Working with stakeholders to identify evidence gaps: an example from autism

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Background

Adults with autism spectrum disorder (ASD) without intellectual impairment may face challenges including social isolation, difficulties with activities of daily living, unemployment, and mental and physical health problems. Statutory guidance in England requires local authorities to provide 'low-level' support services for people with ASD.

The Department of Health and Social Care Policy Reviews Facility was commissioned to review evidence relevant to the delivery of support services. We convened an Advisory Group including service users and carers, policy-makers, practitioners and representatives of patient organisations.

Stakeholder engagement

Our Advisory Group included service user representatives, practitioners and policy stakeholders (see right). Through a face-to-face meeting and consultation by phone and email, the Advisory Group contributed to:

• defining the scope of the project
• developing the project protocol
• identifying data for the review and the service mapping
• synthesis and presentation of data
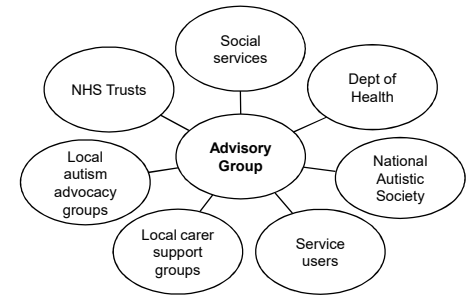
Logic model

With input from the Advisory Group, we first developed a logic model of the types of components which might be included in interventions, and how these relate to outcomes. The model includes five broad intervention components and six outcomes, as well as intermediate outcomes which can be seen as mediators of intervention pathways and/or as proxy outcomes.
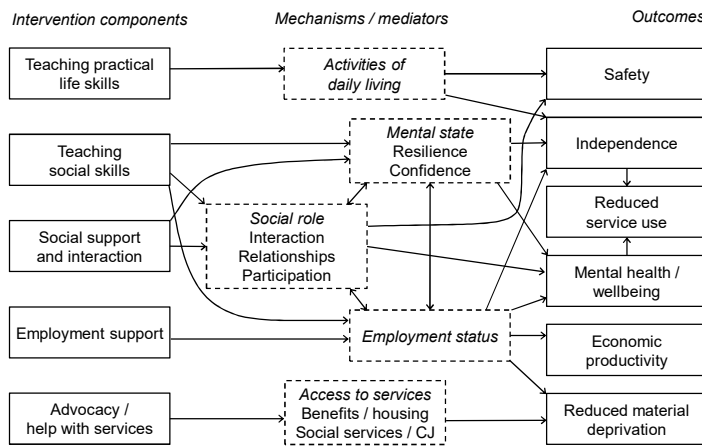
Service mapping

We mapped information on the whole range of services currently delivered in practice, to better understand the types of support available in England for people with ASD without intellectual impairment.

We included 128 services. The table below shows the types or components of service most commonly delivered.

	Component	N
Categories of intervention	Teaching / training service users	48
	Employment support	32
	Individualised / one-to-one support	32
	Peer support	24
	Family / carer support	10
	Other support / activity groups	23
	Information resources / signposting	25
	Social / creative events and activities	24
	Advice and guidance	23
	Advocacy / liaison	21
	Training professionals / public / families / employers	20
	Needs assessment / post-diagnostic support	19
	Mentoring	11
Modes of delivery	Drop-in / hubs	15
	Health professional involvement	12
	Telephone / email / online support	9
	Collaboration and coordination	8
	Social enterprise	6
	Outreach services	5
	Assistive technology (mobile apps, virtual services)	6
	Social media	3
	Other	13

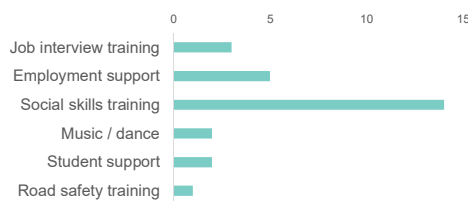## Review of interventions

Inclusion criteria

1. Study type: Primary intervention study (RCT, nRCT, uncontrolled)
2. Population: adults (≥18 years) with autism without intellectual impairment (IQ≥70)
3. Intervention: any except clinical or psychological interventions focused on specific morbidity
4. Outcome: any except purely cognitive or skills outcomes
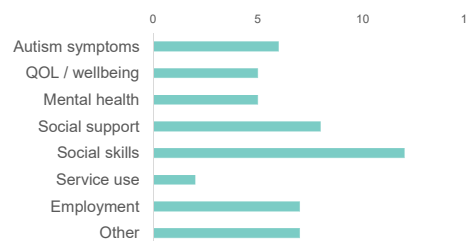5. Language: English

Results

We identified over 9,500 unique records; 27 studies were included in the synthesis.

The findings suggest that job interview training improves interview performance; employment support increases employment and earnings; and social skills training improves self-rated social skills and autism symptoms. Evidence on other interventions and outcomes is inconclusive.

Descriptive statistics on the interventions and outcomes evaluated in the studies are shown in the bar charts below.

Interventions evaluated in the studies (N=27)

Outcomes measured in the studies (N=27, not exclusive)

Comparing the service mapping to the review findings

There are some areas of overlap between the research evidence and the services available in practice, particularly around employment support and social skills training (although there are still divergences between what is delivered by local services and the interventions evaluated in research studies). However, a number of intervention types identified in the service mapping have little or no relevant research evidence, such as skills training (other than social skills), support for families or carers, and individualised social support.

Comparing the logic model to the review findings

Interventions: social skills and employment support are well represented in the review data, but there is much less research on other intervention types.

Outcomes: outcomes corresponding to the 'social role' domain are well represented in the review data; there is some information on mental health and employment, but limited data relevant to other outcomes.

Conclusions

There is a gap between what is important to service users and the interventions and outcomes which have been evaluated in research studies.[1] This is a challenge for ensuring that research addresses service users' needs, and that practice is informed by evidence.[2]

1. Cf. Autistica and James Lind Alliance, http://www.jla.nihr.ac.uk/priority-setting-partnerships/autism/
2. Cf. Greenhalgh 2018, https://oxfordbrc.nihr.ac.uk/blog/oxfordimpact2018/

The methods used in this project may be applicable to other complex policy areas, particularly where services are decentralised and provided by small-scale, local and/or informal organisations. In such cases, making research relevant to practice may require substantial work to find out what current practice is. Involving service users and other stakeholders can make an important contribution to mapping practice, identifying evidence gaps, and clarifying the relevance of review findings for policy and practice.

Research recommendations

1. Evaluations of the impact of supportive services, such as peer support, advocacy services and drop-in centres.
2. Process evaluation / qualitative studies of support services.
3. Cost-effectiveness studies, particularly of the 'hub' model
4. Evaluation of support services tailored to older adults, black or minority ethnic groups, and women
5. Further randomised trials of focused interventions, such as employment support and skills training
6. Development and validation of 'real-world' outcome measures reflecting the priorities of people with autism.