

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

The SHAPE project

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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 as 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.

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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.

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