Mean (SD)** | **Median (Range)** | **T-test** | | |
| **Health-related Quality of Life (EQ-5D-5L) (2017 Tariff)** | | | | **Diff. in mean score (95% CI)** | | **P-value** |
| SAT cohort: SO group | 87 | 0.72 (0.21) | 0.78 (0.09, 1) | SO vs D&S | -0.03 (-0.09, 0.02) | 0.25 |
| SAT cohort: D&S group | 163 | 0.69 (0.22) | 0.73 (-0.12, 1) |  | | |
| DO Cohort | 53 | 0.67 (0.22) | 0.70 (0.05, 1) | D&S vs DO | 0.02 (-0.05, 0.09) | 0.50 |
| **Interpersonal Support Evaluation List (ISEL): Belonging sub-scale** | | | | | | |
| SAT cohort: SO group | 88 | 6.35 (2.82) | 6 (0, 12) | SO vs D&S | 0.54 (-0.21, 1.30) | 0.16 |
| SAT cohort: D&S group | 164 | 6.89 (2.92) | 7 (0, 12) |  | | |
| DO Cohort | 56 | 7.30 (2.84) | 7 (0, 12) | D&S vs DO | -0.41 (-1.30, 0.47) | 0.36 |
| **WHOQOL-BREF Social relationships Domain** | | | | | | |
| SAT cohort: SO group | 88 | 47.96 (24.9) | 50.00 (0, 100) | SO vs D&S | -4.18 (-10.61, 2.25) | 0.20 |
| SAT cohort: D&S group | 163 | 43.79 (24.56) | 41.67 (0, 100) |  | | |
| DO Cohort | 55 | 39.24 (18.19) | 41.67 (0, 91.67) | D&S vs DO | 4.55 (-2.57, 11.66) | 0.21 |
| **WHOQOL-BREF Physical health Domain** | | | | | | |
| SAT cohort: SO group | 87 | 55.43 (19.41) | 57.14 (3.57, 92.86) | SO vs D&S | -3.83 (-8.99, 1.34) | 0.15 |
| SAT cohort: D&S group | 163 | 51.61 (19.91) | 50 (3.57, 100) |  | | |
| DO Cohort | 56 | 53.64 (21.36) | 53.57 (14.29, 92.86) | D&S vs DO | -2.03 (-8.22, 4.16) | 0.52 |
| **WHOQOL-BREF Environment Domain** | | | | | | |
| SAT cohort: SO group | 87 | 56.86 (16.27) | 59.38 (15.63, 93.75) | SO vs D&S | -0.85 (-5.23, 3.53) | 0.70 |
| SAT cohort: D&S group | 164 | 56.01 (17.13) | 56.25 (3.13, 96.88) |  | | |
| DO Cohort | 56 | 56.10 (19.74) | 56.25 (15.63, 96.88) | D&S vs DO | -0.09 (-5.56, 5.38) | 0.97 |

Appendix 11: SAT cohort: outcomes at each time-point

Table 34: Mental health outcomes by group (D&S, SO): T0 to T5

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **T0** | **T1** | **T2** | **T3** | **T4** | **T5** |
| **D&S GROUP** | | | | | | |
| **WHOQOL-BREF Psychological Domain** | | | | | | |
| Sample size | 164 | 138 | 137 | 132 | 95 | 61 |
| Mean (SD) | 38.81 (19.61) | 39.52 (20.05) | 39.96 (19.49) | 40.09 (20.62) | 38.77 (19.21) | 42.21 (19.96) |
| Median (Range) | 33.33 (0, 95.83) | 37.5 (4.17, 100) | 37.5 (0, 100) | 41.67 (0, 95.83) | 37.5 (0, 83.33) | 41.67 (0, 91.67) |
| **General Health Questionnaire (GHQ-12)** | | | | | | |
| Sample size | 164 | 138 | 137 | 133 | 95 | 62 |
| Mean (SD) | 18.33 (7.27) | 17.13 (6.97) | 17.12 (7.18) | 17.14 (7.56) | 17.53 (7.78) | 17.05 (6.68) |
| Median (Range) | 18 (3, 36) | 16 (0, 33) | 16 (5, 36) | 16 (2, 36) | 16 (4, 36) | 16.5 (4, 36) |

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **GHQ caseness: under vs at or above sample mean score @T0** | | | | | | | | | | | | |
| Under | 92 | (56.1) | 84 | (60.9) | 88 | (64.2) | 91 | (68.4) | 60 | (63.2) | 38 | (61.3) |
| At/above | 72 | (43.9) | 54 | (39.1) | 49 | (35.8) | 42 | (31.6) | 35 | (36.8) | 24 | (38.7) |
| *Sample size* | *164* | | *138* | | *137* | | *133* | | *95* | | *62* | |

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **SO GROUP** | | | | | | |
| **WHOQOL-BREF Psychological Domain** | | | | | | |
| Sample size | 88 | 76 | 68 | 75 | 56 | 42 |
| Mean (SD) | 44.2 (18.8) | 45.23 (19.66) | 41.74 (19.29) | 42.6 (19.63) | 36.89 (18.4) | 39.88 (18.15) |
| Median (Range) | 45.83 (0, 87.5) | 45.83 (8.33, 87.5) | 45.83 (4.17, 87.5) | 45.83 (0, 95.83) | 37.5 (4.17, 83.33) | 39.58 (8.33, 75) |
| **General Health Questionnaire (GHQ-12)** | | | | | | |
| Sample size | 88 | 77 | 70 | 75 | 56 | 42 |
| Mean (SD) | 17.17 (7.31) | 14.91 (6.27) | 17.34 (7.61) | 17.16 (6.9) | 19.39 (6.82) | 17.12 (7.54) |
| Median (Range) | 16 (0, 36) | 14 (3, 32) | 16.5 (0, 36) | 16 (5, 34) | 19 (7, 33) | 16 (4, 36) |

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **GHQ caseness: under vs at or above sample mean score @T0** | | | | | | | | | | | | |
| under | 50 | (56.8) | 56 | (72.7) | 39 | (55.7) | 41 | (54.7) | 25 | (44.6) | 25 | (59.5) |
| at or above | 38 | (43.2) | 21 | (27.3) | 31 | (44.3) | 34 | (45.3) | 31 | (55.4) | 17 | (40.5) |
| *Sample size* | *88* | | *77* | | *70* | | *75* | | *56* | | *42* | |

Table 35 Quality of life outcomes by group (D&S, SO): T0 – T5

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | **T0** | **T1** | **T2** | **T3** | | **T4** | **T5** |
| **D&S group** | | | | | | | |
| **Health-related Quality of Life (EQ-5D-5L) (2017 Tariff)** | | | | | | | |
| Sample size | 163 | 138 | 137 | 131 | | 95 | 62 |
| Mean (SD) | 0.69 (0.22) | 0.68 (0.23) | 0.68 (0.25) | 0.67 (0.27) | | 0.69 (0.24) | 0.65 (0.25) |
| Median (Range) | 0.73 (-0.12, 1) | 0.73 (-0.15, 1) | 0.73 (-0.18, 1) | 0.76 (-0.17, 1) | | 0.76 (-0.17, 1) | 0.71 (-0.25, 1) |
| **WHOQOL-BREF Social relationships Domain** | | | | | | | |
| Sample size | 163 | 137 | 137 | 133 | | 95 | 61 |
| Mean (SD) | 43.79 (24.56) | 43.8 (23.67) | 45.1 (23.42) | 45.39 (23.5) | | 45.18 (21.76) | 40.85 (24.14) |
| Median (Range) | 41.67 (0, 100) | 41.67 (0, 100) | 50 (0, 100) | 50 (0, 100) | | 41.67 (0, 91.67) | 41.67 (0, 83.33) |
| **WHOQOL-BREF Physical health Domain** | | | | | | | |
| Sample size | 163 | 138 | 137 | 132 | | 95 | 61 |
| Mean (SD) | 51.61 (19.91) | 52.23 (19.87) | 52.61 (20.4) | 52.73 (20.77) | | 51.95 (22.13) | 53.34 (21.59) |
| Median (Range) | 50.00 (3.57, 100) | 53.57 (0, 100) | 53.57 (3.57, 100) | 57.14 (3.57, 100) | | 53.57 (0, 100) | 57.14 (3.57, 96.43) |
| **WHOQOL-BREF Environment Domain** | | | | | | | |
| Sample size | 164 | 138 | 137 | | 133 | 95 | 61 |
| Mean (SD) | 56.01 (17.13) | 55.1 (17.33) | 54.72 (19.12) | | 55.43 (17.71) | 54.57 (18.28) | 56.51 (17.27) |
| Median (Range) | 56.25 (3.13, 96.88) | 56.25 (12.5, 100) | 53.13 (3.13, 100) | | 56.25 (3.13, 100) | 56.25 (0, 100) | 56.25 (3.13, 90.63) |

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **SO group** | | | | | | | |
| **Health-related Quality of Life (EQ-5D-5L) (2017 Tariff)** | | | | | | | |
| Sample size | 88 | 77 | 70 | 75 | | 56 | 42 |
| Mean (SD) | 17.17 (7.31) | 14.91 (6.27) | 17.34 (7.61) | 17.16 (6.9) | | 19.39 (6.82) | 17.12 (7.54) |
| Median (Range) | 16 (0, 36) | 14 (3, 32) | 16.5 (0, 36) | 16 (5, 34) | | 19 (7, 33) | 16 (4, 36) |
| **WHOQOL-BREF Social relationships Domain** | | | | | | | |
| Sample size | 88 | 76 | 68 | 75 | | 56 | 42 |
| Mean (SD) | 47.96 (24.9) | 49.67 (22.17) | 42.4 (22.71) | 41.67 (22.42) | | 41.44 (24.44) | 43.25 (24.71) |
| Median (Range) | 50 (0, 100) | 50 (8.33, 100) | 45.83 (0, 91.67) | 41.67 (0, 83.33) | | 41.67 (0, 91.67) | 50 (0, 91.67) |
| **WHOQOL-BREF Physical health Domain** | | | | | | | |
| Sample size | 87 | 77 | 67 | 75 | | 56 | 42 |
| Mean (SD) | 55.43 (19.41) | 58.53 (19.08) | 54.69 (19.8) | 55.1 (19.35) | | 51.02 (19.89) | 53.23 (19.08) |
| Median  (Range) | 57.14  (3.57, 92.86) | 58.33  (12.5, 96.43) | 57.14  (7.14, 92.86) | 57.14  (14.29, 89.29) | | 53.57  (10.71, 92.86) | 53.57  (10.71, 96.43) |
| **WHOQOL-BREF Environment Domain** | | | | | | | |
| Sample size | 88 | 77 | 69 | | 75 | 56 | 42 |
| Mean (SD) | 56.86 (16.27) | 58.33 (18.47) | 55.39 (17.48) | | 55.54 (17.08) | 54.58 (17.29) | 54.09 (17.67) |
| Median  (Range) | 59.38  (15.63, 93.75) | 59.38  (3.13, 93.75) | 59.38  (18.75, 87.5) | | 56.25  (15.63, 93.75) | 54.69  (15.63, 90.63) | 51.56  (6.25, 93.75) |

Table 36 Perception of social networks outcome by group (D&S, SO): T0 – T5

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **D&S group** | | | | | | |
| **Interpersonal Support Evaluation List (ISEL): Belonging sub-scale** | | | | | | |
| Sample size | 164 | 138 | 137 | 132 | 95 | 62 |
| Mean (SD) | 6.89 (2.92) | 7.07 (2.96) | 6.82 (2.92) | 6.79 (2.82) | 6.71 (3.02) | 6.77 (3.25) |
| Median (Range) | 7 (0, 12) | 7 (0, 12) | 7 (0, 12) | 7 (0, 12) | 7 (0, 12) | 7 (0, 12) |

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Interpersonal Support Evaluation List (ISEL): Belonging sub-scale** | | | | | | |
| Sample size | 88 | 76 | 70 | 75 | 56 | 42 |
| Mean (SD) | 6.35 (2.82) | 5.46 (2.83) | 6.46 (2.75) | 6.31 (2.91) | 6.41 (2.82) | 6.5 (3.04) |
| Median (Range) | 6 (0, 12) | 5 (0, 12) | 7 (0, 12) | 6 (0, 12) | 6 (1, 12) | 7 (0, 12) |

Table 37 Managing daily living outcomes by group (D&S, SO): T0 – T5

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **T0** | | | **T1** | | | **T2** | | | **T3** | | | **T4** | | **T5** | |
| n | | *%* | n | | *%* | n | *%* | | n | | *%* | n | *%* | n | *%* |
| **D&S group** | | | | | | | | | | | | | | | | |
| **Managing usual activities of daily living (EQ-5D-5L Usual activities domain)** | | | | | | | | | | | | | | | | |
| unable | 4 | | *2.4* | 1 | | *0.7* | 1 | *0.7* | | 5 | | *3.8* | 3 | *3.2* | 2 | *3.2* |
| severe problems | 15 | | *9.1* | 9 | | *6.5* | 11 | *8.0* | | 11 | | *8.3* | 7 | *7.4* | 3 | *4.8* |
| moderate problems | 55 | | *33.5* | 44 | | *31.9* | 34 | *24.8* | | 26 | | *19.7* | 22 | *23.2* | 13 | *21.0* |
| slight problems | 36 | | *22.0* | 39 | | *28.3* | 42 | *30.7* | | 45 | | *34.1* | 26 | *27.4* | 22 | *35.5* |
| no problems | 54 | | *32.9* | 45 | | *32.6* | 49 | *35.8* | | 45 | | *34.1* | 37 | *38.9* | 22 | *35.5* |
| *Sample size* | *164* | | | *138* | | | *137* | | | *132* | | | *95* | | *62* | |
| **Availability of information needed for daily living (WHOQOL-BREF q13)** | | | | | | | | | | | | | | | | |
| not at all | 8 | *4.9* | | 8 | *5.8* | | 9 | | *6.6* | 8 | *6* | | 8 | *8.4* | 2 | *3.3* |
| a little | 25 | *15.2* | | 21 | *15.2* | | 21 | | *15.4* | 23 | *17.3* | | 18 | *18.9* | 9 | *14.8* |
| moderately | 49 | *29.9* | | 39 | *28.3* | | 41 | | *30.1* | 32 | *24.1* | | 22 | *23.2* | 19 | *31.1* |
| mostly | 56 | *34.1* | | 53 | *38.4* | | 46 | | *33.8* | 54 | *40.6* | | 34 | *35.8* | 25 | *41* |
| completely | 26 | *15.9* | | 17 | *12.3* | | 19 | | *14.0* | 16 | *12* | | 13 | *13.7* | 6 | *9.8* |
| *Sample size* | *164* | | | *138* | | | *136* | | | *133* | | | *95* | | *61* | |

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **SO group** | | | | | | | | | | | | | | | | |
| **Managing usual activities of daily living (EQ-5D-5L Usual activities domain)** | | | | | | | | | | | | | | | | |
| unable | 1 | | *1.1* | 1 | | *1.3* | 0 | *0.0* | | 3 | | *4.0* | 1 | *1.8* | 1 | *2.4* |
| severe problems | 10 | | *11.4* | 5 | | *6.6* | 7 | *10.0* | | 7 | | *9.3* | 10 | *18.2* | 4 | *9.8* |
| moderate problems | 17 | | *19.3* | 13 | | *17.1* | 20 | *28.6* | | 16 | | *21.3* | 10 | *18.2* | 11 | *26.8* |
| slight problems | 24 | | *27.3* | 31 | | *40.8* | 18 | *25.7* | | 20 | | *26.7* | 17 | *30.9* | 11 | *26.8* |
| no problems | 36 | | *40.9* | 26 | | *34.2* | 25 | *35.7* | | 29 | | *38.7* | 17 | *30.9* | 14 | *34.1* |
| *Sample size* | *88* | | | *76* | | | *70* | | | *75* | | | *55* | | *41* | |
| **Availability of information needed for daily living (WHOQOL-BREF q13)** | | | | | | | | | | | | | | | | |
| not at all | 4 | *4.5* | | 3 | *3.9* | | 2 | | *2.9* | 4 | *5.3* | | 1 | *1.8* | 1 | *2.4* |
| a little | 15 | *17.0* | | 14 | *18.2* | | 16 | | *23.2* | 13 | *17.3* | | 12 | *21.4* | 9 | *21.4* |
| moderately | 23 | *26.1* | | 20 | *26* | | 21 | | *30.4* | 23 | *30.7* | | 17 | *30.4* | 13 | *31* |
| mostly | 34 | *38.6* | | 29 | *37.7* | | 23 | | *33.3* | 22 | *29.3* | | 17 | *30.4* | 17 | *40.5* |
| completely | 12 | *13.6* | | 11 | *14.3* | | 7 | | *10.1* | 13 | *17.3* | | 9 | *16.1* | 2 | *4.8* |
| *Sample size* | *88* | | | *77* | | | *69* | | | *75* | | | *56* | | *42* | |

Table 38 Employment & leisure time outcomes by group (D&S, SO): T0 – T5

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **T0** | | | **T1** | | | **T2** | | | **T3** | | | **T4** | | **T5** | |
| n | | *%* | n | | *%* | n | *%* | | n | | *%* | n | *%* | n | *%* |
| **D&S group** | | | | | | | | | | | | | | | | |
| **Employment status** | | | | | | | | | | | | | | | | |
| paid work | 49 | *30.1* | | 44 | *31.9* | | 39 | | *28.9* | 41 | *31.3* | | 32 | *33.7* | 24 | *38.7* |
| student | 25 | *15.3* | | 17 | *12.3* | | 15 | | *11.1* | 13 | *9.9* | | 10 | *10.5* | 5 | *8.1* |
| job-seeking | 14 | *8.6* | | 6 | *4.3* | | 10 | | *7.4* | 10 | *7.6* | | 5 | *5.3* | 3 | *4.8* |
| unable due to ill/dis | 65 | *39.9* | | 51 | *37* | | 54 | | *40.0* | 47 | *35.9* | | 31 | *32.6* | 25 | *40.3* |
| other | 10 | *6.1* | | 20 | *14.5* | | 17 | | *12.6* | 20 | *15.3* | | 17 | *17.9* | 5 | *8.1* |
| *Sample size* | *164* | | | *138* | | | *135* | | | *131* | | | *95* | | *62* | |
| **Satisfaction with capacity for work (WHOQOL-BREF q18)** | | | | | | | | | | | | | | | | |
| very dissatisfied | 36 | *22.3* | | 23 | *16.7* | | 29 | | *21.2* | 24 | *18.2* | | 18 | *18.8* | 13 | *21.3* |
| dissatisfied | 53 | *32.7* | | 53 | *38.4* | | 49 | | *35.8* | 35 | *26.5* | | 24 | *25.3* | 18 | *29.5* |
| neither sat / dissat | 36 | *22.2* | | 32 | *23.2* | | 30 | | *21.9* | 38 | *28.7* | | 25 | *26.3* | 10 | *16.4* |
| satisfied | 30 | *18.5* | | 26 | *18.8* | | 18 | | *13.1* | 27 | *20.5* | | 23 | *24.2* | 19 | *31.2* |
| very satisfied | 7 | *4.3* | | 4 | *2.9* | | 11 | | *8.0* | 8 | *6.1* | | 5 | *5.3* | 1 | *1.6* |
| *Sample size* | *162* | | | *138* | | | *137* | | | *132* | | | *95* | | *61* | |
| **Satisfaction with leisure time (Standalone item: “I am satisfied with how I spend my free time.”** | | | | | | | | | | | | | | | | |
| definitely true | 24 | *14.7* | | 19 | *13.8* | | 18 | | *13.1* | 22 | *16.7* | | 14 | *14.7* | 9 | *14.8* |
| probably true | 53 | *32.5* | | 43 | *31.2* | | 37 | | *27.1* | 41 | *31.0* | | 36 | *37.9* | 21 | *34.4* |
| probably false | 52 | *31.9* | | 53 | *38.3* | | 61 | | *44.5* | 36 | *27.3* | | 25 | *26.3* | 19 | *31.1* |
| definitely false | 34 | *20.9* | | 23 | *16.7* | | 21 | | *15.3* | 33 | *25.0* | | 20 | *21.1* | 12 | *19.7* |
| *Sample size* | *163* | | | *138* | | | *137* | | | *132* | | | *95* | | *61* | |

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **SO group** | | | | | | | | | | | | |
| **Employment status** | | | | | | | | | | | | |
| paid work | 12 | *13.8* | 11 | 14.7 | 9 | *12.9* | 11 | 14.9 | 10 | *17.9* | 11 | 26.2 |
| student | 29 | *33.3* | 19 | 25.3 | 21 | *30.0* | 21 | 28.4 | 18 | *32.1* | 9 | 21.4 |
| job seeking | 11 | *12.6* | 9 | 12 | 4 | *5.7* | 11 | 14.9 | 8 | *14.3* | 5 | 11.9 |
| unable due to dis/ill | 27 | *31.0* | 23 | 30.7 | 25 | *35.7* | 26 | 35.1 | 16 | *28.6* | 13 | 31 |
| other | 8 | *9.2* | 13 | 17.3 | 11 | *15.7* | 5 | 6.8 | 4 | *7.1* | 4 | 9.5 |
| *Sample size* | *87* | | *75* | | *70* | | *74* | | *56* | | *42* | |
| **Satisfaction with capacity for work (WHOQOL-BREF q18)** | | | | | | | | | | | | |
| very dissatisfied | 16 | *18.4* | 10 | *13.5* | 11 | *16.4* | 12 | *16.0* | 13 | *23.2* | 7 | *16.7* |
| dissatisfied | 25 | *28.7* | 20 | *27.0* | 22 | *32.8* | 21 | *28.0* | 19 | *33.9* | 15 | *35.7* |
| neither sat / dissat | 19 | *21.8* | 21 | *28.4* | 19 | *28.4* | 23 | *30.7* | 12 | *21.4* | 10 | *23.8* |
| satisfied | 24 | *27.6* | 17 | *23* | 13 | *19.4* | 17 | *22.7* | 12 | *21.4* | 7 | *16.7* |
| very satisfied | 3 | *3.4* | 6 | *8.1* | 2 | *3.0* | 2 | *2.7* | 0 | *0.0* | 3 | *7.1* |
| *Sample size* | *87* | | *74* | | *67* | | *75* | | *56* | | *42* | |
| **Satisfaction with leisure time (Standalone item: “I am satisfied with how I spend my free time.”** | | | | | | | | | | | | |
| definitely true | 16 | *18.2* | 12 | *15.8* | 8 | *11.4* | 9 | *12.0* | 5 | *8.9* | 3 | *7.1* |
| probably true | 30 | *34.1* | 26 | *34.2* | 22 | *31.4* | 33 | *44.0* | 18 | *32.1* | 14 | *33.3* |
| probably false | 24 | *27.3* | 28 | *36.8* | 23 | *32.9* | 19 | *25.3* | 17 | *30.4* | 15 | *35.7* |
| definitely false | 18 | *20.5* | 10 | *13.2* | 17 | *24.3* | 14 | *18.7* | 16 | *28.6* | 10 | *23.8* |
| *Sample size* | *88* | | *76* | | *70* | | *75* | | *56* | | *42* | |

Table 39 Access to autism networks/organisations by group (D&S, SO): T0 - T5

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **T0** | | | | **T1** | | | | **T2** | | | | **T3** | | | **T4** | | | | **T5** | | |
| n | | *%* | | n | | *%* | | n | | *%* | | n | | *%* | n | | *%* | | n | *%* | |
| **D&S group** | | | | | | | | | | | | | | | | | | | | | | |
| **Are you a member of any autism-specific voluntary organisations or charities?** | | | | | | | | | | | | | | | | | | | | | | |
| None | 155 | *94.5* | | 119 | | *86.2* | | 111 | | *81.0* | | 109 | | *82.6* | | | 79 | | *84.0* | 47 | | *77.0* |
| Only ‘local/regional group or nat. org.’ | 2 | *1.2* | | 7 | | *5.1* | | 10 | | *7.3* | | 11 | | *8.3* | | | 8 | | *8.5* | 9 | | *14.8* |
| Only ‘online-only group/forum’ | 7 | *4.3* | | 9 | | *6.5* | | 11 | | *8.0* | | 8 | | *6.1* | | | 5 | | *5.3* | 5 | | *8.2* |
| Both | 0 | *0.0* | | 3 | | *2.2* | | 5 | | *3.6* | | 4 | | *3.0* | | | 2 | | *2.1* | 0 | | *0.0* |
| *Sample size* | *164* | | | *138* | | | | *137* | | | | *132* | | | | | *95* | | | *62* | | |
| **Number of contacts with any autism-specific voluntary organisation or charity in past 4 weeks?** | | | | | | | | | | | | | | | | | | | | | | |
| 0 | 140 | *85.4* | | 102 | | *73.9* | | 94 | | *68.6* | | 96 | | *72.2* | | | 76 | | *80* | 47 | | *75.8* |
| 1 | 19 | *11.6* | | 23 | | *16.7* | | 34 | | *24.8* | | 22 | | *16.5* | | | 15 | | *15.8* | 12 | | *19.4* |
| 2 | 3 | *1.8* | | 13 | | *9.4* | | 8 | | *5.8* | | 11 | | *8.3* | | | 4 | | *4.2* | 2 | | *3.2* |
| 3 | 1 | *0.6* | | 0 | | *0.0* | | 1 | | *0.7* | | 4 | | *3.0* | | | 0 | | *0.0* | 1 | | *1.6* |
| 4 | 1 | *0.6* | | 0 | | *0.0* | | 0 | | *0.0* | | 0 | | *0.0* | | | 0 | | *0.0* | 0 | | *0.0* |
| *Sample size* | *164* | | | *138* | | | | *137* | | | | *133* | | | | | *95* | | | *62* | | |

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **SO group** | | | | | | | | | | | | |
| **Are you a member of any autism-specific voluntary organisations or charities?** | | | | | | | | | | | | |
| None | 74 | *85.1* | 61 | *79.2* | 56 | *82.4* | 61 | *81.3* | 42 | *77.8* | 37 | *88.1* |
| Only ‘local/regional group or nat. org.’ | 9 | *10.3* | 13 | *16.9* | 9 | *13.2* | 11 | *14.7* | 8 | *14.8* | 2 | *4.8* |
| Only ‘online-only group/forum’ | 3 | *3.4* | 2 | *2.6* | 2 | *2.9* | 2 | *2.7* | 3 | *5.6* | 2 | *4.8* |
| Both | 1 | *1.1* | 1 | *1.3* | 1 | *1.5* | 1 | *1.3* | 1 | *1.9* | 1 | *2.4* |
| *Sample size* | *87* | | *77* | | *68* | | *75* | | *54* | | *42* | |
| **Number of contacts with any autism-specific voluntary organisation or charity in past 4 weeks?** | | | | | | | | | | | | |
| 0 | 67 | *77.0* | 63 | *81.8* | 54 | *78.3* | 60 | *80* | 42 | *77.8* | 33 | *78.6* |
| 1 | 16 | *18.4* | 11 | *14.3* | 11 | *15.9* | 12 | *16* | 11 | *20.4* | 7 | *16.7* |
| 2 | 4 | *4.6* | 2 | *2.6* | 2 | *2.9* | 2 | *2.7* | 1 | *1.9* | 2 | *4.8* |
| 3 | 0 | *0.0* | 1 | *1.3* | 2 | *2.9* | 1 | *1.3* | 0 | *0.0* | 0 | *0.0* |
| 4 | 0 | *0.0* | 0 | *0.0* | 0 | *0.0* | 0 | *0.0* | 0 | *0.0* | 0 | *0.0* |
| *Sample size* | *87* | | *77* | | *69* | | *75* | | *54* | | *42* | |

Appendix 12: SAT Cohort: longer term outcomes

Table 40: D&S group: Changes in mental health: T0 - T4, T0 - T5

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **T4 (18 month follow-up)** | | | | | | | | | | | |
| **Outcome** | | | **Sample size** | | **Mean Score** | | **Difference in mean score (95% CI)** | **P value** | | **Effect size\*** | |
| **T0** | **T4** |
| WHOQOL-BREF Psychological Domain | | | 95 | | 38.27 | 38.77 | 0.50 (-3.53, 2.53) | 0.74 | | 0.03 | |
| GHQ-12 | | | 95 | | 18.64 | 17.53 | 1.12 (-0.40, 2.63) | 0.15 | | 0.15 | |
| **GHQ-12 caseness: movement around cut-off point\*\*** | | | | | | | | | | | |
|  | | | | **T4 (n)** | | | | | | | |
| above cut-off | | | below cut-off | *Total* | | | |
| **T0 (n)** | above cut-off | | | 25 | | | 18 | 43 | | | |
| below cut-off | | | 10 | | | 42 | 52 | | | |
| *Total* | | | | 35 | | | 60 | **95** | | | |
| *Mcnemar’s Chisq =2.29 (df 1), exact p=0.185* | | | | | | | | | | | |
| **T5 (24 month follow-up)** | | | | | | | | | | | |
| **Outcome** | | | **Sample size** | | **Mean Score** | | **Difference in mean score (95% CI)** | | **P value** | | **Effect size\*** |
| **T0** | **T5** |
| WHOQOL-BREF Psychological Domain | | | 61 | | 37.13 | 42.21 | 5.08 (-8.93, -1.23) | | 0.01 | | 0.34 |
| GHQ-12 | | | 62 | | 19.29 | 17.05 | 2.24 (0.51, 3.98) | | 0.01 | | 0.33 |
| **GHQ-12 caseness: movement around cut-off point\*\*** | | | | | | | | | | | |
|  | | | | ***T5 (n)*** | | | | | | | |
| above cut-off | | | below cut-off | *Total* | | | |
| **T0 (n)** | above cut-off | | | 18 | | | 15 | 33 | | | |
| below cut-off | | | 6 | | | 23 | 29 | | | |
| *Total* | | | | 24 | | | 38 | 62 | | | |
|  | | *Mcnemar’s Chisq =3.86 (df 1), exact p=0.078* | | | | | | | | | |

\*Cohen’s d= (mean2 – mean1)/standard deviation, (d=0.2 small, d=0.5 medium, d=0.8 large effect).

\*\*Caseness: above or below the baseline GHQ-12 population mean

Table 41 SO group: Changes in mental health: T0 -T4, T0 - T5

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **T4 (18 month follow-up)** | | | | | | | | | |
| **Outcome** | | **Sample size** | **Mean Score** | | **Difference in mean score**  **(95% CI)** | | **P value** | | **Effect size\*** |
| **T0** | **T4** |
| WHOQOL-BREF Psychological Domain | | 56 | 42.80 | 36.89 | 6.01 (2.58, 9.45) | | 0.00 | | 0.47 |
| GHQ-12 | | 56 | 18.16 | 19.39 | 1.23 (-3.15, 0.69) | | 0.20 | | 0.17 |
| **GHQ-12 caseness: movement around cut-off point\*\*** | | | | | | | | | |
|  | | | **T4 (n)** | | | | | | |
| above cut-off | | | below cut-off | | *Total* | |
| **T0 (n)** | above cut-off | | 21 | | | 7 | | 28 | |
| below cut-off | | 10 | | | 18 | | 28 | |
| *Total* | | | 31 | | | 25 | | 56 | |
| *Exact McNemar: Chisq =0.53 (df 1), exact p=0.629* | | | | | | | | | |
| **T5 (24 month follow-up)** | | | | | | | | | |
| **Outcome** | | **Sample size** | **Mean Score** | | **Difference in mean score**  **(95% CI)** | | **P value (CI)** | | **Effect size\*** |
| **T0** | **T5** |
| WHOQOL-BREF Psychological Domain | | 42 | 41.27 | 39.88 | 1.39 (-3.28, 6.05) | | 0.55 | | 0.09 |
| GHQ-12 | | 42 | 18.31 | 17.12 | 1.19 (1.55, 3.93) | | 0.39 | | 0.14 |
| **GHQ-12 caseness: movement around cut-off point\*\*** | | | | | | | | | |
|  | | | **T5 (n)** | | | | | | | |
| above cut-off | | | below cut-off | | *Total* | |
| **T0 (n)** | above cut-off | | 9 | | | 13 | | 22 | |
| below cut-off | | 8 | | | 12 | | 20 | |
| *Total* | | | 17 | | | 25 | | 42 | |
| *Exact McNemar: Chisq =1.19 (df 1), exact p=0.383* | | | | | | | | | |

\*Cohen’s d= (mean2 – mean1)/standard deviation, (d=0.2 small, d=0.5 medium, d=0.8 large effect).

\*\*Caseness: above or below GHQ-12 mean score at baseline

Table 42 D&S group: Changes in quality of life & social networks: T0 -T4, T0-T5

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Outcome** | **Sample size** | **Mean Score** | | **Difference in mean score (95% CI)** | **P value** | **Effect size\*** |
| **T0** | **T4** |
| **T4 (18 month follow-up)** | | | | | | |
| EQ-5D-5L | 94 | 0.68 | 0.69 | 0.004 (-0.04, 0.03) | 0.81 | 0.03 |
| WHOQOL-BREF Social Domain | 95 | 42.37 | 45.17 | 2.81 (-7.21, 1.59) | 0.21 | 0.13 |
| WHOQOL-BREF Physical Domain | 95 | 52.20 | 51.95 | 0.24 (-2.96, 3.46) | 0.88 | 0.02 |
| WHOQOL-BREF Environment Domain | 95 | 56.64 | 54.57 | 2.08 (-0.74, 4.90) | 0.15 | 0.15 |
| ISEL-SF: Belonging sub-scale | 95 | 7.21 | 6.71 | 0.51 (-0.11, 1.12) | 0.10 | 0.17 |
| **T5 (24 month follow-up)** | | | | | | |

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  |  | **T0** | **T5** |  |  |  |
| EQ-5D-5L | 62 | 0.67 | 0.65 | 0.02 (-0.01, 0.10) | 0.04 | 0.11 |
| WHOQOL-BREF Social Domain | 61 | 41.67 | 40.85 | 0.82 (-5.28, 6.92) | 0.79 | 0.03 |
| WHOQOL-BREF Physical Domain | 61 | 52.20 | 53.34 | 1.14 (-5.08, 2.79) | 0.56 | 0.07 |
| WHOQOL-BREF Environment Domain | 61 | 56.78 | 56.51 | 0.28 (-3.41, 3.97) | 0.88 | 0.02 |
| ISEL-SF: Belonging sub-scale | 62 | 7.19 | 6.77 | 0.42 (-0.37, 1.21) | 0.29 | 0.14 |

Table 43: SAT cohort - SO group: Changes in quality of life & social networks: T0 - T4, T0 - T5

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Outcome** | **Sample size** | **Mean Score** | | **Difference in mean score**  **(95% CI)** | **P value** | **Effect size\*** |
| **T0** | **T4** |
| **T4 (18 month follow-up)** | | | | | | |
| EQ-5D-5L | 54 | 0.717 | 0.66 | 0.056  (-0.01; 012) | 0.078 | 0.244 |
| WHOQOL-BREF Social Domain | 56 | 47.25 | 41.44 | 5.80  (-0.35, 11.95) | 0.06 | 0.25 |
| WHOQOL-BREF Physical Domain | 55 | 56.64 | 50.91 | 3.73  (-0.28, 7.75) | 0.07 | 0.25 |
| WHOQOL-BREF Environment Domain | 56 | 55.60 | 54.58 | 1.03  (-2.46, 4.52) | 0.56 | 0.08 |
| ISEL-SF: Belonging sub-scale | 56 | 6.46 | 6.41 | 0.05  (-0.67, 0.77) | 0.88 | 0.02 |
| **T5 (24 month follow-up)** | | | | | | |

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  |  | **T0** | **T5** |  |  |  |
| EQ-5D-5L | 40 | 0.68 | 0.69 | 0.007  (0.08-0.06) | 0.84 | 0.03 |
| WHOQOL-BREF Social Domain | 42 | 49.11 | 43.25 | 5.85  (-1.37, 13.07) | 0.11 | 0.25 |
| WHOQOL-BREF Physical Domain | 42 | 52.93 | 53.23 | 5.85  (-4.88, 4.28) | 0.89 | 0.02 |
| WHOQOL-BREF Environment Domain | 42 | 56.47 | 54.09 | 2.38  (-2.53, 7.29) | 0.33 | 0.15 |
| ISEL-SF: Belonging sub-scale | 42 | 6.64 | 6.50 | 0.14  (-0.78, 1.07) | 0.75 | 0.05 |

\*Cohen’s d= (mean2 – mean1)/standard deviation, (d=0.2 small, d=0.5 medium, d=0.8 large effect).

Table 44 D&S group: Changes in day-time occupation/usual activities: T0-T4

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Managing usual activities of daily living (EQ-5D-5L Usual activities domain)a** | | **T4 (n)** | | | | | | | | | |  |
| unable/severe problems | | | moderate problems | | | | no/slight problems | | | *Total* |
| **T0 (n)** | unable/severe problems | 5 | | | 3 | | | | 4 | | | *12* |
| moderate problems | 3 | | | 12 | | | | 18 | | | *33* |
| no/slight problems | 2 | | | 7 | | | | 41 | | | *50* |
| *Total* | | *10* | | | *22* | | | | *63* | | | *95* |
| *Symmetry test, Chi=5.51, p=0.138* | | | | | | | | | | | | |
| **Availability of information needed for daily living (WHOQOL-BREF q13)a** | | **T4 (n)** | | | | | | | | | | |
| not at all / a little / moderately | | | | | mostly/  completely | | | | *Total* | |
| **T0 (n)** | not at all / a little/ moderately | 34 | | | | | 14 | | | | *48* | |
| mostly /completely | 14 | | | | | 33 | | | | *47* | |
| *Total* | | *48* | | | | | *47* | | | | *95* | |
| *Mcnemar’s Chisq =0.00 (df=1), p=1.0* | | | | | | | | | | | | |
| **Employment statusb** | | **T4 (n)** | | | | | | | | | | |
| paid work | | unable to work due to illness/disability or job-seeking | | | | | | | | *Total* |
| **T0 (n)** | paid work | 23 | | 5 | | | | | | | | *28* |
| unable to work due to illness/ disability or job-seeking | 8 | | 25 | | | | | | | | *33* |
| *Total* | | *31* | | *30* | | | | | | | | *61* |
| *Mcnemar’s Chisq =0.69 (df 1), exact p=0.405* | | | | | | | | | | | | |
| **Satisfaction with capacity for work (WHOQOL-BREF q18)d** | | **T4 (n)** | | | | | | | | | |  |
| very dissat. /dissat | | | | neither | | | | very sat. / sat. | | *Total* |
| **T0 (n)** | very dissat. /dissat. (n) | 32 | | | | 10 | | | | 10 | | *52* |
| neither (n) | 6 | | | | 10 | | | | 5 | | *21* |
| very sat. / sat. (n) | 4 | | | | 5 | | | | 12 | | *21* |
| *Total* | | *42* | | | | *25* | | | | *27* | | *94* |
| *Symmetry Test: Chisq =3.57 (df 3), p=0.312* | | | | | | | | | | | | |
| **I am satisfied with how I spend my free timee** | | | **T4 (n)** | | | | | | | | | |
| true | | | | | false | | | | *Total* |
| **T0 (n)** | true | | 35 | | | | | 10 | | | | *45* |
| false | | 14 | | | | | 35 | | | | *49* |
| *Total* | | | *49* | | | | | *45* | | | | *94* |
| *Mcnemar’s Chisq =0.67 (df 1), exact p=0.414* | | | | | | | | | | | | |
| a Response categories collapsed as indicated.  b Individuals reporting ‘Other’ (volunteering, student, maternity/paternity leave, parent/carer, retired) excluded from this analysis. | | | | | | | | | | | | |

**Table 45 D&S group: Changes in day-time occupation/usual activities: T0 - T5**

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Managing usual activities of daily living (EQ-5D-5L Usual activities domain)a** | | **T5 (n)** | | | | | | | | | |  |
| unable/severe problems | | | moderate problems | | | | no/slight problems | | | *Total* |
| **T0 (n)** | unable/severe problems | 4 | | | 2 | | | | 3 | | | *9* |
| moderate problems | 0 | | | 7 | | | | 16 | | | *23* |
| no/slight problems | 1 | | | 4 | | | | 25 | | | *30* |
| *Total* | | *5* | | | *13* | | | | *44* | | | *62* |
| *Symmetry Test: Chisq= 10.2, df=3, p=0.017* | | | | | | | | | | | | |
| **Availability of information needed for daily living (WHOQOL-BREF q13)a** | | **T5 (n)** | | | | | | | | | | |
| not at all / a little / moderately | | | | | mostly/  completely | | | | *Total* | |
| **T0 (n)** | not at all / a little/ moderately | 24 | | | | | 8 | | | | *32* | |
| mostly /completely | 6 | | | | | 23 | | | | *29* | |
| *Total* | | *30* | | | | | *31* | | | | *61* | |
| *Mcnemar’s Chisq =0.29, df=1, exact p=0.593* | | | | | | | | | | | | |
| **Employment statusb** | | **T5 (n)** | | | | | | | | | | |
| paid work | | unable to work due to illness/disability or job-seeking | | | | | | | | *Total* |
| **T0 (n)** | paid work | 18 | | 3 | | | | | | | | *21* |
| unable to work due to illness/ disability or job-seeking | 5 | | 20 | | | | | | | | *25* |
| *Total* | | *23* | | *23* | | | | | | | | *46* |
| *Mcnemar’s Chisq = 0.50 (df 1), exact p=0.480* | | | | | | | | | | | | |
| **Satisfaction with capacity for work (WHOQOL-BREF q18)d** | | **T5 (n)** | | | | | | | | | |  |
| very dissat. /dissat | | | | neither | | | | very sat. / sat. | | *Total* |
| **T0 (n)** | very dissat. /dissat. (n) | 25 | | | | 4 | | | | 7 | | 36 |
| neither (n) | 3 | | | | 5 | | | | 2 | | 10 |
| very sat. / sat. (n) | 2 | | | | 1 | | | | 11 | | 14 |
| *Total* | | 30 | | | | 10 | | | | 20 | | *60* |
| *Symmetry Test: Chisq= 3.25 df(3), p=0.354* | | | | | | | | | | | | |
| **I am satisfied with how I spend my free timee** | | | **T5 (n)** | | | | | | | | | |
| true | | | | | false | | | | *Total* |
| **T0 (n)** | true | | 19 | | | | | 7 | | | | 26 |
| false | | 10 | | | | | 24 | | | | 34 |
| *Total* | | | 29 | | | | | 31 | | | | *60* |
| *Mcnemar’s Chisq=0.53 (df 1), exact p=0.467* | | | | | | | | | | | | |
| a Response categories collapsed as indicated.  b Individuals reporting ‘Other’ (volunteering, student, maternity/paternity leave, parent/carer, retired) excluded from this analysis. | | | | | | | | | | | | |

Table 46: SO group: Changes in day-time occupation/usual activities: T0 - T4

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Managing usual activities of daily living (EQ-5D-5L Usual activities domain)a** | | **T4 (n)** | | | | | | | | | |  |
| unable/severe problems | | | moderate problems | | | | no/slight problems | | | *Total* |
| **T0 (n)** | unable/severe problems | 2 | | | 2 | | | | 2 | | | 6 |
| moderate problems | 2 | | | 4 | | | | 8 | | | 14 |
| no/slight problems | 7 | | | 4 | | | | 24 | | | 35 |
| *Total* | | 11 | | | 10 | | | | 34 | | | *55* |
| *Symmetry Test: Chisq= 4.11 (df=3), p=0.250* | | | | | | | | | | | | |
| **Availability of information needed for daily living (WHOQOL-BREF q13)a** | | **T4 (n)** | | | | | | | | | | |
| not at all / a little / moderately | | | | | mostly/  completely | | | | *Total* | |
| **T0 (n)** | not at all / a little/ moderately | 22 | | | | | 9 | | | | *31* | |
| mostly /completely | 8 | | | | | 17 | | | | *25* | |
| *Total* | | *30* | | | | | *26* | | | | *56* | |
| *Mcnemar’s Chisq =0.06 (df=1), exact p=0.81* | | | | | | | | | | | | |
| **Employment statusb** | | **T4 (n)** | | | | | | | | | | |
| paid work | | unable to work due to illness/disability or job-seeking | | | | | | | | *Total* |
| **T0 (n)** | paid work | 8 | | 0 | | | | | | | | *8* |
| unable to work due to illness/ disability or job-seeking | 0 | | 17 | | | | | | | | *17* |
| *Total* | | *8* | | *17* | | | | | | | | *25* |
| *Mcnemar’s Chisq=0.00, p=1* | | | | | | | | | | | | |
| **Satisfaction with capacity for work (WHOQOL-BREF q18)d** | | **T4 (n)** | | | | | | | | | |  |
| very dissat. /dissat | | | | neither | | | | very sat. / sat. | | *Total* |
| **T0 (n)** | very dissat. /dissat. (n) | 24 | | | | 2 | | | | 1 | | 27 |
| neither (n) | 5 | | | | 2 | | | | 3 | | 10 |
| very sat. / sat. (n) | 3 | | | | 7 | | | | 8 | | 18 |
| *Total* | | 32 | | | | 11 | | | | 12 | | *55* |
| *Symmetry Test: Chisq= 3.89 (df=3), p=0.274* | | | | | | | | | | | | |
| **I am satisfied with how I spend my free timee** | | | **T4 (n)** | | | | | | | | | |
| true | | | | | false | | | | *Total* |
| **T0 (n)** | true | | 17 | | | | | 11 | | | | *28* |
| false | | 6 | | | | | 22 | | | | *28* |
| *Total* | | | *23* | | | | | *33* | | | | *56* |
| *Mcnemar’s Chisq =1.47 (df 1), exact p=0.225* | | | | | | | | | | | | |
| a Response categories collapsed as indicated.  b Individuals (n=27/130) reporting ‘Other’ (volunteering, student, maternity/paternity leave, parent/carer, retired) excluded from this analysis. | | | | | | | | | | | | |

**Table 47: SO group: Changes in day-time occupation/usual activities: T0 - T5**

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Managing usual activities of daily living (EQ-5D-5L Usual activities domain)a** | | **T5 (n)** | | | | | | | | | |  |
| unable/severe problems | | | moderate problems | | | | no/slight problems | | | *Total* |
| **T0 (n)** | unable/severe problems | 2 | | | 3 | | | | 1 | | | 6 |
| moderate problems | 1 | | | 3 | | | | 8 | | | 12 |
| no/slight problems | 2 | | | 5 | | | | 16 | | | 23 |
| *Total* | | 5 | | | 11 | | | | 25 | | | *41* |
| *Symmetry Test: Chisq= 2.03 (df=3), p=0.567* | | | | | | | | | | | | |
| **Availability of information needed for daily living (WHOQOL-BREF q13)a** | | **T5 (n)** | | | | | | | | | | |
| not at all / a little / moderately | | | | | mostly/  completely | | | | *Total* | |
| **T0 (n)** | not at all / a little/ moderately | 13 | | | | | 8 | | | | *21* | |
| mostly /completely | 10 | | | | | 11 | | | | *21* | |
| *Total* | | *23* | | | | | *19* | | | | *42* | |
| *Mcnemar’s Chisq =0.22, df=1,exact p=0.637* | | | | | | | | | | | | |
| **Employment statusb** | | **T5 (n)** | | | | | | | | | | |
| paid work | | unable to work due to illness/disability or job-seeking | | | | | | | | *Total* |
| **T0 (n)** | paid work | 5 | | 0 | | | | | | | | *5* |
| unable to work due to illness/ disability or job-seeking | 0 | | 15 | | | | | | | | *15* |
| *Total* | | *5* | | *15* | | | | | | | | *20* |
| *Mcnemar’s Chisq = 0.00, p=1.00* | | | | | | | | | | | | |
| **Satisfaction with capacity for work (WHOQOL-BREF q18)d** | | **T5 (n)** | | | | | | | | | |  |
| very dissat. /dissat | | | | neither | | | | very sat. / sat. | | *Total* |
| **T0 (n)** | very dissat. /dissat. (n) | 14 | | | | 4 | | | | 1 | | 19 |
| neither (n) | 6 | | | | 4 | | | | 1 | | 11 |
| very sat. / sat. (n) | 2 | | | | 2 | | | | 7 | | 11 |
| *Total* | | 22 | | | | 10 | | | | 9 | | *41* |
| *Symmetry Test: Chisq=1.07 (df=3), p=0.785* | | | | | | | | | | | | |
| **I am satisfied with how I spend my free timee** | | | **T5 (n)** | | | | | | | | | |
| true | | | | | false | | | | *Total* |
| **T0 (n)** | true | | 11 | | | | | 7 | | | | *18* |
| false | | 6 | | | | | 19 | | | | *24* |
| *Total* | | | *17* | | | | | *25* | | | | *42* |
| *Mcnemar’s Chisq =0.08 (df 1), exact p=0.782* | | | | | | | | | | | | |
| a Response categories collapsed as indicated.  b Individuals (n=27/130) reporting ‘Other’ (volunteering, student, maternity/paternity leave, parent/carer, retired) excluded from this analysis. | | | | | | | | | | | | |

Table 48: D&S group: Changes in access to autism-specific networks: T0 - T4, T0 - T5

|  |  |  |  |
| --- | --- | --- | --- |
| **T4 (18 month follow-up)** | | | |
| **Membership of autism-specific voluntary organisations and/or on-line community?** | | | |
|  | **T4 (n)** | |  |
| **T0 (n)** | Member of org. and/or community | No membership | *Total* |
| Member of org.and/ community | 3 | 4 | *7* |
| No membership | 12 | 75 | *87* |
| *Total* | *15* | *79* | *94* |
| *Mcnemar’s Chisq = 4.00 (df 1), exact p=0.077* | | | |
| **Any contact with autism-specific voluntary organisations / communities?** | | | |
|  | **T4 (n)** | |  |
| **T0 (n)** | 1 + contact | No contact | *Total* |
| 1 + contact | 7 | 10 | *17* |
| No contact | 12 | 66 | *78* |
| *Total* | *19* | *76* | *95* |
| *Mcnemar’s Chisq = 0.18 (df 1), exact p=0.670* | | | |
| **T5 (24 month follow-up)** | | | |
| **Membership of autism-specific voluntary organisations and/or on-line community?** | | | |
|  | **T5 (n)** | |  |
| **T0 (n)** | Member of org. and/or community | No membership | *Total* |
| Member of org.and/ community | 2 | 1 | *3* |
| No membership | 12 | 46 | *58* |
| *Total* | *14* | *47* | *61* |
| *Mcnemar’s Chisq = 9.31 df(1), exact p=0.003* | | | |
| **Any contact with autism-specific voluntary organisations / communities?** | | | |
|  | **T5 (n)** | |  |
| **T0 (n)** | 1 + contact | No contact | *Total* |
| 1 + contact | 2 | 7 | *9* |
| No contact | 13 | 40 | *53* |
| *Total* | *15* | *47* | *62* |
| *Mcnemar’s Chisq = 1.80 df(1), exact p=0.26* | | | |

Table 49: SO group: Changes in access to autism-specific networks: T0 - T4, T0 - T5

|  |  |  |  |
| --- | --- | --- | --- |
| **T4 (18 month follow-up)** | | | |
| **Membership of autism-specific voluntary organisations and/or on-line community?** | | | |
|  | **T4 (n)** | |  |
| **T0 (n)** | Member of org. and/or community | No membership | *Total* |
| Member of org.and/ community | 4 | 3 | *7* |
| No membership | 7 | 39 | *46* |
| *Total* | *11* | *42* | *53* |
| *Mcnemar’s Chisq =1.60 (df1), exact p=0.344* | | | |
| **Any contact with autism-specific voluntary organisations / communities?** | | | |
|  | **T4 (n)** | |  |
| **T0 (n)** | 1 + contact | No contact | *Total* |
| 1 + contact | 6 | 5 | *11* |
| No contact | 6 | 36 | *42* |
| *Total* | *12* | *41* | *53* |
| *Mcnemar’s Chisq =0.09 (df 1), exact p=0.763* | | | |
| **T5 (24 month follow-up)** | | | |
| **Membership of autism-specific voluntary organisations and/or on-line community?** | | | |
|  | **T5 (n)** | |  |
| **T0 (n)** | Member of org. and/or community | No membership | *Total* |
| Member of org.and/ community | 3 | 2 | *5* |
| No membership | 2 | 35 | *37* |
| *Total* | *5* | *37* | *42* |
| *Mcnemar’s Chisq =0.00, exact p=1.00* | | | |
| **Any contact with autism-specific voluntary organisations / communities?** | | | |
|  | **T5 (n)** | |  |
| **T0 (n)** | 1 + contact | No contact | *Total* |
| 1 + contact | 4 | 4 | *8* |
| No contact | 5 | 29 | *34* |
| *Total* | *9* | *33* | *42* |
| *Mcnemar’s Chisq=0.11, exact p=1* | | | |

Appendix 13: DO cohort: changes in non-mental health outcomes T0-T3

Table 50: DO cohort: quality of life & perception of social networks outcomes T0-T3

|  |  |
| --- | --- |
| **Health-related Quality of Life (EQ-5D-5L) (2017 Tariff)** | *(n= 48)* |
| Mean score | T0 = 0.670; T3 = 0.680 |
| Difference in mean score | 0.0105 |
| (95% CI) | (-0.070, 0.489) |
| p value | p = 0.724 |
| Effect size\*\* | 0.051 |
| **ISEL-SF: Belonging sub-scale** | *(n= 52)* |
| Mean score | T0 = 7.35; T3 = 6.96 |
| Difference in mean score | 0.385 |
| (95% CI) | (-0.36, 1.13) |
| p value | p= 0.307 |
| Effect size\*\* | 0.143 |
| **WHOQOL-BREF Social Domain** | *(n= 51)* |
| Mean score | T0 = 38.89; T3 = 42.48 |
| Difference in mean score | 3.595 |
| (95% CI) | (-9.44, 2.25) |
| p value | p= 0.222 |
| Effect size\*\* | 0.173 |
| **WHOQOL-BREF Physical Domain** | *(n= 52)* |
| Mean score | T0 = 53.43; T3 = 51.85 |
| Difference in mean score | 1.580 |
| (95% CI) | (-2.85, 6.01) |
| p value | p= 0.477 |
| Effect size\*\* | 0.099 |
| **WHOQOL-BREF Environment Domain** | *(n= 51)* |
| Mean score | T0 = 56.39; T3 = 55.23 |
| Difference in mean score | 1.155 |
| (95% CI) | (-2.55, 4.86) |
| p value | p= 0.534 |
| Effect size\*\* | 0.088 |
| \*\*Cohen’s d= (mean2 – mean1)/standard deviation, (d=0.2 small, d=0.5 medium, d=0.8 large effect). | |

Table 51: DO cohort: changes in daily living outcomes T0-T3

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Managing usual activities of daily living (EQ-5D-5L Usual activities domain)a** | | **T3 (n)** | | | | | | | | | |  |
| unable/severe problems | | | moderate problems | | | | no/slight problems | | | *Total* |
| **T0 (n)** | unable/severe problems | 6 | | | 2 | | | | 0 | | | *8* |
| moderate problems | 2 | | | 5 | | | | 9 | | | *16* |
| no/slight problems | 1 | | | 4 | | | | 22 | | | *27* |
| *Total* | | *9* | | | *11* | | | | *31* | | | *51* |
| *Chi-square=2.92 (df 3), p= 0.404* | | | | | | | | | | | | |
| **Availability of information needed for daily living (WHOQOL-BREF q13)a** | | **T3 (n)** | | | | | | | | | | |
| not at all / a little / moderately | | | | | mostly/  completely | | | | *Total* | |
| **T0 (n)** | not at all / a little/ moderately | 15 | | | | | 8 | | | | *23* | |
| mostly /completely | 13 | | | | | 16 | | | | *29* | |
| *Total* | | *28* | | | | | *24* | | | | *52* | |
| *Chi-square=1.19, (df 1), p=0.275* | | | | | | | | | | | | |
| **Employment statusb** | | **T3 (n)** | | | | | | | | | | |
| paid work | | unable to work due to illness/disability or job-seeking | | | | | | | | *Total* |
| **T0 (n)** | paid work | 15 | | 4 | | | | | | | | *19* |
| unable to work due to illness/ disability or job-seeking | 3 | | 12 | | | | | | | | *15* |
| *Total* | | *18* | | *16* | | | | | | | | *34* |
| *Chisq= 0.14 (df 1), p= 0.706* | | | | | | | | | | | | |
| **Satisfaction with capacity for work (WHOQOL-BREF q18)d** | | **T3 (n)** | | | | | | | | | |  |
| very dissat. /dissat | | | | neither | | | | very sat. / sat. | | *Total* |
| **T0 (n)** | very dissat. /dissat. (n) | 20 | | | | 6 | | | | 4 | | *30* |
| neither (n) | 4 | | | | 0 | | | | 2 | | *6* |
| very sat. / sat. (n) | 5 | | | | 1 | | | | 10 | | *16* |
| *Total* | | *29* | | | | *7* | | | | *16* | | *52* |
| *Cell counts too low for analysis.* | | | | | | | | | | | | |
| **I am satisfied with how I spend my free timee** | | | **T3 (n)** | | | | | | | | | |
| true | | | | | false | | | | *Total* |
| **T0 (n)** | true | | 19 | | | | | 9 | | | | *28* |
| false | | 9 | | | | | 15 | | | | *24* |
| *Total* | | | *28* | | | | | *24* | | | | *52* |
| *Chisq=0.00 (df 1), p= 1.00* | | | | | | | | | | | | |
| a Response categories collapsed as indicated.  b Individuals (n=27/130) reporting ‘Other’ (volunteering, student, maternity/paternity leave, parent/carer, retired) excluded from this analysis. | | | | | | | | | | | | |

Table 52: DO cohort: Change in access to autism-specific organisations: T0-T3

|  |  |  |  |
| --- | --- | --- | --- |
| **Membership of autism-specific voluntary organisations and/or on-line community?** | | | |
|  | **T3 (n)** | |  |
| **T0 (n)** | Member of org. and/or community | No membership | *Total* |
| Member of org. and/ community | 6 | 1 | *7* |
| No membership | 7 | 38 | *45* |
| *Total* | *13* | *39* | *52* |
| *McNemar’s chisq= 4.50 (df 1), exact p= 0.034 [note: small cell counts]* | | | |
| **Any contact with autism-specific voluntary organisations / communities?** | | | |
|  | **T3 (n)** | |  |
| **T0 (n)** | 1 + contact | No contact | *Total* |
| 1 + contact | 7 | 3 | *10* |
| No contact | 5 | 37 | *42* |
| *Total* | *12* | *40* | *52* |
| *McNemar’s chisq= 0.50 (df 1), exact p= 0.480* | | | |

Appendix 14: T3 mental health outcomes: DO cohort vs D&S group

Table 53 WHOQOL-BREF Psychological Domain @ T3 DO cohort vs D&S group

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **ANCOVA** | **Adjusted means** | **95% CI** | **F Statistics** | **p-value** |
| **USING TOTAL D&S GROUP** | | | | |
| ***Model 1 (n=182)*** |  |  | 91.34 | < 0.001 |
| **Comparing T3 WHOQOL-BREF Psychological Domain scores** | | | | |
| DO Cohort | 40.93 | (36.87, 44.99) |  |  |
| D&S group | 39.25 | (36.69, 41.81) |  |  |
| Difference in means | -1.680 | (-6.48, 3.12) | 0.48 | 0.491 |
| *Controlling for:* | | | | |
| T0 WHOQOL-BREF (Psychological) |  |  | 182.41 | <0.001 |
|  | | | | |
| ***Model 2 (n=181)*** |  |  | 40.47 | < 0.001 |
| **Comparing T3 WHOQOL-BREF Psychological Domain scores** | | | | |
| DO Cohort | 41.91 | (37.58, 46.24) |  |  |
| D&S group | 40.82 | (37.57, 44.07) |  |  |
| Difference in means | -1.087 | (-5.85, 3.68) | 0.20 | 0.653 |
| *Controlling for:* | | | | |
| T0 WHOQOL-BREF (Psychological) |  |  | 64.77 | < 0.001 |
| GHQ-12 score at T0 |  |  | 7.22 | 0.008 |
| Age |  |  | 1.20 | 0.276 |
| Gender |  |  | 2.62 | 0.107 |
| **USING D&S SUB-SAMPLE (identical diagnostic assessment protocol to DO cohort)** | | | | |
| ***Model 1 (n=94)*** |  |  | 41.79 | <0.001 |
| **Comparing T3 WHOQOL-BREF Psychological Domain scores** | | | | |
| DO Cohort | 40.21 | (36.03, 44.39) |  |  |
| D&S group | 36.52 | (31.89, 41.15) |  |  |
| Difference in means | -3.69 | (-9.93, 2.54) | 1.38 | 0.242 |
| *Controlling for:* | | | | |
| T0 WHOQOL-BREF (Psychological) |  |  | 83.34 | <0.001 |
|  |  |  |  |  |
| ***Model 2 (n=93)*** |  |  | 16.60 | <0.001 |
| **Comparing T3 WHOQOL-BREF Psychological Domain scores** | | | | |
| DO Cohort | 41.50 | (36.54, 46.47) |  |  |
| D&S group | 38.08 | (32.80, 43.36) |  |  |
| Difference in means | -3.42 | (-9.84, 2.99) | 1.12 | 0.292 |
| *Controlling for:* | | | | |
| T0 WHOQOL-BREF (Psychological) |  |  | 41.91 | <0.001 |
| T0 GHQ-12 |  |  | 0.00 | 0.946 |
| Age |  |  | 0.44 | 0.511 |
| Gender |  |  | 2.13 | 0.148 |

Table 54 GHQ-12 @ T3 DO cohort vs D&S group

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **ANCOVA** | **Adjusted means** | **95% CI** | **F Statistics** | **p-value** |
| **USING TOTAL D&S GROUP** | | | | |
| ***Model 1 (n=183)*** |  |  | 30.43 | <0.001 |
| **Comparing T3 GHQ-12** | | | | |
| DO cohort | 17.88 | (16.04, 19.72) |  |  |
| D&S group | 17.46 | (16.30, 18.61) |  |  |
| Difference in means | -0.424 | (-2.60, 1.75) | 0.15 | 0.701 |
| *Controlling for:* | | | | |
| T0 GHQ-12 |  |  | 59.79 | <0.001 |
|  | | | | |
| ***Model 2 (n=182)*** |  |  | 12.67 | <0.001 |
| **Comparing T3 GHQ-12** | | | | |
| DO Cohort | 17.36 | (15.34, 19.38) |  |  |
| D&S group | 16.78 | (15.28, 18.29) |  |  |
| Difference in means | -0.574 | (-2.80, 1.65) | 0.26 | 0.611 |
| *Controlling for:* | | | | |
| T0 GHQ-12 |  |  | 22.48 | <0.001 |
| T0 WHOQOL-BREF (Psychological) |  |  | 0.93 | 0.336 |
| Age |  |  | 0.04 | 0.844 |
| Gender |  |  | 1.92 | 0.168 |
| **USING D&S SUB-SAMPLE (identical diagnostic assessment protocol to DO cohort)** | | | | |
| ***Model 1 (n=94)*** |  |  | 8.67 | <0.001 |
| **Comparing T3 GHQ-12** | | | | |
| DO Cohort | 18.40 | (16.31, 20.49) |  |  |
| D&S group | 19.36 | (17.04, 21.69) |  |  |
| Difference in means | 0.966 | (-2.16, 4.09) | 0.38 | 0.541 |
| *Controlling for:* | | | | |
| T0 GHQ-12 |  |  | 16.81 | <0.001 |
|  | | | | |
| ***Model 2 (n=93)*** |  |  | 4.23 | 0.002 |
| **Comparing T3 GHQ-12** | | | | |
| Diagnosis Only | 17.31 | (14.83, 19.79) |  |  |
| Diagnosis and Support | 18.75 | (16.11, 21.39) |  |  |
| Difference in means | 1.439 | (-1.77, 4.65) | 0.79 | 0.375 |
| *Controlling for:* | | | | |
| T0 GHQ-12 |  |  | 4.12 | 0.046 |
| T0 WHOQOL-BREF (Psychological) |  |  | 1.98 | 0.163 |
| Age |  |  | 0.55 | 0.461 |
| Gender |  |  | 1.70 | 0.196 |

Appendix 15: Economic evaluation outputs

Table 55: Costs (£) over the 12-month period to T3

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  |  |  |  |  |  | Bootstrapped 95% confidence interval | |
|  | Group | Statistic |  | Bias | Std. Error | Lower | Upper |
| GP | D&S  N=148 | Mean | 209.63 | 0.61 | 20.61 | 168.90 | 256.57 |
|  | SD | 248.97 | -1.10 | 21.87 | 205.77 | 288.23 |
|  | SE mean | 20.47 |  |  |  |  |
|  | SO  N=79 | Mean | 207.24 | 0.46 | 26.63 | 158.47 | 261.38 |
|  | SD | 229.94 | -2.51 | 18.02 | 196.26 | 259.17 |
|  | SE mean | 25.87 |  |  |  |  |
| Psychologist | D&S N=148 | Mean | 267.10 | -0.92 | 48.18 | 183.98 | 366.95 |
|  | SD | 597.50 | -25.34 | 161.47 | 334.31 | 856.97 |
|  | SE mean | 49.11 |  |  |  |  |
|  | SO N=79 | Mean | 154.38 | 1.55 | 32.62 | 92.80 | 222.72 |
|  | SD | 294.04 | -3.10 | 39.68 | 205.83 | 364.85 |
|  | SE mean | 33.08 |  |  |  |  |
| Occupational therapist | D&S N=148 | Mean | 124.08 | 0.84 | 79.44 | 33.17 | 283.44 |
| SD | 951.80 | -168.51 | 539.22 | 118.26 | 1619.58 |
| SE mean | 78.24 |  |  |  |  |
|  | SO N=79 | Mean | 24.84 | -0.26 | 10.79 | 7.90 | 45.14 |
|  | SD | 97.22 | -5.81 | 28.41 | 40.11 | 132.01 |
|  | SE mean | 10.94 |  |  |  |  |
| Nurse | D&S N=148 | Mean | 323.60 | -0.13 | 110.13 | 161.44 | 536.10 |
|  | SD | 1349.28 | -116.76 | 546.17 | 395.29 | 2112.17 |
|  | SE mean | 110.91 |  |  |  |  |
|  | SO N=79 | Mean | 97.39 | -0.10 | 27.71 | 48.09 | 153.27 |
|  | SD | 236.32 | -5.96 | 43.34 | 151.31 | 297.83 |
|  | SE mean | 26.59 |  |  |  |  |
| Speech & language therapist | D&S N=148 | Mean | 11.23 | -0.02 | 4.50 | 3.54 | 19.49 |
| SD | 54.45 | -1.71 | 12.21 | 28.66 | 72.37 |
| SE mean | 4.48 |  |  |  |  |
| SO N=79 | Mean | 4.21 | -0.03 | 3.16 | 0.00 | 10.21 |
|  | SD | 27.74 | -3.93 | 13.65 | 0.00 | 42.87 |
|  | SE mean | 3.12 |  |  |  |  |
| Social worker | D&S N=148 | Mean | 26.17 | 0.28 | 12.55 | 5.45 | 52.08 |
| SD | 150.62 | -7.40 | 46.88 | 54.25 | 217.06 |
|  | SE mean | 12.38 |  |  |  |  |
|  | SO N=79 | Mean | 16.34 | -0.51 | 8.79 | 3.42 | 32.43 |
|  | SD | 79.52 | -7.26 | 28.05 | 31.29 | 113.42 |
|  | SE mean | 8.95 |  |  |  |  |
| Support worker | D&S N=148 | Mean | 130.71 | 1.10 | 39.71 | 67.88 | 215.32 |
| SD | 474.23 | -18.25 | 139.49 | 194.94 | 693.33 |
| SE mean | 38.98 |  |  |  |  |
|  | SO N=79 | Mean | 181.28 | -5.18 | 67.94 | 72.65 | 307.31 |
|  | SD | 615.10 | -64.17 | 224.87 | 151.41 | 896.28 |
|  | SE mean | 69.20 |  |  |  |  |
| Group activities lasting fixed number of sessions | D&S N=148 | Mean | 40.18 | 0.38 | 7.74 | 26.08 | 56.04 |
| SD | 95.83 | -0.39 | 10.73 | 72.64 | 114.95 |
| SE mean | 7.88 |  |  |  |  |
| SO N=79 | Mean | 18.49 | -0.25 | 7.95 | 6.43 | 32.84 |
| SD | 70.89 | -4.07 | 20.27 | 35.97 | 97.56 |
| SE mean | 7.98 |  |  |  |  |
| Support group | D&S N=148 | Mean | 45.46 | 0.18 | 8.81 | 29.86 | 62.39 |
| SD | 106.65 | -0.96 | 14.51 | 79.43 | 130.41 |
|  | SE mean | 8.77 |  |  |  |  |
|  | SO  N=79 | Mean | 34.99 | 0.19 | 16.20 | 10.60 | 67.31 |
|  | SD | 141.92 | -9.55 | 49.50 | 50.91 | 212.49 |
|  | SE mean | 15.97 |  |  |  |  |
| Social group | D&S N=148 | Mean | 34.89 | -0.14 | 11.95 | 17.15 | 57.77 |
|  | SD | 144.54 | -6.97 | 38.99 | 78.05 | 197.25 |
|  | SE mean | 11.88 |  |  |  |  |
|  | SO N=79 | Mean | 60.08 | 0.79 | 17.07 | 31.03 | 96.60 |
|  | SD | 155.83 | -2.17 | 25.98 | 106.08 | 200.68 |
|  | SE mean | 17.53 |  |  |  |  |
| Outpatient care | D&S N=148 | Mean | 289.88 | -0.93 | 60.56 | 181.28 | 409.95 |
| SD | 732.16 | -12.12 | 127.27 | 483.39 | 952.01 |
|  | SE mean | 60.18 |  |  |  |  |
|  | SO N=79 | Mean | 329.30 | -1.98 | 81.93 | 181.50 | 499.18 |
|  | SD | 715.82 | -25.96 | 141.70 | 483.87 | 914.64 |
|  | SE mean | 80.54 |  |  |  |  |
| Accident & Emergency | D&S N=148 | Mean | 77.54 | 0.26 | 23.17 | 39.30 | 122.95 |
| SD | 281.22 | -4.01 | 46.78 | 194.67 | 358.81 |
|  | SE mean | 23.12 |  |  |  |  |
|  | SO N=79 | Mean | 59.42 | -1.40 | 28.94 | 12.89 | 112.22 |
|  | SD | 263.96 | -15.03 | 74.53 | 119.14 | 358.68 |
|  | SE mean | 29.70 |  |  |  |  |
| Walk-in-Centre | D&S N=148 | Mean | 91.63 | 1.34 | 24.30 | 50.51 | 143.16 |
| SD | 289.98 | -1.98 | 43.82 | 205.13 | 366.41 |
|  | SE mean | 23.84 |  |  |  |  |
|  | SO N=79 | Mean | 105.64 | 1.45 | 43.33 | 33.48 | 195.60 |
|  | SD | 367.69 | -10.23 | 88.01 | 189.00 | 510.29 |
|  | SE mean | 41.37 |  |  |  |  |
| Day case | D&S N=148 | Mean | 32.69 | 0.21 | 23.24 | 0.00 | 79.05 |
|  | SD | 280.24 | -28.00 | 122.01 | 0.00 | 427.43 |
|  | SE mean | 23.04 |  |  |  |  |
|  | SO N=79 | Mean | 91.86 | -1.24 | 55.24 | 0.00 | 196.58 |
|  | SD | 465.30 | -34.87 | 159.32 | 0.00 | 658.63 |
|  | SE mean | 52.35 |  |  |  |  |
| Inpatient care | D&S N=148 | Mean | 162.82 | -0.49 | 61.54 | 57.97 | 286.88 |
| SD | 759.50 | -19.11 | 150.29 | 464.62 | 991.53 |
|  | SE mean | 62.43 |  |  |  |  |
|  | SO N=79 | Mean | 101.68 | -4.74 | 67.76 | 0.00 | 217.10 |
|  | SD | 634.93 | -82.80 | 274.60 | 0.00 | 897.16 |
|  | SE mean | 71.44 |  |  |  |  |
| Police officer | D&S N=148 | Mean | 12.69 | -0.13 | 4.77 | 4.42 | 22.18 |
|  | SD | 56.30 | -1.71 | 11.78 | 31.53 | 74.30 |
|  | SE mean | 4.63 |  |  |  |  |
|  | SO N=79 | Mean | 25.75 | -0.30 | 13.80 | 3.92 | 50.81 |
|  | SD | 121.29 | -7.70 | 37.80 | 25.72 | 168.88 |
|  | SE mean | 13.65 |  |  |  |  |
| Private appts with other therapists | D&S N=148 | Mean | 37.49 | -0.83 | 18.65 | 10.94 | 71.72 |
| SD | 228.10 | -23.76 | 87.90 | 83.56 | 341.86 |
| SE mean | 18.75 |  |  |  |  |
|  | SO N=79 | Mean | 216.81 | -0.26 | 94.10 | 77.98 | 400.40 |
|  | SD | 832.63 | -54.50 | 277.11 | 317.33 | 1216.59 |
|  | SE mean | 93.68 |  |  |  |  |
| Days taken off due to sickness | D&S N=148 | Mean | 155.29 | -0.73 | 49.54 | 68.26 | 248.48 |
| SD | 622.82 | -25.01 | 159.14 | 289.45 | 863.90 |
| SE mean | 51.20 |  |  |  |  |
|  | SO N=79 | Mean | 48.88 | -1.27 | 25.64 | 11.10 | 93.72 |
|  | SD | 233.64 | -21.46 | 83.51 | 60.19 | 329.97 |
|  | SE mean | 26.29 |  |  |  |  |
| Health & social care costs | D&S N=164 | Mean | 2546.21 | -2.82 | 277.94 | 2122.26 | 3079.15 |
| SD | 3496.49 | -198.124 | 1079.46 | 1763.57 | 5131.56 |
| SE mean | 273.03 |  |  |  |  |
| SO N=88 | Mean | 1669.44 | 2.9 | 219.34 | 1267.34 | 2108.41 |
| SD | 2003.87 | -26.483 | 280.589 | 1423.11 | 2453.65 |
| SE mean | 213.613 |  |  |  |  |
| Societal costs | D&S N=164 | Mean | 2733.54 | -3.97 | 293.92 | 2271.11 | 3308.36 |
| SD | 3714.10 | -175.88 | 1040.63 | 2046.85 | 5262.59 |
| SE mean | 290.02 |  |  |  |  |
| SO N=88 | Mean | 1931.08 | 5.40 | 259.29 | 1449.79 | 2493.76 |
| SD | 2347.04 | -30.33 | 317.00 | 1713.76 | 2880.36 |
| SE mean | 250.20 |  |  |  |  |

Table 56: Bootstrap for Independent Samples Test

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Mean difference** | **Bootstrapa bias** | **Standard error** | **Sig. (2-tailed)** | **BCa 95% Confidence Interval** | |
| Lower | Upper |
| **Health & social care costsb (£)** | 876.77 | -5.73 | 352.25 | 0.024 | 199.29 | 1620.76 |
| **Societal costsb (£)** | 802.46 | -9.37 | 387.99 | 0.046 | 78.07 | 1575.64 |

a Unless otherwise noted, bootstrap results are based on 1000 bootstrap samples

b Excluding SAT costs

Table 57: Independent t-test for differences between SAT-D&S and SAT-SO sub-cohorts in annual cost (£) components

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | Levene's test for equality of variances | | t-test for equality of means | |  |  |  | 95% CI | |
|  | F | Sig. | t | df | Sig. (2-tailed) | Mean diff | Std error diff | Lower | Upper |
| GP | 0.35 | 0.56 | 0.34 | 229.00 | 0.73 | 11.65 | 33.96 | -55.26 | 78.56 |
| Psychologist | 4.18 | 0.04 | 2.00 | 226.24 | 0.05 | 116.58 | 58.38 | 1.53 | 231.63 |
| Occupational therapist | 2.83 | 0.09 | 0.95 | 231.00 | 0.34 | 98.78 | 104.17 | -106.47 | 304.03 |
| Nurse | 5.04 | 0.03 | 2.01 | 164.94 | 0.05 | 225.46 | 112.44 | 3.45 | 447.47 |
| Speech & language therapist | 5.16 | 0.02 | 1.33 | 229.11 | 0.19 | 7.08 | 5.32 | -3.41 | 17.57 |
| Social worker | 1.39 | 0.24 | 0.57 | 230.00 | 0.57 | 10.08 | 17.72 | -24.84 | 45.00 |
| Support worker | 0.39 | 0.53 | -0.50 | 231.00 | 0.62 | -35.58 | 71.62 | -176.69 | 105.53 |
| Fixed group | 11.58 | 0.00 | 1.99 | 214.38 | 0.05 | 21.68 | 10.92 | 0.16 | 43.20 |
| Support group | 0.57 | 0.45 | 0.61 | 230.00 | 0.54 | 9.97 | 16.29 | -22.13 | 42.06 |
| Social group | 3.53 | 0.06 | -1.13 | 231.00 | 0.26 | -22.76 | 20.09 | -62.34 | 16.82 |
| Outpatient | 0.21 | 0.65 | -0.39 | 231.00 | 0.70 | -38.42 | 98.43 | -232.36 | 155.53 |
| A&E | 0.14 | 0.71 | -0.13 | 230.00 | 0.90 | -5.60 | 44.75 | -93.78 | 82.58 |
| Walk-in Centre | 0.39 | 0.53 | -0.24 | 231.00 | 0.81 | -10.14 | 43.13 | -95.13 | 74.85 |
| Day case | 5.33 | 0.02 | -1.01 | 116.85 | 0.32 | -55.18 | 54.80 | -163.70 | 53.34 |
| Inpatient | 0.08 | 0.78 | 0.15 | 231.00 | 0.88 | 15.49 | 103.21 | -187.88 | 218.85 |
| Police officer | 3.22 | 0.07 | -0.84 | 231.00 | 0.40 | -9.90 | 11.76 | -33.07 | 13.26 |
| Private costs | 18.61 | 0.00 | -1.86 | 89.10 | 0.07 | -169.37 | 91.18 | -350.54 | 11.80 |
| Days taken off | 6.88 | 0.01 | 1.89 | 208.33 | 0.06 | 106.70 | 56.40 | -4.48 | 217.87 |

**Table 58: Nurse and psychologist costs (£) by different service arrangements**

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| **Service characteristic** | | **Costs over 12-month period to T3 (£)** | | | | | |
| **Nurse** | | **Psychologist** | | **Support worker** | |
| **Mean** | **Std error** | **Mean** | **Std**  **error** | **Mean** | **Std**  **error** |
| LA involvement | Joint LA/CCG | 101.06 | 29.17 | 246.52 | 47.94 | 241.46 | 92.27 |
| CCG | 237.13 | 75.64 | 186.27 | 33.83 | 98.16 | 26.61 |
| Team structure | Multi-service | 53.43 | 18.15 | 272.35 | 78.58 | 114.55 | 39.01 |
| Single service | 247.29 | 78.91 | 192.25 | 34.37 | 97.72 | 27.59 |
| Autism vs neuro-developmental (ND) | ND | 309.88 | 168.42 | 253.58 | 45.79 | 111.64 | 24.52 |
| Autism only | 166.45 | 43.84 | 175.23 | 41.99 | 93.61 | 35.47 |
| Psychoeducation | Dominant mode is 1:1 | 333.55 | 191.49 | 198.74 | 45.99 | 91.11 | 23.54 |
| Group | 164.70 | 41.34 | 206.05 | 41.14 | 104.44 | 33.89 |
| Skill mix | Number of professional disciplines = 4 or more | 155.45 | 38.93 | 165.14 | 30.25 | 123.25 | 59.17 |
| Number = 2 or 3 disciplines | 227.06 | 80.15 | 210.96 | 37.26 | 130.31 | 32.94 |
| One-to-one work | Routinely do 1:1 work for mental health problems | 91.86 | 25.99 | 218.77 | 43.14 | 222.7 | 81.56 |
| Not done routinely | 245.21 | 78.45 | 192.66 | 35.03 | 98.68 | 27.58 |
| Delivery of care plan | Managed | 216.82 | 74.84 | 218.27 | 35.42 | 129.94 | 30.93 |
| Episodic | 175.76 | 45.94 | 125.68 | 25.26 | 122.81 | 73.16 |
| Drop in provision and/or named contact whilst in service | No drop-in provision | 171.63 | 43.24 | 168.22 | 32.12 | 136.12 | 66.31 |
| Drop-in provision available | 219.43 | 77.19 | 208.29 | 36.02 | 126.13 | 31.74 |

**Table 59: Cost-outcome links: WHOQOL-BREF Psychological Domain**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Coeffic’nt** | **Standard error** | **Z** | **P>z** | **95% Confidence**  **Interval** | |
| Diagnostic status at referral (1=SO; 0=D&S) | -1.489 | 2.061 | -0.720 | 0.470 | -5.529 | 2.552 |
| Age | 0.106 | 0.084 | 1.270 | 0.205 | -0.058 | 0.270 |
| Gender (1=female; 0=male | -0.050 | 1.865 | -0.030 | 0.978 | -3.705 | 3.605 |
| WHOQOL-BREF Psychological Domain score at T0 | 0.760 | 0.050 | 15.120 | 0.000 | 0.662 | 0.859 |
| Societal cost at T0 (£) | 0.002 | 0.002 | 0.900 | 0.366 | -0.002 | 0.006 |
| GP costs | -0.011 | 0.004 | -2.640 | 0.008 | -0.020 | -0.003 |
| Psychologist costs | -0.002 | 0.002 | -0.810 | 0.420 | -0.007 | 0.003 |
| OT costs | 0.002 | 0.003 | 0.810 | 0.418 | -0.003 | 0.008 |
| Nurse costs | -0.002 | 0.002 | -1.000 | 0.318 | -0.007 | 0.002 |
| Speech-language costs | -0.018 | 0.020 | -0.910 | 0.363 | -0.058 | 0.021 |
| Social worker costs | -0.001 | 0.010 | -0.130 | 0.900 | -0.021 | 0.019 |
| Support worker costs | 0.001 | 0.003 | 0.350 | 0.725 | -0.004 | 0.006 |
| Fixed group costs | -0.001 | 0.012 | -0.070 | 0.941 | -0.025 | 0.024 |
| Support group costs | 0.009 | 0.009 | 1.080 | 0.280 | -0.008 | 0.026 |
| Social group costs | 0.001 | 0.006 | 0.100 | 0.917 | -0.012 | 0.013 |
| Outpatient costs | 0.001 | 0.002 | 0.940 | 0.350 | -0.002 | 0.004 |
| A&E costs | 0.008 | 0.005 | 1.710 | 0.088 | -0.001 | 0.017 |
| Walk-in centre costs | 0.004 | 0.003 | 1.160 | 0.247 | -0.003 | 0.010 |
| Day care costs | 0.000 | 0.003 | 0.060 | 0.952 | -0.005 | 0.006 |
| Inpatient care costs | -0.003 | 0.002 | -1.690 | 0.091 | -0.006 | 0.000 |
| Police officer costs | 0.013 | 0.011 | 1.190 | 0.234 | -0.008 | 0.034 |
| Private appointments with other therapist costs | -0.003 | 0.002 | -1.420 | 0.154 | -0.006 | 0.001 |
| Constant term | 9.460 | 3.942 | 2.400 | 0.016 | 1.735 | 17.185 |

Table 60: Factors associated with variations in WHOQOL-BREF Psychological Domain from a health and social care perspective

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Coefficient** | **Robust std error** | **z** | **P>z** | **95% Confidence**  **Interval** | |
| Diagnostic status at referral (1=SO; 0=D&S) | 1.011 | 1.249 | 0.810 | 0.418 | -1.437 | 3.459 |
| Baseline health and social care cost (£) | 0.001 | 0.003 | 0.330 | 0.740 | -0.005 | 0.007 |
| Age | 0.038 | 0.070 | 0.550 | 0.584 | -0.098 | 0.175 |
| Gender (1=female; 0=male | -1.023 | 2.779 | -0.370 | 0.713 | -6.470 | 4.423 |
| Living with parents at T0 (1=yes; 0=no) | 1.950 | 2.105 | 0.930 | 0.354 | -2.176 | 6.075 |
| Time off work/education due to illness (1=yes; 0=no) | -3.089 | 2.722 | -1.130 | 0.256 | -8.424 | 2.246 |
| WHOQOL-BREF Psychological Domain score at T0 | 0.724 | 0.079 | 9.110 | 0.000 | 0.568 | 0.880 |
| LA involvement1 | -6.075 | 4.726 | -1.290 | 0.199 | -15.338 | 3.188 |
| Team structure2 | 4.874 | 1.928 | 2.530 | 0.011 | 1.095 | 8.653 |
| Autism vs ND3 | -9.986 | 0.943 | -10.590 | 0.000 | -11.835 | -8.138 |
| Psychoeducation4 | 2.631 | 2.138 | 1.230 | 0.219 | -1.560 | 6.822 |
| Skill mix5 | -5.872 | 4.000 | -1.470 | 0.142 | -13.712 | 1.967 |
| One-to-one work6 | 17.097 | 1.152 | 14.840 | 0.000 | 14.839 | 19.355 |
| Delivery of care plan7 | -6.762 | 5.247 | -1.290 | 0.197 | -17.046 | 3.522 |
| Constant term | 19.905 | 6.063 | 3.280 | 0.001 | 8.022 | 31.787 |
| 1 LA involvement is joint local authority and clinical commissioning group (CCG) (coded as 1) or just CCG (coded as 0)  2 Team structure is multi-service team (= 1) or single service (= 0)  3 Autism vs ND: service is neurodevelopmental service (ND) (= 1) or autism only (= 0)  4 Psychoeducation: whether dominant mode of delivering psychoeducation post-diagnosis is one-to-one (= 1) or group (= 0)  5 Skill mix: in addition to clinical psychology, the number of professional disciplines represented on team (an indicator of degree to which SAT takes a holistic approach) is 4 or more disciplines (= 1) or 2 or 3 disciplines (= 0)  6 One-to-one work: routinely do 1:1 work for (non-complex) mental health problems (1 = yes; 0 = no)  7 Delivery of care plan is managed (= 1) or episodic (= 0) | | | | | | |

Table 61: Factors associated with variations in WHOQOL-BREF Psychological Domain from societal perspective

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Coefficient** | **Robust std error** | **z** | **P>z** | **95% Confidence**  **Interval** | |
| Diagnostic status at referral (1=SO; 0=D&S) | 1.696 | 1.344 | 1.260 | 0.207 | -0.939 | 4.330 |
| Baseline societal cost (£) | 0.004 | 0.002 | 2.260 | 0.024 | 0.001 | 0.007 |
| Age | -0.022 | 0.063 | -0.350 | 0.728 | -0.145 | 0.101 |
| Gender (1=female; 0=male | -2.780 | 1.938 | -1.430 | 0.151 | -6.578 | 1.019 |
| Time off work/ education due to illness (1=yes; 0=no) | -4.399 | 2.342 | -1.880 | 0.060 | -8.988 | 0.190 |
| WHOQOL-BREF psychological Domain score at T0 | 0.714 | 0.074 | 9.630 | 0.000 | 0.568 | 0.859 |
| LA involvement | -8.574 | 3.364 | -2.550 | 0.011 | -15.168 | -1.980 |
| Team structure | 4.002 | 1.771 | 2.260 | 0.024 | 0.531 | 7.472 |
| Autism vs ND | -9.966 | 0.797 | -12.500 | 0.000 | -11.528 | -8.404 |
| Psychoeducation | 1.077 | 1.074 | 1.000 | 0.316 | -1.028 | 3.181 |
| Skill mix | -4.977 | 3.031 | -1.640 | 0.101 | -10.917 | 0.962 |
| One-to-one work | 19.510 | 1.536 | 12.700 | 0.000 | 16.499 | 22.520 |
| Delivery of care plan | -5.490 | 3.576 | -1.540 | 0.125 | -12.499 | 1.519 |
| Constant term | -30.69 | 744.21 | -0.040 | 0.967 | -1489.31 | 1427.94 |
| 1 LA involvement is joint local authority and clinical commissioning group (CCG) (coded as 1) or just CCG (coded as 0)  2 Team structure is multi-service team (= 1) or single service (= 0)  3 Autism vs ND: service is neurodevelopmental service (ND) (= 1) or autism only (= 0)  4 Psychoeducation: whether dominant mode of delivering psychoeducation post-diagnosis is one-to-one (= 1) or group (= 0)  5 Skill mix: in addition to clinical psychology, the number of professional disciplines represented on team (an indicator of degree to which SAT takes a holistic approach) is 4 or more disciplines (= 1) or 2 or 3 disciplines (= 0)  6 One-to-one work: routinely do 1:1 work for (non-complex) mental health problems (1 = yes; 0 = no)  7 Delivery of care plan is managed (= 1) or episodic (= 0) | | | | | | |

Table 62: Factors associated with variations in QALY from a health and social care perspective

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | Coefficient | Robust std error | Z | P>z | 95% Confidence  Interval | |
| Referral (1=SO; 0=D&S) | -0.059 | 0.058 | -1.020 | 0.309 | -0.173 | 0.055 |
| Age | 0.001 | 0.002 | 0.310 | 0.758 | -0.004 | 0.005 |
| Gender (1=female; 0=male) | 0.039 | 0.039 | 0.990 | 0.320 | -0.038 | 0.115 |
| Living with parents at T0 (1=yes; 0=no) | -0.004 | 0.059 | -0.070 | 0.941 | -0.121 | 0.112 |
| Time off work/education due to illness (1=yes; 0=no) cost | -0.105 | 0.045 | -2.350 | **0.019** | -0.194 | -0.017 |
| Baseline utility score | 0.681 | 0.124 | 5.470 | **0.000** | 0.437 | 0.925 |
| Baseline health and social care cost (£) | 0.000 | 0.000 | 0.260 | 0.791 | 0.000 | 0.000 |
| LA involvement | 0.638 | 0.234 | 2.730 | **0.006** | 0.179 | 1.096 |
| Team structure | 0.007 | 0.093 | 0.080 | 0.937 | -0.175 | 0.190 |
| Autism vs ND | -0.182 | 0.086 | -2.110 | **0.034** | -0.351 | -0.013 |
| Psychoeducation | 0.161 | 0.094 | 1.710 | 0.087 | -0.023 | 0.345 |
| Skill mix | -0.283 | 0.196 | -1.440 | 0.149 | -0.667 | 0.102 |
| One-to-one work | -0.395 | 0.121 | -3.270 | **0.001** | -0.632 | -0.159 |
| Delivery of care plan | -0.274 | 0.216 | -1.270 | 0.204 | -0.698 | 0.149 |
| Constant term | 0.459 | 0.239 | 1.920 | 0.055 | -0.009 | 0.927 |

Table 63: Factors associated with variations in QALY from a societal perspective

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | Coefficient | Robust std error | Z | P>z | 95% Confidence  Interval | |
| Referral (1=SO; 0=D&S) | -0.062 | 0.055 | -1.120 | 0.263 | -0.171 | 0.046 |
| Baseline societal cost (£) | 0.000 | 0.000 | -1.290 | 0.197 | 0.000 | 0.000 |
| Age | 0.001 | 0.002 | 0.580 | 0.564 | -0.003 | 0.005 |
| Gender (1=female; 0=male | 0.051 | 0.039 | 1.310 | 0.191 | -0.026 | 0.128 |
| Time off work/education due to illness (1=yes; 0=no) | -0.085 | 0.046 | -1.860 | 0.062 | -0.175 | 0.004 |
| Baseline utility score | 0.634 | 0.126 | 5.010 | **0.000** | 0.386 | 0.882 |
| LA involvement | 0.585 | 0.218 | 2.680 | **0.007** | 0.157 | 1.013 |
| Team structure | 0.042 | 0.093 | 0.450 | 0.652 | -0.141 | 0.225 |
| Autism vs ND | -0.194 | 0.085 | -2.280 | **0.023** | -0.361 | -0.027 |
| Psychoeducation | 0.163 | 0.088 | 1.860 | 0.063 | -0.009 | 0.335 |
| Skill mix | -0.247 | 0.192 | -1.290 | 0.197 | -0.623 | 0.129 |
| One-to-one work | -0.381 | 0.113 | -3.360 | **0.001** | -0.603 | -0.159 |
| Delivery of care plan | -0.235 | 0.208 | -1.130 | 0.258 | -0.642 | 0.173 |
| Constant term | 0.442 | 0.234 | 1.890 | 0.059 | -0.016 | 0.901 |

Appendix 16: Assessment by Local Authority for care or support needs: SAT cohort

Table 64: Reports of assessment by Local Authority for care or support needs: SAT cohort

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Response options** | **T0 (n=201)** | | **T3 (n=204)** | |
| *n* | *%* | *n* | *&* |
| No | 176 | 87.56 | 170 | 83.33 |
| Waiting | 8 | 3.98 | 5 | 2.45 |
| currently being assessed | 5 | 2.49 | 7 | 3.43 |
| Yes, not eligible | 4 | 1.99 | 8 | 3.92 |
| Yes, have care plan and receive Direct Payments | 7 | 3.48 | 11 | 5.39 |
| Yes, have care plan and council manage my Individual Budget | 1 | 0.5 | 3 | 1.47 |
| Total | 201 | 100 | 204 | 100 |

1. Social needs = social care, employment, housing and welfare needs [↑](#footnote-ref-1)