

Age appropriate services for young adults with neurodevelopmental disorders

Summary of research findings

Research supported by Big Lottery Fund

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Introduction

By 2015, Big Lottery Fund wants to have used funding to make a discernible impact on reducing problems associated with transition as a key theme of its work. Big Lottery Fund identified young adults with neurodevelopmental disorders as having needs that are unmet by current service provision, using previous evidence collected by the Young Foundation (2009). In January 2010, BIG commissioned ECOTEC to conduct research intended to inform thinking about a potential stream of funding to support these groups. Neurodevelopmental problems arise from an impairment of the growth and development of the brain or central nervous system, affecting brain functioning with regard to emotion, learning and memory. Specifically this study explored autism spectrum disorder and ADHD. This brochure summarises the key research findings.

Autism affects around 1 in 100 of the population

Around 8% of the population demonstrate characteristics of ADHD

Aim of the research: to investigate the issues facing young people with an autism spectrum disorder (ASD) or attention deficit hyperactivity disorder (ADHD) who are about to make, or who have recently made, the transition to adulthood, in particular looking at age-appropriate support for those groups.

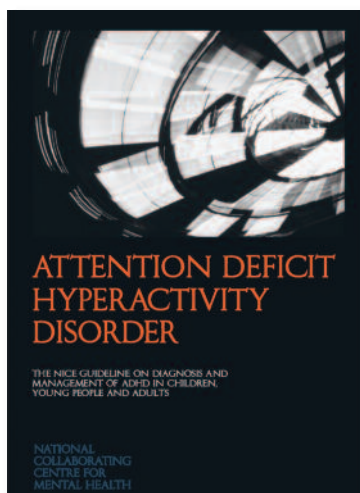
Method: a short scoping review of relevant literature; consultations with 19 staff and stakeholders working in the sector and 43 young people aged 17-25 who were in transition, or had transitioned, to adulthood.

Key findings

Transition to adulthood is a major challenge for young people with neurodevelopmental difficulties; young people with ADHD and those with autism face difficult transitions that place them at added risk. Gaps exist in statutory services for young people aged 16 upwards, so in many cases, young people aged 17–25 with ADHD or autism (particularly those with high functioning autism and Aspergers) are too old for Child and Adolescent Mental Health Services (CAMHS) and don't qualify for adult mental health or Special Educational Needs (SEN) services.

Recent policy advances:

- ADHD was only recently recognised as persisting into adulthood.
- National Institute for Clinical Excellence published guidelines (2009) recommending a process for smooth transition to adult services; however since the guidelines are so newly established, health services across the country are still developing their service response.
- The new Autism Act (2010) required the government to publish the Autism Strategy (2010). It aims to ensure adults with autism can benefit fully from mainstream services.



Current statutory sector provision

// What you have is a Catch 22 situation, and it will take time to resolve this even though the Act sets out that it must be resolved. If you have neither a mental health condition nor a learning disability, and many people with autism have neither, they are of normal intelligence, they just have an ASD, then there's nothing for them because they fall between the learning disability teams and the mental health teams. //

(Stakeholder)

- Currently statutory sector provision for transition is patchy
- There are no relevant specialist adult services to meet people's needs
- When young people are eligible for Special Educational Needs (SEN) support, transition planning is statutory
- There are gaps in support for young people with ADHD or with high functioning autism (including Aspergers)
- People fall between the gaps in statutory mental health and Special Educational Needs (SEN) services
- Mainstream services should cater for needs but lack awareness and understanding of the disorders

Current voluntary sector provision

The voluntary sector plays an important role for both disorders around providing services and raising awareness. There are however significant differences between the sectors that are relevant to potential funding decisions. Evidence from this study suggests the voluntary sector for autism is fairly patchy and localised. One major national charity (The National Autistic Society) provides focus as well as a number of regional bodies.

The voluntary sector for ADHD is also patchy and is less mature. There is no large scale national body; fewer organisations are formally constituted, or have formal accounting procedures. In both sectors voluntary organisations deliver services funded through local authority or health commissioning (e.g. residential care or short breaks) and use fundraising to deliver other services.

There are issues for both sectors around the lack of a robust evidence base, limited experience of evaluation and around quality assurance and accreditation.

In relation to policy developments surrounding both ADHD and ASD, this study and the potential funding stream are very timely.

Transitional issues for young people

The key transitional issues expressed by young people were:

- **finding and staying in appropriate employment**

"If you are not in work, being in work will make the biggest difference to [our] lives, to help people with autism help themselves." (Young person with autism)

- **forming and maintaining social and personal relationships**

"Social isolation is a big issue for this group. They can often be at home with parents and live there until the parents die. Then there's nobody out there to support them." (Stakeholder)

- **accessing and completing further or higher education**

"I need help with staying in college. Every time there is a problem I seem to press the self destruct button... I fear one time I will capitulate and have life changing consequences." (Young person with Aspergers)

- **moving out from home and living independently**

"I'm most worried about leaving home and coping on my own ... I'm dependent on my parents so life on my own is going to be a shock." (Young person with ADHD and Aspergers)

- **learning life skills such as money management, using transport and doing your own cooking, washing or cleaning.**

"I don't think I could deal with the pressure of having to cook a meal every night. I need the time and space to be alone and re-charge after being out in the social world." (Young person with autism)



Appropriate services

Young people suggested a range of activities or services that they would welcome, including:

- **awareness raising:** around mainstream services that young people come into contact with during transition (for instance further and higher education, Connexions and Jobcentre Plus) to help them meet the needs of young people with ADHD or autism
- access to high quality **information advice and guidance**
- **mentoring and buddy schemes:** having someone there as much or as little as needed
- **support networks:** and opportunities to socialise with peers
- **involvement:** in terms of giving young people a say about services
- **support:** in helping young people navigate systems, fill in forms and attend appointments
- **training:** to help develop skills such as money management and using public transport

Effective services for young adults with ADHD and autism might be characterised by:

Flexibility – there is no 'one size fits all' and needs of those on the autistic spectrum will vary greatly

Need – based on local need assessments and good data about numbers of those in need

Joining up – joint working between local statutory and voluntary services

Staff trained specifically on ADHD and autism and how to work with people with the disorders

Quality – offering a consistent 'standard' of service to all young adults with autism and ADHD

Timely – allowing adequate time for preparation for transitions e.g. into work or further education

Delivered in non stigmatising environments

Consultation – involving young people effectively in service design and delivery

Age appropriate – considering what young people aged 16-25 years would like and offering the same

Recommendations to Funders

Raising awareness of the needs of young people with ADHD and autism is a key area where funders could explore ways of using their influence. Funders might consider providing strategic funding that supports improved outcomes for young people with ADHD and autism.

Any funding should have at its heart a commitment to filling gaps and adding value to services already in place, and contributing to the currently limited evidence base on what models and interventions work best and why.

Characteristics of any potential funding could include:

- improving outcomes around life chances, access to work, education, life skills and social support for young people with ADHD and autism aged 16-25
- targeting young people with high functioning autism, Aspergers and ADHD where gaps in support currently exist
- supporting applications from voluntary sector organisations or from partnerships led by the voluntary sector working with local mainstream statutory services
- promoting local assessment of needs
- supporting national, regional and local projects or services
- grants of minimum 1 and maximum of 5 years long to enable organisations to test new models, deliver within an adequate timeframe and offer a quality service
- awareness raising activities such as training for staff in mainstream services, that complement existing statutory provision and latest legislation and guidelines
- providing activities like life skills, social support, mentoring and support for finding and staying in work or education
- activities that are delivered in age appropriate settings and that follow and develop elements of accepted good practice.

Funders might consider funding 'development support' work to build capacity in the voluntary sector for ADHD and autism. This will assist organisations in putting applications together and help ensure strategic fit with local mainstream statutory provision.

Involving stakeholders in a reference group or as brokers to provide support might help support parts of the voluntary sector.

Funders could also support projects that effectively engage and involve young people in service design and delivery.

Sources

Audit Commission (2009) 'Supporting people with autism through adulthood.'

Department of Health (2010) 'Fulfilling and Rewarding Lives. The strategy for Adults with Autism in England'.

National Institute for Clinical Excellence (2009) 'ADHD Guidelines: young people and adults'.

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To download a copy of the report visit www.biglotteryfund.org.uk

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