acer Autism Centre for
Education and Research

HEAR ME OUT!

Supporting young people (16-18) on the Autism Spectrum living in Warwickshire: an evaluation of the adult model

Summary Report

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Acknowledgements

Service users

The voice of young people and adults on the autism spectrum and their families/carers has been a key element of this evaluation, and the team would like to acknowledge your essential and invaluable contribution; your opinions, ideas and description of your support experiences have been of immense importance in helping us work towards our responsibilities in respect of the Autism Strategy. You have used a range of ways to express yourselves, and this will enable service providers to understand your challenges better and to work with you to improve your support services.

Staff

Many staff, both in front of and behind the scenes, have been involved in this evaluation. An enormous thank you goes to everybody for contributing that extra time in an already busy week. In particular, mention should go to Donna Kilgour, Adrian Hutchins and Sam Burkin, without whose assistance, service users would not have been able to participate in this evaluation of their support.

Autism west midlands

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front cover:

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Executive summary

Introduction

Research has shown that poor adult outcome in autism is related to a failure to understand their support needs and the challenges of daily living (Howlin, 2000). Lack of support often leads to exclusion from social and educational settings, which impacts negatively on future employment and independent living prospects (Passey, 2010). How successful individuals and families are at dealing with their individual challenges depends greatly on the support and understanding they encounter within their micro and macro social worlds. Support is thus needed to help combat isolation, deal with independent living and access appropriate and rewarding employment:

'I have Asperger syndrome. I have been out of college for 4 and a half years now and don't work. My high anxiety and low stress tolerance mean that I find it very difficult to function well or comfortably in most social situations……The support that has been given to me has helped me to be where I am today, in permanent accommodation, and will continue to help me find employment and how to deal with my independence' (adult male with Asperger syndrome).

Autism-specific legislation *(Fulfilling and Rewarding Lives: the strategy for adults with autism in England, 2010)* places a responsibility on local authorities and health bodies to make provision for people on the autism spectrum. Engaging the voice of people on the autism spectrum concerning their needs is a central element of the strategy.

Warwickshire Social Care responded to the Autism Strategy in 2009 by consulting with people on the autism spectrum and their parents/carers. Warwickshire then set up a service for adults on the autism spectrum aged 18 years and over in 2009. This service was deemed to be successful, and so the Integrated Disability Service (IDS) was keen to extend and test the model for 16-18 year olds on the autism spectrum who were either in college or NEET (not in education, employment or training). The IDS were keen to assess whether preventative work would reduce the need for support at a later stage. Warwickshire is particularly concerned about individuals at the higher end of the spectrum, including those with Asperger syndrome, who do not meet Fair Access to Care Services (FACS) criteria set by the Council in relation to social care, yet still have unmet needs.

This study

A successful bid to Aiming High for Disabled People provided funding to enable the IDS to implement a pilot study to evaluate the service. The Autism Centre for Education and Research (ACER) at the University of Birmingham was asked to conduct this study. The purpose of the evaluation was to consider the suitability of the support model used by the Adult Autism and Asperger Service for 16-18 year olds who are in college or NEET. This entailed evaluation of what support the Adult Autism and Asperger Service provided for adults aged 18 and over; assessment of how this support was delivered, and by whom; consideration of how well the model worked with the 16-18 year olds and identification of the issues in providing this service for the 16-18 year olds. Views on the success of the model were obtained from people on the autism spectrum in receipt of the support from both the 16-18 and post 18 age groups, parents/carers, and professionals. In total, 21 service users, 23 parent/carers and 14 professionals provided information. These voices lay the foundations for future developments for this service and have implications for national development in relation to young people and adults on the autism spectrum.

Taking into consideration the different communication preferences (Hill, 2006) and social challenges faced by people on the autism spectrum around transition (Cameron and Murphy, 2002), a range of tools was developed to access their voices. These included photomontages, narrative diaries, interviews, stories, questionnaires and documentary analysis.

Main Findings

The methods were quick and easy to use, although many individuals on the spectrum found it difficult to participate and therefore needed support to make that initial step into engaging with the study. Factors which affected their engagement were the time frame imposed by the study's funding, demands for support made on staff additional to their daily workload and general anxieties experienced by people on the spectrum around engaging in a new activity and meeting a new person. That said, participants were nevertheless able to provide clear, detailed information concerning support needs and solutions in a very short space of time. They wanted to engage in the evaluation, and were able to use the methods offered to visualise their feelings, to reflect on support they needed and to comment on what they would like to achieve if support were to be provided. Young people and adults were able to give real insight and understanding about how their autism/Asperger syndrome impacts on them and their ability to engage with other people and activities.

The researcher (Susy Ridout) successfully engaged the participation of adults (post 18) and teenagers (16-18), and feedback from individuals highlighted the importance of offering mixed-methods over an appropriate time span. This encouraged people with differing preferences of expressing themselves and provided some opportunity for them to deal with anxieties that might arise around how they wish to engage in the activity and when, thus providing a more accurate record of their views. This points to an important area for future development in terms of implementing *Fulfilling and Rewarding Lives (2010)* and engaging with service users as the methods used showed potential for future development. The fact that service users contributes is a major finding of this study and shows that if methods are used which recognize their difficulties in expressing their opinions, people on the autism spectrum can and should be effective advisors.

In terms of the support service, there were 11 staff involved with the IDS 16-18 Autism pilot:

- IDS manager (overseeing and managing the pilot)
- Operations manager (co-ordinating, meetings, engaging staff, administration)
- Transitions Co-ordinator (administration and support worker)
- 5 additional support workers
- Advisory team (the 3 team members from the Adult Autism and Asperger Service)

The team offered an initial assessment of support needs and then support for a period of time ranging from October to March depending on when the young person engaged with the service and the support need(s) and goals identified. Support was available for each young person for a maximum of 3 hours per week, and in the majority of cases occurred at evenings or weekends due to college commitments.

In contrast, the Adult Autism and Asperger Service had a manager and two support workers who dealt with all aspects of this support service for adults. They had over ten times the number of clients as engaged in the IDS 16-18 Autism Pilot, and had intermittent administrative support. Both teams were extremely committed, yet encountered considerable difficulties as colleagues in other key services are not sufficiently trained in autism awareness.

Since its initiation in 2009, the Warwickshire Adult Autism and Asperger Service has supported 80 adults (aged 18 +) in 4 key areas:

- managing anxiety and depression
- accessing the community
- employment/benefits

developing independent living skills.

The IDS 16-18 Autism Pilot provided support in 7 key areas:

- getting out into the community
- managing anxiety and stress
- relationships
- employment
- looking after yourself
- new activities

- funding new activities (through the Individual Budget Pilot)

The pilot support model implemented with the 16-18 year olds was successful in recruiting 7 young people. One of these young men said:

> *'I found it very helpful and do not think I would be doing the activities I'm accessing without the support'.*

The areas that young people found most useful were:

- help accessing and engaging in activities
- school support
- managing anxiety
- building confidence
- accessing information
- discussing their needs (present and future)

Families and carers of young people and adults on the autism spectrum highlighted that many have support needs directly related to frustrations and stresses concerning the current support needs and the future of their family member(s). They reported that they often feel overwhelmed by inconsistent and poorly targeted support: and that provision of support needs to be clear and co-ordinated:

> *I feel there are too many 'satellites' (my word) for the various organizations dealing with disadvantaged teenagers'* (carer of a 17 year old on the autism spectrum).

Many felt that the responsibility for support rests predominantly on the shoulders of parents and carers, and that the balance needs to be addressed, in line with *'Fulfilling and Rewarding Lives (2010):*

> *'We as carers (parents) feel we are being ignored. We have the stress that it all entails, but nobody does anything for us'* (parent of an adult on the autism spectrum).
>
> *'A member of the team supported my son to complete a job application and attend a job interview, which he would have been unable to do without support…'* (parent of an adult on the autism spectrum).

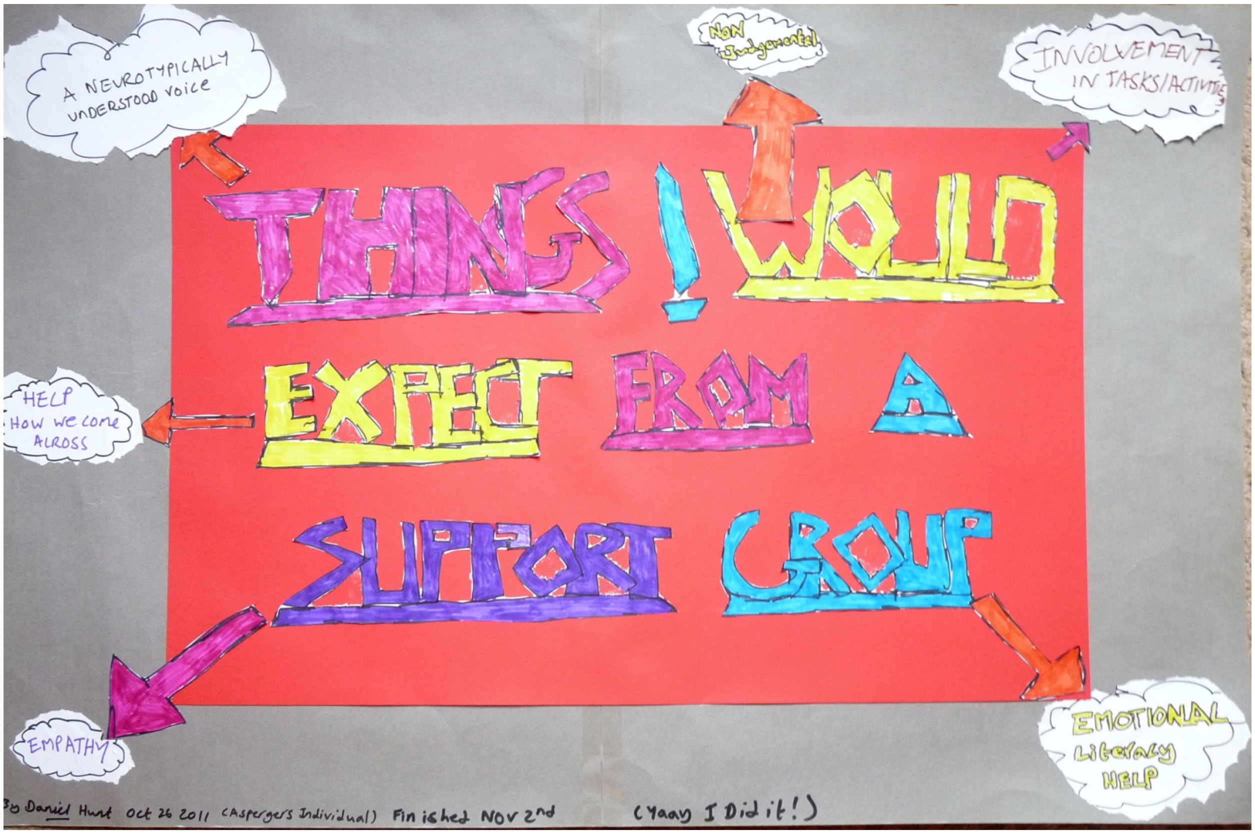
Conclusion

The support model being provided to adults is appropriate for young people (16-18), although consideration needs to be taken into account as to how to involve parents/carers. The time frame did not allow support workers to explore anxieties experienced by young people in depth, or issues related to planning for the future and independent living, including employment opportunities. These were two key support areas for adults, and there was clear indication that intervention at an earlier stage with young people would be more cost-effective in the long-term. This was evidenced by comparing the data provided from the two support services, and an example of this is where assisting young people to access activities and relevant and appropriate employment would help combat the reported isolation experienced by adults and a reliance on more costly support provided by the benefits system and mental health teams.

The importance of the in-depth information readily provided when individuals on the spectrum and their parents/carers were offered an opportunity to express their views should not be ignored. People on the autism spectrum often need more time to engage in consultation activities, and this was reflected in the overall numbers of participants. Nevertheless, the methods used offer plenty of scope for further exploration in the process of consulting with individuals on the autism spectrum and their families and carers to provide appropriate services.

Establishment of a management partnership between IDS and the Adult Autism and Asperger Service led by IDS and involving the Transitions Co-ordinator. The support service for the 16-18 year olds should be developed working to the strengths that exist within both the IDS and the Adult Autism and Asperger Service. The strengths of each team compliment those of the other, and would enable Warwickshire to build a seamless service provision for people on the autism spectrum. Both teams have skilled, focused and committed staff, and they need to have a clear lead with sufficient time and support to develop this service and build on the strengths that already exist. The demand for the adult service and the extent of the support required is a clear indicator that preventative support at an earlier stage is essential in helping people on the autism spectrum achieve their chosen lifestyle, living as independently as possible.

There is a clear need for a support service of this type; a service that takes note of the time it takes individuals on the autism spectrum to engage in support, build good working relationships with staff, and learn new skills. There is a clear need to recognise the very real skills that individuals with autism have to offer, and to include them in all aspects of community life. Most importantly, there is a need to take the time to ask and listen to the voices of individuals and families affected by autism, to understand their needs and to act accordingly. Warwickshire is well-placed to do this. Consistent support now needs to come from the Local Authority and Health Services by recognising that it is more cost-effective to train staff in autism awareness across all services to implement the requirements set out in *Fulfilling and Rewarding Lives: the strategy for adults with autism in England (2010)* and provide support for the many people on the autism spectrum with different skills and abilities who are able and willing to contribute to society.



References

Autism Act (2009) London: The Stationary Office.

Barnard, J., Harvey, V., Potter, D. and Prior, A. (2001) Ignored or ineligible? The reality for adults with autistic spectrum disorders. **London: National Autistic Society.**

Billington, T. (2006) Working with autistic children and young people: sense, experience and the challenges for services, policies and practices. **Disability and Society 21 (1): 1-13.**

Cameron, L. and Murphy, J. (2002) Enabling young people with a learning disability to make choices at the time of transition. **British Journal of Learning Disabilities 30: 105-112.**

DCSF (2008) **Working Together: listening to the voices of children and young people.** London: DCSF.

DfES (2001) **SEN Code of Practice.** Nottingham: DfES Publications.

DoH (2001) **Valuing People: a new strategy for learning disability for the 21st Century.** London: Department of Health.

DoH (2003) **Fair Access to Care Services: guidance on eligibility criteria for adult social care.** London: The Stationary Office.

DoH (2010) **Fulfilling and Rewarding Lives: the strategy for adults with autism in England.** London: The Stationary Office.

DoH (2010) **Implementing “Fulfilling and rewarding lives”: statutory guidance for local authorities and NHS organizations to support implementation of the autism strategy.** London: The Stationary Office.

Eaves, L.C. and Ho, H.H. (2008) Young adult outcome of autism spectrum disorders. **Journal of Autism and Developmental Disorders 38: 739-747.**

Equality Act (2010) London: The Stationary Office.

Ghaziuddin, M., Ghaziuddin, N. and Greden, J. (2002) Depression in persons with autism: implications for research and clinical care. **Journal of Autism and Developmental Disorders 32 (4): 299-306.**

Gillott, A. and Standen, P.J. (2007) Levels of anxiety and sources of stress in adults with autism. **Journal of Intellectual Disabilities 11 (4): 359-370.**

Graetz, J. (2010) Autism grows up: opportunities for adults with autism. **Disability and Society 25(1): 33-47.**

Hare, D.J., Pratt, C., Burton, M. Bromley, J. and Emerson, E. (2004) The health and social care needs of family carers supporting adults with autistic spectrum disorders. **Autism 8(4): 425-444.**

Hill, M. (2006) Children's voices on ways of having a voice: Children's and young people's perspectives on methods used in research and consultation. **Childhood 13: 69-83.**

Howard, B., Cohn, E. and Orsmond, G.I. (2006) Understanding and negotiating friendships: perspectives from an adolescent with Asperger syndrome. **Autism 10 (6): 619-627.**

Howlin, P. and Moore, A. (1997) Diagnosis in autism: A survey of over 1200 patients in the UK. **Autism 1 (2): 135-162.**

Howlin, P., Goode, S., Hutton, J. and Rutter, M. (2004) Adult outcomes for children with autism. **Journal of Child Psychology and Psychiatry 45: 212-29.**

Howlin, P., Alcock, J. and Burkin, C. (2005) An 8 year follow-up of a specialist supported employment service for high-ability adults with autism or Asperger syndrome. **Autism 9: 533-549.**

Humphrey, N. and Lewis, S. (2008) 'Make me normal': The views and experiences of pupils on the autistic spectrum in mainstream secondary schools. **Autism 12 (1): 23-46.**

Jones, G., English, A., Guldberg, K., Jordan, R., Richardson, P. and Waltz, M (2008) **Educational Provision for Children and Young People on the Autism Spectrum Living in England: a review of current practice, issues and challenges.** London: The Autism Education Trust. http://www.autismeducationtrust.org.uk

Lewis, A. (2010) Silence in the context of 'child voice'. **Children and Society 24: 14-23.**

Lewis, A. and Porter, J. (2004) **British Journal of Learning Disabilities 32: 191-197.**

Muller, E., Schuler, A. and Yates, G.B. (2008) Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities. **Autism 12: 173-190.**

National Autistic Society http://www.autism.org.uk

National Institute for Health and Clinical Excellence (2011) **Autism: recognition, referral and diagnosis of children and young people on the autism spectrum.** London: NICE publications.

Osborne, L.A. and Reed, P. (2008) Parent's perceptions of communication with professionals during the diagnosis of autism. **Autism 12 (3): 309-324.**

Orsmond, G.I., Kuo, H-Y., and Seltzer, M.M. (2009) Siblings of individuals with an autism spectrum disorder. **Autism 13 (1): 59-80.**

Plimley, L.A. (2007) A review of quality of life issues and people with autism spectrum disorders. **British Journal of learning Disabilities 35: 205-213.**

Preece, D, and Jordan, R. (2007) Social workers' understanding of autistic spectrum disorders: and exploratory investigation. **British Journal of Social Work 37: 925-936.**

Tantum, D. (2000) Psychological disorder in adolescents and adults with Asperger syndrome. **Autism 4 (1): 47-62.**

Tidball, M. (2011) **Statutory Guidance and the Autism Strategy.** Autism West Midlands.

Veasey, S. (2011) Interview with Susy Ridout from the ACER team evaluating the Warwickshire Adult Autism and Asperger Support Service.

White, S.W. and Roberson-Nay, R. (2009) Anxiety, social deficits and loneliness in youth with autism spectrum disorders. **Journal of Autism and Developmental Disorders 39: 1006-1013.**

Williamson, S., Craig, J. and Slinger, R. (2008) Exploring the relationship between measures of self-esteem and psychological adjustment among adolescents with Asperger syndrome. **Autism 12 (4): 391-402.**

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