

# Crossing the divide: a longitudinal study of effective treatments for people with autism and attention deficit hyperactivity disorder across the lifespan

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## **Scientific summary**

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# Scientific summary

## Background

Autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD) both frequently persist into adolescence and young adulthood. However, there are few clinical services that support those with these disorders through adulthood. Research into the needs of young adults with an ASD or ADHD (and their carers) is important in order to design effective care programmes, but little is known about the service use and needs of these groups as they reach adolescence and transition to adulthood.

## Research questions

1. What are the needs of affected individuals and their carers and are these met by health services?
2. Are people with ADHD and ASD already in contact with clinical services recognised and treated by the services?
3. Can we improve the diagnosis of ADHD and ASD by clinical services?
4. Can we improve the treatment of ADHD and ASD by clinical services?

## Methods

The research comprised findings from four different work packages within this study over 5 years, from 2009 to 2013.

We (1) interviewed > 180 affected individuals (and their families) with a confirmed diagnosis of ASD and/or ADHD, (2) screened for ASD and ADHD in approximately 1600 patients currently in receipt of clinical services in community medical (general practice) and mental health services (including general adult, forensic and prison settings) and (3) surveyed general practitioner (GP) prescribing to 5651 ASD individuals across the UK (as prescribing in ADHD has already been reported). Finally, we tested the effectiveness of (1) new ASD diagnostic interview measures in 169 twins, 145 families and 150 non-twins, (2) a magnetic resonance imaging-based diagnostic aid in 40 ASD individuals, (3) psychological treatments in 46 ASD individuals and (4) the feasibility of e-learning in 28 clinicians.

## Results

### *The needs of affected individuals and their carers*

Young people with ASD and ADHD have very significant needs as they transition through adolescence and young adulthood. A major contributor to this is associated mental health symptoms and/or ongoing educational and other functional impairments related to the 'core disorder'. However, the additional/residual mental health problems (e.g. depression and anxiety) in ASD and ADHD are mostly undiagnosed (and untreated) by clinical services. Furthermore, the largest determinant of service provision is age and not severity of symptoms (e.g. in ADHD each 1-year increase in a young person's age reduces the odds of being seen by services by 38%). This leads to a carer burden that is similar to looking after somebody with a traumatic brain injury or dementia.

## Implications

Needs-led services are required that can both identify individuals with the 'core symptoms' of ASD and ADHD and treat their residual symptoms and associated conditions such as anxiety and depression.

### **Are people with ADHD and ASD already in contact with clinical services recognised and treated?**

Clinical services have a relatively high prevalence of people with ASD and ADHD, but these people are mainly unrecognised. Furthermore, these (unrecognised) individuals are functionally more impaired, have a higher rate of suicide attempts and spend longer periods in seclusion.

Overall, costs for both disorders are mainly borne by education and social care services – with much less accounted for by physical (and especially mental) health services. Finally, as individuals with ADHD and ASD grew older, mental health service costs reduce very significantly.

#### **Implications**

As individuals ‘transition’, their contact with treatment and support services reduces significantly. It is essential to increase diagnostic awareness and service provision.

### **Can we aid the diagnosis of ADHD and ASD by clinical services?**

We took the pragmatic decision to adapt existing instruments (rather than developing completely new ones). In addition, relatively easy-to-use instruments for screening/diagnosing ADHD already exist. Hence, as a first step, we focused on ASD by testing the utility of the Development and Well-Being Assessment (DAWBA) and Strengths and Difficulties Questionnaire (SDQ) for diagnosing the core disorder and for identifying associated mental health symptoms, respectively.

The DAWBA performed well in our study of children and it has the potential to be a useful tool in community settings. In addition, the SDQ is a valid way to screen for comorbid anxiety disorders, depression and ADHD in adults with ASD.

In the next study, we explored the effect that changes to clinical diagnostic practice [as recommended in *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition (DSM-V)] would have on affected individuals. We found that DSM-V is a relatively insensitive measure of ASD in young adults compared with alternatives that are currently used in the UK [such as *International Classification of Diseases*, Tenth Edition (ICD-10)]. This is noteworthy as ICD-10 is about to be revised – and if similar approaches are adopted in *International Classification of Diseases*, Eleventh Edition, to those now used in DSM-V, or if DSM-V is adopted in the UK as a service ‘gatekeeper’, then many affected individuals with ASD could be excluded from services.

We therefore next determined if, in young adults, we could establish proof of concept that new advances in brain imaging provide objective measures that may help categorise young adults with ASD and/or ADHD. We could correctly classify 85% of all cases overall at a sensitivity and specificity as high as 90% and 80%, respectively.

#### **Implications**

Interview-based tools can help to diagnose the core disorder and associated symptoms in ASD; and there is proof of concept for the potential utility of brain biomarkers to help aid classification of ASD and ADHD in young adults.

### **Can we improve the treatment of ADHD and ASD?**

In other parts of this programme, we found very high rates of associated mental health symptoms in people with ASD (e.g. depression and anxiety). However, relatively few individuals had been diagnosed with these symptoms by their GPs, and although approximately one-third of individuals with ASD received at least one psychotropic drug prescription, these were mostly for stimulants, antiepileptic drugs and mood stabilisers, and antipsychotics. Furthermore, as people aged prescribing rates for risperidone remained high (whereas others decreased).

Our pilot study on the effectiveness of cognitive-behavioural therapy (CBT) treatment was comparable to clinical trials of obsessive-compulsive disorder (OCD) in people without ASD. Unexpectedly, however, anxiety management (AM) training was also effective in bringing about a reduction in OCD symptoms.

## Implications

1. Those who are prescribed antipsychotics are (relatively) unlikely to be taken off them.
2. People with ASD and ADHD are often not prescribed appropriate medications to treat common mental health symptoms.
3. AM training may allow more people to be treated (and at lower cost) for OCD in ASD, as it can be provided more simply and with a lower degree of staff expertise, than CBT.

## Conclusions

As individuals 'transition' their contact with treatment and support services reduces significantly. Needs-led services are required, which can both identify individuals with the 'core symptoms' of ASD and ADHD and treat their residual symptoms and associated conditions.

## Future work

To test our new diagnostic measures and treatment approaches in larger controlled trials.

## Trial registration

This trial is registered as ISRCTN87114880.

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