



# AUTISM

## **REPORT OF THE ADULTS AND HOUSING SCRUTINY COMMITTEE**

## **Introduction**

1. This is the final report of the Autism Review Group, established by the Adults and Housing Scrutiny Committee to look at the support and advice services available in Darlington for adults with autism.

## **Background Information**

2. All Members of the Adults and Housing Scrutiny Committee were invited to participate in the Review, which was led by Councillor Knowles.
3. The Review Group acknowledges the support and assistance provided in the course of their investigations and would like to place on record its thanks to the following :-
  - (a) Anne Tate, MAIN Project;
  - (b) Stuart Dexter, Chief Executive, Daisy Chain Project;
  - (c) Tracy Roberts, Darlington Association on Disability;
  - (d) Kevin Kelly, Head of Learning Disability and Mental Health, Darlington Borough Council;
  - (e) Mark Humble, (former Development and Commissioning Manager, Learning Disability and Mental Health; Darlington Borough Council);
  - (f) Gary Emmerson, MIND;
  - (g) North East Autistic Society;
  - (h) Helen Whitten, Manager of Resourced Based Provision for Children and Young People with ASD/Social Communication Needs and Social Communication Outreach Co-ordinator, Hurworth School;
  - (i) Jacqui Dyson, Autism Strategy Manager, Tees, Esk and Wear Valley's NHS Foundation Trust;
  - (j) Sheila Halpin, Head of Adult Learning Disability Services (Durham and Darlington) Tees, Esk and Wear Valley's NHS Foundation Trust;
  - (k) Sarah Gibbon, Senior Practitioner, Life Stages Service, Darlington Borough Council;
  - (l) Helen Whiting, Human Resource Manager (Policy and Strategy), Darlington Borough Council;
  - (m) Lead Community Partner, Department for Works and Pensions

## **Structure of Report**

4. This report is a brief summary of the evidence considered by the Review Group with the main recommendations arising.

5. The report covers :-

- (a) Terms of Reference
- (b) Methods of Investigation
- (c) What is Autism
- (d) What Causes Autism
- (e) Is there a Cure?
- (f) Characteristics of Autism
- (g) Diagnostics and Signposting
- (h) Training of Health Professionals who Provide Services to Adults with Autism
- (i) Support through Transition
- (j) Employability and Supporting People with Autism in the Workplace
- (k) Monitoring and Review of Recommendations

### **Terms of Reference**

6. The Terms of Reference for the Group were quite detailed, however, as we progressed with our review, our work became more focused on the employment and employability of those living with autism as a specific work strand.

### **Methods of Investigation**

7. The Review Group met on a number of occasions between June 2017 and March 2018.

8. The methods of scrutiny and types of evidence considered by the Group comprised :-

- (a) presentations by Council Officers and external partners;
- (b) site visits to meet providers of services and see the facilities offered to support people living with autism and their families;
- (c) research of a wide range of documents and background material.

9. A list of background papers used for consideration is set out in **Appendix 1**.

### **What is Autism?**

10. Autism is a lifelong development disability, sometimes referred to as an autism spectrum condition (ASC) or autism spectrum disorder (ASD). It affects the way a person communicates and relates to people around them.

11. The word 'spectrum' is used because all people with autism share three main areas of difficulty, but their condition will affect them in very different ways. For instance, some people are able to live relatively everyday lives whilst others will require a lifetime of specialist support.

12. Identifying that a person has autism can sometimes be difficult, as people with the condition do not 'look' disabled. Therefore, parents of children with autism often say that other people simply think their child is naughty, while adults believe they are misunderstood.

13. Adults with autism will have had very different experiences, depending on factors such as their position on the autistic spectrum, the professions they have come into contact with and even how and when they got their diagnosis.
14. Everyone with autism can benefit from a timely diagnosis and access to appropriate support services.

### **What Causes Autism?**

15. The exact cause of autism is still being investigated. However, research suggests that a combination of factors – genetic and environmental – may account for changes in brain development. People from all nationalities and cultural, religious and social backgrounds can have autism, although it appears to affect more men than women. It is not caused by person's upbringing or their social circumstances and is not the fault of the individual with the condition.

### **Is there a Cure?**

16. At present, there is no 'cure' for autism. However, there are a range of interventions, which enable learning and development that can be helpful for the individual.

### **Characteristics of Autism**

17. The characteristics of autism vary from one person to another, but are generally divided into three main difficulties, which are sometimes known as the 'triad of impairments': social communication, social interaction and social imagination.

#### **Social Communication**

- People with autism can have difficulties with the use and interpretation of both verbal and non-verbal language. This can cause difficulties in expressing themselves and understanding the intended language of others – for example, when using or interpreting facial expressions, tone of voice, jokes and sarcasm and common phrases or sayings.

#### **Social Interaction**

- Socialising is something that most people take for granted, but for someone with autism, understanding how to interact is a major barrier. The difficulty lies in the person not being able to recognise or understand others emotions and feelings and their inability to express their own. Some examples of this would be that they appear to be insensitive because they have not recognised how someone else is feeling, or appear to behave 'strangely' or inappropriately, as it is not always easy for them to express feelings, emotions or needs.

## **Social Imagination**

- This allows us to understand and predict others behaviour, make sense of abstract ideas and to imagine situation outside of our immediate daily routine. Difficulties with social imagination means that people with autism find it hard to understand and interpret others thoughts, understand the concept of danger, prepare for change and plan for the future and cope in new or unfamiliar surroundings.

18. In addition to the triad of impairments, other related characteristics include the love of routines, sensory sensitivity, special interests and learning disabilities.

## **Love of Routine**

- The world can seem a very unpredictable and confusing place to people with autism, who often prefer to have a fixed daily routine so that they know what is going to happen every day. Rules can also be important; it may be difficult for a person with autism to take a different approach to something once they have been taught the 'right' way to do it. People with autism may not be comfortable with the idea of change but can cope well if they are prepared for it in advance.

## **Sensory Sensitivity**

- People with autism may experience some form of sensory sensitivity. This can occur in one or more of the five senses – sight, sound, smell, touch and taste. A person's senses are either intensified (hypersensitive) or under-sensitive (hypo-sensitive). For instance, a person with autism may find certain background sounds, which other people ignore or block out, unbearably loud or distracting. This can cause anxiety or even physical pain. People who are hypo-sensitive may not feel pain or extremes of temperature. Some may rock, spin or flap their hands to stimulate sensation, to help with balance and posture or to deal with stress.

## **Special Interests**

- Many people with autism have intense special interest, often from a fairly young age. These can change over time or be lifelong and can be anything from art to music to trains or computers. Some people with autism may eventually be able to work or study in related areas, whilst for others it will remain a hobby.

## **Learning Disabilities**

- People with autism may have learning difficulties, which can affect all aspects of their lives, from studying in school to learning how to wash themselves or make a meal. As with autism, people can often have different degrees of learning disability, so some will be able to live fairly independently – although they may need a degree of support to achieve this – while others may require lifelong, specialist support. However, all people with autism can, and do, learn and develop with the right sort of support.

## **Diagnostics and Signposting**

19. It is thought that early interventions and interventions throughout childhood can have a significant bearing on the individual skills and abilities of adults with autism.
20. Some people enter adulthood without their condition being recognised and do not have a diagnosis, however, getting an diagnosis as an adult can often help a person and their families to understand the condition and work out what type of advice and support they need.
21. The Adult Autistic Spectrum Disorder diagnostic pathway in Darlington is a commissioned service through the Clinical Commissioning Groups, and is provided by Tees, Esk and Wear Valley NHS Foundation Trust. The assessment process is undertaken at its site in Stockton.
22. Darlington has above average waiting times for Adult Autism Diagnosis which are currently longer than the NICE recommended 3 months at 26 weeks between referral and assessment. Locally, this compares to 56 weeks for Durham, 20 weeks for Hartlepool and an average of 7 weeks for Stockton, Middlesbrough and Redcar and Cleveland.
23. Due to the extended wait for diagnosis it is important that whilst awaiting an assessment or undergoing the assessment process that people have access to services that meet their presenting needs regardless of whether a diagnosis is in place. Commissioners are working jointly with local providers to ensure that support is offered to individuals throughout the process.
24. In addition to accessing support services, Adults with Autism (diagnosed or not) are able to access crisis services. As part of the assessment, there is consideration given to a crisis management plan that is developed in conjunction with specialist mental health services. Currently, Darlington's provider of Crisis services Tees, Esk and Wear Valley NHS FT (TEWV) are embedding a 3 level training programme to ensure Adults with Autism are able to get the interventions required at the time they are required. Crisis services support people irrespective of an Autism diagnosis.
25. Depending on the needs of the individual, following diagnosis TEWV will signpost to various mainstream support organisations as well as arranging reasonably adjusted specialist assessments for a range of services including: Speech and Language Therapy, Psychology and Occupational Therapy. Recognising Autism and subsequent diagnosis is important in ensuring the support takes account of how a person's autism affects them and their family and it is important that the correct support is provided.
26. During its work, Darlington MIND have identified a need to support those individuals with higher-functioning Autism/Asperger's where the current provisions from learning disabilities providers doesn't really meet their needs.

## **Training of Health Professionals who Provide Services to Adults with Autism**

27. The Department of Health's Statutory Guidance for Local Authorities and NHS Organisations to support implementation of the Adult Autism Strategy, highlights the need for improved training around autism for all public service staff but particularly for those working in health and social care. The training should be delivered not only to those in the delivery of front line services but to those who may have another key role to play in making a more positive experience for adults with autism, such as those responsible for making adjustments to the environment to make it accessible for adults with autism.
28. In accordance with the guidance, Tees, Esk and Wear Valley's NHS Foundation Trust (TEWV) are undertaking a programme of autism awareness training for all staff, as part of its general equality and diversity training programme, which is proving very successful and positive feedback is being received. One of our Members attended a training session provided by TEWV.
29. Darlington Borough Council also runs a number of training courses to support its professionals in working with both children and adults with autism. The sessions are run by an external provider and are bespoke to the target audience, for example, one of the sessions was particularly targeted at housing staff and focussed on the issues that tenants with autism may experience. Positive feedback is received from these sessions.
30. Additional sessions aimed at enhancing awareness of social communication difficulties and looking at strategies that could be used to support professionals are also planned.

## **Support Through Transition**

31. We met with Helen Whitten, Manager of the Resource Based Provision and the Social Communication Outreach Co-ordinator, at Hurworth School. We discussed the strategies in use to support the transition of children and young people with ASD and/or social communication difficulties, into college or employment.
32. The Hurworth Resource Base is delivered through a contractual arrangement between the local authority and SWIFT Academies, the sponsor academy for Hurworth School. The Academy is commissioned to provide 14 places for children and young people with both ASD diagnosis and social and communication needs. The funding is set by the Education Skills and Funding Agency at £6,000 per place plus top up funding which is currently £6,992.10 per pupil. Each pupil also attracts an 'average weighted pupil unit'. The current SEND Strategy and funding review is consulting on a new funding structure, which may affect the top up funding for resource bases.
33. We also met with Officers of the Council from the Lifestages Service to ascertain the work Darlington Borough Council undertakes both with individuals to support them through transition and help them into employment and in engaging with employers to seek opportunities.

## **Employability and Supporting People with Autism in the Workplace**

34. Adults with autism are currently significantly under-represented in the labour market which has a detrimental impact on their financial circumstances and social inclusion as well as a waste of skills and abilities. By making some adjustments in the workplace, it could provide a person with autism with the environment and support they need to excel at their job. The type and level of support required will depend on the person's individual needs.
35. Most people with autism want to work, however, it can be difficult for them to find a job, they might find the work environment too noisy, or travelling to work may be too stressful because of crowds and sudden changes to routine can also be upsetting. People with autism have some very valuable skills and talents and can make effective and highly valued employees. People with autism are often focused and have considerable skills in specific areas, some of the transferable skills include attention to detail, a methodical approach, strong research skills, good long-term memory and excellent record-keeping.
36. Although they have a great deal to offer to employers, getting a job in the first place can be hard. Simple adjustments at the recruitment stage can make the process of applying for jobs much more accessible.
37. We looked at the actions and commitments within the Autism 2010 Strategy and Think Autism which aimed to increase the number of adults with autism in work through the provision of guidance and training to employers and employment support services and ensure that they benefit from employment initiatives.
38. We contacted the Department for Works and Pensions (DWP) to obtain information on the work and activities it was undertaking to help unemployed people who were on the autistic spectrum to find and remain in employment and we received a very detailed response which outlined the work and many initiatives they undertook.
39. Other organisations such as MAIN, Daisy Chain and the North East Autistic Society do support adults with autism to find and retain employment and also work closely with employers and with the DWP on employment projects. We visited the facilities provided by the North East Autistic Society and Daisy Chain as part of our review.
40. We drafted and circulated, through a newsletter which goes to local businesses once a month, a questionnaire seeking their views on the employability of adults with autism, however, we received a very disappointing response rate.

## **Monitoring and Review of Recommendations**

41. As a result of this Scrutiny Review, we have identified a number of recommendations which we hope will enhance and support the services already provided.



## Recommendations

42. That, taking into account the information and evidence obtained, this Task and Finish Review Group is relatively satisfied with the support services in Darlington for people with autism, however, it would wish to make the following recommendations :-

- (i) a review of the TEWV Adult Autism Spectrum Diagnosis pathway be undertaken considering the increase in demand and how this can be managed through a range of support services across the Health and Social Care system;
- (ii) in relation to waiting time reduction and interim contingency, the workforce development programme be continued to support teams in their ability to provide services in response to need;
- (iii) that knowledge of ASD be promoted within Primary Care to facilitate gateway into services that exist from provider trusts. Ongoing developments around the GP Practice Equalities Champion role, should become an integral role to support this within Primary Care;
- (iv) work around reasonable adjustments within all provider trust(s) and within the wider Health and Social Care workforce, through various partnership forums, be promoted;
- (v) that the Darlington Learning Impairment Network, with appropriate representation from the Local Authority, the Clinical Commissioning Group, Elected Members as well as Health and Third Sector support providers, be re-established to ensure that there continues to be close interagency working between partners and stakeholders; and
- (vi) meaningful engagement be undertaken with individuals and their parents and carers in relation to individual care planning and review.

## **APPENDIX 1**

### **Background Papers**

Autism Self-assessment Framework 2015/16

Think Autism – April 2014

NICE Clinical Guidelines

Department of Health Statutory Guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy 2015

Employability Survey

Letter dated 27 April, 2018 from the Department for Works and Pensions

### **Visits**

Daisy Chain Project

North East Autistic Society