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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Plain English summary

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Autistic adults without learning disabilities struggle to access diagnostic services and find that mainstream services do not provide support in ways that they find helpful. In the past decade, some places in England have set up specialist autism, multidisciplinary services to address these problems. National clinical guidance describes these as Specialist Autism Teams. To our knowledge, this study was the first to evaluate such services. We found that not many places in England have a Specialist Autism Team and that the funding these teams receive varies greatly. Staff in these services report a growing demand. They would like more funding so that they can spend more time helping mainstream services to care for autistic adults, and so that they can offer ongoing 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 Team 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 learning difficulties.
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