

Department of Health Reviews Facility

To support national policy development and implementation



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Evidence Summary

Support for adults with autism spectrum disorders without intellectual disability

- Adults with autism spectrum disorders are at risk of social isolation, mental and physical health problems, and unemployment.
- Current guidance recommends that local authorities provide 'low-level' services such as social and vocational support, and advocacy for people with ASD.
- Local authorities and third-sector organisations currently provide a range of services including 'hubs' and drop-in centres which provide responsive, person-centred support, including training and employment support
- Research evidence suggests that social skills training improves self-rated social skills and autism symptoms.
- Research evidence suggests that employment support increases rates of employment and job interview training improves mock interview performance.
- Evidence for other types of intervention is very limited.
- Local authorities, NHS bodies and third-sector providers would benefit from engaging at a strategic level to develop greater integration and sustainability of supportive services for adults with autism spectrum disorders without intellectual disability.

The Department of Health Reviews Facility is a collaboration between the following centres of excellence

Evidence Summary

This summary is based on the findings of a systematic review of international research and a comprehensive map of 'low-level support' services in England for adults with autism spectrum disorders without intellectual disability.

The systematic review assessed the effects of support interventions. Studies were identified through searching of electronic databases and findings were synthesised narratively. Half of the studies were rated as high quality and half as low, with the high-quality studies focusing on employment interventions or social skills training.

We summarised the overall aims of existing 'low-level support' services in England and tabulated the main elements of each. We selected

three services as illustrative case studies, providing further detail about the services, their implementation and potential challenges in delivery.

Details of the project are presented in the full report at <http://eppi.ioe.ac.uk/cms/Default.aspx?tabid=3678>

Evidence Sources

Evaluation studies: 27

Economic evaluations: 3

Qualitative studies: 8

Low level support services: 128

Background

Approximately half a million people in England are estimated to have an autism spectrum disorder (ASD).¹ It is estimated that almost 50% of people with ASD do not also have learning disabilities.² People with so-called 'high-functioning autism' may find it difficult to get the support they need, and are often not eligible for social care. Adults with ASD are at risk of social isolation, mental and physical health problems, unemployment, and are often unable to live independently. Although a diverse group with different needs, they are likely to benefit from preventive (or low-level) support. Current guidance for local authorities focuses on the provision of 'low-level' support for people with ASD to help reduce mental health crises. Low-level support includes practical assistance with daily life, strengthening social networks, providing education or training, social, emotional and vocational support, and facilitating access to services.

What services are provided in England?

We identified 128 local services. Some form part of statutory health or social care provision, while others are run by small organisations or networks (sometimes with local authority or CCG funds). Some operate physical or virtual 'hubs' or drop-in centres, providing a first point of contact and information and signposting to external organisations and programmes. Others offer a range of services including education and training, advocacy, employment support, assistive technology, and one-to-one social and emotional support. Many services favour a person-centred approach, responding to individual needs in a flexible way.

Providers argue that the services they offer enable continuity of care and a personalised, responsive approach, which leads to greater trust and motivation in service users. Because of their focus on ASD, they often have specialist expertise which more generic services are unlikely to have and are better able to meet the specific needs of people with ASD without intellectual disability.

Types of intervention:

- Teaching / training service users
- Employment support
- Individualised / one-to-one support
- Peer support
- Family / carer support
- Other support / activity groups
- Information resources / signposting
- Social / creative events and activities
- Advice and guidance
- Advocacy / liaison
- Teaching / training professionals / public / families / employers
- Needs assessment / post-diagnostic support
- Mentoring

Modes of delivery:

- Drop-in / hubs
- Health professional involvement
- Telephone / email / online support
- Collaboration and coordination with other organisations
- Social enterprise
- Outreach services
- Assistive technology (mobile apps / cloud based or virtual services)
- Social media

Which interventions are effective?

One economic study of diagnostic assessment and co-ordination of services by specialist multi-disciplinary teams found that this type of service is probably (80% probability) cost-saving to the public sector.³ Costs are offset by savings from reductions in use of residential care, supported accommodation and other services.

Evidence is lacking on the ‘hub’ or drop-in centre approach to service provision. But, there is evidence to support some of the individual components offered by many service providers including social skills training (14 studies) and employment based interventions (8 studies).

Focused social skills training programmes may help to improve social skills and empathy, at least in the short term. However, it is unclear whether other outcomes such as mental health or wellbeing are improved.

Supported employment, where caseworkers, individuals and employers work together to identify suitable jobs and help people to retain them, may reduce unemployment^{4, 5} and is likely to be cost-effective.⁶ Training for job interviews improves performance in mock interviews, but it is unclear whether it reduces unemployment. Employment interventions do not appear to improve wellbeing.

There is no evidence of harm from any intervention.

What are the implications for practice?

Robust evidence about the most effective and cost-effective ways to support adults with ASD without intellectual disability is lacking. Anecdotally, person-centred services are valued, seem to make a positive difference to the lives of service users and are felt to be cost-effective through prevention of inappropriate use of services in the longer term.

Available evidence relates to narrowly focused interventions such as employment support and social skills training. Some support services do offer this type of intervention and the evidence supports their continued use. Where they are not currently available, service providers could offer them to people identified as having the potential to benefit from them and as part of a flexible package of support.

Evidence Summary

A range of innovative forms of low-level support are being offered by local services, which relate to statutory social care and health services in different ways. Because most services are small and locally focused they can deliver support tailored to the needs of their population, but there seems to be limited communication between practitioners in different areas. Increased opportunities for networking and sharing best practice between local practitioners and policy-makers would be valuable.

Greater strategic engagement between mainstream statutory services and supportive services would help to make such services more sustainable and properly integrated into existing mainstream health and social care provision. Existing services often rely on the expertise and enthusiasm of a few individual staff members and there is a need to incorporate sustainability and scalability into future planning. Service providers will also need to consider how the incorporation of local supportive services for adults with ASDs without intellectual disability relates to existing statutory care coordination and management arrangements, particularly when there has been no previous contact with mainstream health or social care services.

Research priorities

- Evaluations of the impact of supportive and person-centred services, such as peer support, advocacy services and drop-in centres.
- Robust process evaluation and qualitative studies of existing support services.
- Cost-effectiveness studies of the 'hub' model of support.
- Evaluation of support services tailored to older adults and black or minority ethnic groups.

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