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.

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.

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.

Outcomes measured in the studies (N=27, not exclusive)
- Autism symptoms
- QOL / wellbeing
- Mental health
- Social support
- Social skills
- Service use
- Employment
- Other

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.

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

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.

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.

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.