

Evaluating specialist autism teams' provision of care and support for autistic adults without learning disabilities: the SHAPE mixed-methods study

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Disclaimer: This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

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Scientific summary

The SHAPE mixed-methods study

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Scientific summary

Background

Government strategy and National Institute for Health and Care Excellence guidance recommend that localities have an specialist autism, community-based, multidisciplinary team to develop, co-ordinate and deliver services to, and support mainstream services caring for, autistic adults. This recommendation arose from significant concerns about autistic adults' outcomes, difficulties accessing specialist autism diagnostic services and mainstream services' ambivalence about providing care and support to this group of individuals. The National Institute for Health and Care Excellence called this provision 'Specialist Autism Teams'. This was a novel type of service that had no specific evidence underpinning it. The National Institute for Health and Care Excellence recommended that once Specialist Autism Teams had been developed, they were subject to evaluation to generate an evidence base for subsequent service development.

Objectives

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

Methods

Stage 1

Services in England that fulfilled the National Institute for Health and Care Excellence's description of a Specialist Autism Team were identified through desk-based research, a national survey and semistructured interviews with service leads.

Stage 2

Stage 2 comprised a mixed-methods observational study of two cohorts (the Specialist Autism Team cohort and the Diagnosis-Only cohort), and a nested qualitative study of the views and experiences of senior Specialist Autism Team staff. A total of nine Specialist Autism Teams, broadly representative of all Specialist Autism Teams in England, acted as research sites.

The Specialist Autism Team cohort comprised Specialist Autism Team users. It was composed of those referred to the Specialist Autism Team who were already diagnosed with autism ('Support-Only' group) and those referred for diagnostic assessment and ongoing support ('Diagnosis and Support' group). Three sites also provided a regional diagnostic assessment service for individuals living outside its

Clinical Commissioning Group/local authority boundaries; this provision does not include any post-diagnosis care. The Diagnosis-Only 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 use were assessed at baseline, and at 3, 6 and 12 months (T0, T1, T2 and T3, respectively) via standardised measures and questions designed specifically for the study. Those recruited early to the study were also followed up at 18 and 24 months (T4 and T5, respectively).

Over 400 individuals ($n = 424$) were recruited; 114 subsequently became ineligible because they were not diagnosed with autism. Of those remaining, 260 (83.9%) individuals were retained at T3 [Specialist Autism Team cohort, $n = 208$ (Diagnosis and Support group, $n = 133$; Support-Only group, $n = 75$) and Diagnosis-Only cohort, $n = 52$]. In-depth semistructured interviews with 38 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 Specialist Autism Team staff's experiences. Data on service costs were also collected.

Results

Stage 1

Eighteen localities were identified as having a service that aligned to the National Institute for Health and Care Excellence's specification of a Specialist Autism Team. This suggests that in less than one-sixth (25/152, 16%) of local authorities in England, individuals have access to a Specialist Autism Team. All Specialist Autism Teams served autistic adults without learning disabilities. Many reported that the decision to focus on this population arose from the (total) lack of specialist autism services for this group within their locality, and significant concerns about their welfare and well-being. Specialist Autism Teams 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 ongoing support functions delivered by same or different services). All sought to upskill and support practitioners in mainstream services who work with autistic adults without learning disabilities; however, they varied in the extent to which this was resourced or was regarded as a core way of working. A distinct typology of Specialist Autism Team service model did not emerge.

Stage 2

Research with senior Specialist Autism Team 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 resources. In response, all had restricted their service offer and/or changed their delivery model, which, they believed, had adversely affected responsiveness and quality of care. All strongly supported the notion of Specialist Autism Teams. Autism expertise, the multidisciplinary 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 evolved and were evolving. This was driven partly by resource constraints and pressures on services. Furthermore, Specialist Autism Teams were a new model of service provision, which were set up in the relative absence of a body of clinical experience to draw on, as well as no evidence base on service design, delivery and intervention effectiveness.

Senior practitioners identified three factors that were key to ensuring sustainable improvements in support for autistic adults without learning disabilities:

- While retaining Specialist Autism Teams' function as providers of specialist autism interventions and support, commissioning arrangement should allow Specialist Autism Teams to place greater emphasis and investment in upskilling and supporting mainstream services to work with autistic adults.
- Specialist Autism Teams' approaches to care and support should seek to nurture self-management skills.
- Drop-in services or other forms of low-intensity, ongoing support should be a core feature of Specialist Autism Teams provision.

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

Service user views and experiences

The majority of study participants reported that using a Specialist Autism Team had a positive impact on their lives. Responses revealed the potential for Specialist Autism Teams 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 study participants reported that the service use 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.

Study participants who were also interviewed for the study 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 and 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: Specialist Autism Team cohort

A statistically significant improvement in the proportion of study participants scoring below the General Health Questionnaire (12-item version) threshold was observed in the Diagnosis and Support group, but not in the Support-Only group. No statistically significant changes in the study's primary outcome (World Health Organization Quality of Life assessment, abbreviated version – psychological domain) or other standardised outcome measures were observed in the Diagnosis and Support group. In the Support-Only group, a statistically significant deterioration in social quality of life was observed.

With respect to our categorical outcome indicators, in the Diagnosis and Support 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 Support-Only 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 the Diagnosis and Support group, although 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 4 weeks prior to T3 data collection. We found no statistically significant changes in membership or contact in the Support-Only 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 Specialist Autism Teams had addressed their needs. These were (1) the scope of and access to psychoeducation about autism, (2) the overall model of care delivery, (3) the availability of an alternative to group-delivered interventions, (4) the timelines of group-delivered interventions and (5) the 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, functioning at referral, or contact with autism-specific communities. Costs over the 12-month follow-up period were lower for people who were already diagnosed with autism than for those not previously diagnosed, men, people living with parents, foster carers or guardians, those with better mental health at baseline and those with lower service/resource use 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. multiteam), autism versus neurodevelopmental service and predominant mode of delivering post diagnosis psychoeducation (group vs. one to one). 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 a richer skill mix (i.e. 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 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 Specialist Autism Team 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 accessed only a diagnostic assessment service (Diagnosis-Only cohort) with those diagnosed by a Specialist Autism Team (Diagnosis and Support group within the Specialist Autism Team 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 of the Diagnosis and Support 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 one-to-one sessions as an alternative.

The Diagnosis-Only 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. No one had pursued services to which they had been signposted.

We carried out our interviews 6–9 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 Diagnosis-Only cohort interviewees reported long-standing or unresolved difficulties associated with the diagnosis. Almost all of the Diagnosis-Only cohort wanted further help in understanding and coming to terms

with their 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 Diagnosis-Only cohort and the Diagnosis and Support group, with a deterioration observed in the Diagnosis-Only cohort in the immediate post-diagnosis period. At the 12-month follow-up (T3), no statistically significant changes in outcomes were observed in the Diagnosis-Only cohort. This contrasts with findings for the Diagnosis and Support group, in which some positive changes were observed. Our comparison of mental health outcomes at T3 of the Diagnosis-Only cohort and Diagnosis and Support group found no significant difference; however, these analyses were underpowered.

Conclusions

Although still an unusual model of provision, services aligning to the National Institute for Health and Care Excellence's recommendation for each locality to have a Specialist Autism Team were identified in 18 localities. These services 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; however, 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 Specialist Autism Teams (especially given how widely those Specialist Autism Teams varied in terms of service arrangements and scale) and associated data quality. In future research, micro-costing of Specialist Autism Teams activities should be considered.

Post-diagnosis experiences of those diagnosed by a Specialist Autism Team were markedly better than those diagnosed by a Diagnosis-Only service. The intensity and duration of post-diagnosis psychoeducation and the 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.

Specialist Autism Teams practitioners reported that referrals and caseloads increase year on year. Resources to extend consultative support/supervision to mainstream services, and (further) develop provision of low-intensity, ongoing provision were identified as key ways to ensure that sustainable, specialist autism support was available for autistic adults without learning disabilities.

Key research recommendations are a large-scale comparative evaluation of Specialist Autism Teams 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; and evaluation of low-intensity, long-term specialist autism support to autistic adults without learning disabilities.

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