



Nottinghamshire  
County Council

Adult Social Care & Health

Commissioning Strategy

Chapter Six

2007 - 2009



# Commissioning Strategy for People with Aspergers Disorder



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# 1 INTRODUCTION

This strategy has been developed in partnership with Nottinghamshire PCT and encompasses the social care commissioning intentions of Nottinghamshire County Council.

The strategy forms chapter six of the Nottinghamshire County Council Department of Adult social care and Health two year commissioning strategy 2007 – 2009.

Asperger's syndrome is an autistic spectrum disorder. The core features of autism are "impairments in socialisation, communication and imagination"<sup>1</sup>. People with Asperger's syndrome share these features and are usually of average or above average ability and have good spoken language. This level of ability means that they are capable of living independently and, in some cases, achieving a high level of academic success, but this, "does not necessarily ensure that life will be easier for them. Each step towards independence is accompanied by new pitfalls."<sup>2</sup> People with Asperger's find it hard, or are unable, to learn the social rules that most people take for granted; they may take instructions literally or show little empathy or understanding in their dealings with others. They may appear "odd", find it difficult to make friends and relationships and be vulnerable to exploitation. Mental health problems, particularly depression, self harm and suicide, are common amongst this group of people.<sup>3</sup>

## 2 KEY DRIVERS

### 2.1 Relevant Legislation and National guidance

Valuing People Implementation Guidance

*"Adults with Asperger's Syndrome or higher functioning autism are not precluded from using learning disability services, and may, where appropriate, require an assessment of their social functioning and social skills in order to establish their level of need."*<sup>4</sup>

NHSCCA 1990 & FACS

Adults with Asperger's have a right to assessment under the NHS and Community Care Act 1990, which is further enhanced by the Fair Access to Care Services guidance. This guidance requires us to "set a low threshold" for assessment.

The Department of Health have set out a Specialist Service National Definition Set. The definitions identify activity that should be regarded as specialised and therefore subject to collaborative commissioning arrangements. Specialist Learning Disability Services and Specialist Mental Health Services definitions note, "Asperger's Syndrome" gives a general description rationale for service being included in the specialist service definition set, detailed description of specialist activity, outpatient, liaison, inpatient and day services education and training.

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<sup>1</sup> Autism and Asperger Syndrome, Cambridge University Press 1997, edited by Uta Frith, page 2

<sup>2</sup> Ditto, Living with Asperger's Syndrome, Margaret Dewey, page 195

<sup>3</sup> Asperger Syndrome, Hansard's account of a debate in the House of Commons, October 2001

<sup>4</sup> HSC 2001/016: LAC(2001)23, page 5

## **2.2 Local Factors**

### **2.2.1 The Commissioning Environment**

Nottinghamshire County Council, and the Nottinghamshire Primary Care trusts are committed to working together to provide joint commissioning strategies for adult care services.

Although falling outside of existing care provisions, people with Asperger's Syndrome often receive services provided for people with learning disabilities, mental illness or physical and other illnesses and disabilities. Ill prepared to meet the demands of people with Aspergers, these services struggle to meet the needs these of individuals. People may not meet the eligibility criteria for care services and, if they do, the right type of services may not be available to them.

## **3 CURRENT SERVICE PROVISION**

### **3.1 Supporting Carers and Families**

People with Asperger's and their families may be left to cope alone until a crisis occurs. The lack of a co-ordinated service response across both adults and children's services has been highlighted in a number of reports including:

- The Hansard account of a debate in the House of Commons in October 2001
- Taking Responsibility, Good Practice Guidelines for services – adults with Asperger Syndrome, The National Autistic Society, 2002
- National Audit of Support, Services and Provision for Children with Low Incidence Needs, DfES, 2006

The Hansard report says,

*"The key requirements are recognition of the condition; appropriate support before a crisis occurs; and an understanding from professionals and statutory bodies that they cannot provide services in the short term and then walk away....If social services departments were to take the advice from those who specialise in the issue to set up a strategy to support adults with Asperger Syndrome, they would find that lurching from crisis to crisis is not the only option. There are ways of supporting people and improving their quality of life."*<sup>5</sup>

### **3.2 Advocacy services**

A comprehensive advocacy services review, consultation and service re-tendering was undertaken during 2004-5.

A newly specified service commenced on April 1<sup>st</sup> 2006 offering one to one advocacy services provided by paid advocates, targeting the most vulnerable groups. The service specification was based on extensive service user, carer and staff consultation. The development of the advocacy services is now steered by a multi-stakeholder group, the Advocacy Development Group (ADG). Whilst aimed toward people with learning disabilities and mental health needs, people with Aspergers syndrome and their families should have advocacy services made available to them.

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<sup>5</sup> Ditto

### **3.3 Housing and Supporting People Funded Provision**

Tomorrow's Big Problem; housing options for people with autism, The National Autistic Society states, The challenge over the next five years is:

- a better understanding of the range of existing need and provision
- an improvement in the choice available
- information and help for people and their families seeking to plan for the future
- strategies for services in the light of valuing people to include autism
- to use the supporting people programme for a wide range of housing need

### **3.4 Community Care (non-residential)**

There area currently no dedicated supported living or domiciliary services for people with Aspergers. Recent developments in Nottinghamshire County include the Autism Outreach service and the Autism day service commissioned through a local independent specialist Autism provider. Some services are provided to a few individuals through the community learning disability services, and fewer still through community mental health services. For these existing services to continue to include support to people with Asperger's syndrome there would be significant training and development needs.

Direct payments have also been effectively utilised to provide community care services to people with Asperger's Syndrome in some instances. Direct Payments can provide more flexible person centred packages of care to address individual need, which more traditional social care services are unable to provide.

### **3.5 Residential and nursing home placements**

Whilst there are no specific services for people with Aspergers syndrome, there are a small number of services which cater for the needs of people with Autistic Spectrum disorders.

The commissioning of residential care services is currently encompassed by mental health and learning disability services. The number of placements is small, but often highly specialised, requiring placement outside of the Nottinghamshire County area.

### **3.6 Assessment and Care Management Service**

The Implementation Guidance for Valuing People places responsibility with learning disability services for the assessment of some people with Asperger's syndrome where those people also have a learning disability.

Currently people with Asperger's may have a community care assessment using one of three assessment tools; SNAP (Single Nottinghamshire Assessment), the learning disability assessment or the mental health assessment. A clear pathway for assessment needs to be established and this includes identifying or developing one appropriate assessment tool. The care management responsibility and provision of service is often dependent on how the individual accesses services and upon the willingness of individual services to respond.

### **3.7 User and Carer Involvement**

There are currently no user, family or carer support groups within Nottinghamshire focussing on the needs of people with Aspergers. Groups centred on learning disability mental health and autistic spectrum disorders are in place but the extent to which these groups provide representation or support is unknown. The National Autistic Society in Nottingham has a user group for people with Autistic Spectrum disorders and there are parent groups for families of young people north of the county.

### **3.8 Community Health Services**

Identification in Primary Care of people with behaviours which might indicate Asperger's is variable, with developmental issues mainly identified via Health Visitors or Community Paediatricians. Practitioners in Primary Care are reported to feel in need of clear pathways to diagnosis and subsequent treatment/support.

Secondary care services are provided by the Nottinghamshire Healthcare NHS Trust, directorates of mental health and learning disabilities respectively. It is difficult to calculate the number of people being treated or diagnosed with Aspergers disorder as diagnostic categorisation for this group of people covers all autistic spectrum disorders. The Trust provides for a range of services including consultant medical and psychological therapies, community nursing, occupational therapy and speech and language therapy. These services are not dedicated to the needs of people with Aspergers.

Research on current costs of specialist diagnosis suggests that local services are paying between £400 and £3500 for out of area assessment. There are number of clinicians within the Trust who are trained in DISCO assessments, which can be used across the autistic spectrum, including Asperger's syndrome. The distinction may be between autism and Asperger's syndrome, and the current lack of expertise in Asperger's specifically.

By bringing together professionals from different teams and backgrounds, a multi agency panel in the Newark area has been shown to have achieved positive outcomes for people whose needs have been unable to be met by a single agency or individual.

### **3.9 In Patient Assessment and Treatment**

People with Aspergers disorder will normally be accommodated on mental health acute admission wards where they require admission for mental health, behavioural, or psychological needs. The needs of people with a diagnosis of Aspergers disorder are varied; however the disorder itself will not normally require inpatient treatment. There do appear to be high levels of dual needs with mental ill health and learning disability for which inpatient care may be required. There are no dedicated or specialist inpatient services or facilities in the local area.

## **4 ACHIEVEMENTS**

### **4.1 The County Council Vulnerable Adults Policy**

Vulnerable adult workers based in locality care management teams provide for assessment, preventative and short term intervention to people who may not meet the eligibility criteria for specialist services. The service also provides a signposting and liaison service for people whose needs may not be fully apparent on first contact. The vulnerable adult's workers provide for a number of people with Aspergers Disorder

## 4.2 Outcome of Previous Strategies

This document is the first discrete strategy for people with Aspergers syndrome in the Nottinghamshire area. Previous mental health and learning disability strategies have implicitly covered people with autistic spectrum disorders, without making explicit reference to their needs.

## 5 PERFORMANCE AND ACTIVITY

### 5.1 National Prevalence

(taken from the National Autistic Society Website)

There are varying estimates of the prevalence of Asperger's syndrome. The report by the National Autistic Society quotes a study that gives prevalence as approximately 1 in 300 people, with more males than females affected.<sup>6</sup>

#### 5.1.1.1 Estimated prevalence rates in the UK

Estimated prevalence rates of autistic spectrum disorders in the UK	
People with learning disabilities (IQ under 70)	Approximate rates per 10,000
Kanner syndrome	5
Other spectrum disorders	15
<b>Total</b>	<b>20</b>
People with average or high ability (IQ 70 or above)	
Asperger syndrome	
Other spectrum disorders	36
<b>Total</b>	<b>35</b>
	<b>71</b>
<b>Possible total prevalence rate of all autistic spectrum disorders</b>	<b>91</b>

There are no sharp boundaries separating 'typical' autism from other autistic disorders, including Asperger Syndrome. For a complete overview of the problems of establishing prevalence rates and the difficulties of diagnosing and defining autism, see Wing (1993)]. Further references can be found at;

Frith, U. (2004). Emanuel Miller lecture: Confusions and controversies about Asperger syndrome. *Journal of Child Psychology and Psychiatry*, 45 (4), 672-686

<sup>6</sup> Taking Responsibility, National Autistic Society, 2002, page 3  
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Wing, L. (2005). Opening Pandora's box. *Journal of Autism and Developmental Disorders*, 35(2):197-203.

The best estimates of the total prevalence of autistic spectrum disorders are those based on the Camberwell and Gothenburg studies, because these focused on the whole spectrum and not just specific sub-groups.

### 5.1.2 Estimated population of autistic spectrum disorders in the UK

The estimate of **535,000** people with autistic spectrum disorders is a combination of the total figures in the tables below.

#### 5.1.3 Table 2

<b>Estimated population of autistic spectrum disorders in the UK</b>		
<b>People with learning disabilities</b> (IQ under 70) <i>(Note 1: Almost all of these people will require a high level of support throughout their lives)</i>		
	Kanner syndrome	Other spectrum disorders
Children	6,700	20,000
Adults	22,700	68,200
All ages	29,400	88,200
<b>Total</b>	<b>117,600</b>	
<b>People with average or high ability</b> (IQ 70 or above). <i>(Note 2: Many, perhaps most of these people, will become semi or fully independent as adults but need understanding and help as children)</i>		
	Asperger syndrome	Other spectrum disorders
Children	48,100	46,700
Adults	163,600	159,000
All ages	211,700	205,700
<b>Total</b>	<b>417,400</b>	

## 5.2 Local prevalence

A comprehensive needs assessment is required to determine the level of need in adults with Aspergers living in the greater Nottinghamshire area. However based on the national prevalence data, Nottinghamshire County may expect to see 2192 adults with Aspergers Syndrome

Estimates of the number of children and young people with autistic spectrum disorders coming through the school system in Nottinghamshire also vary. Figures from the Connexions service in 2004 suggested that there were around 115 14 to 19 year olds with autism and around 1,500 with "mild" autism. Linda Lyn Cook, Consultant teacher (autism) in the County estimates that there are 1,000 0-19 year olds across the County with autistic spectrum disorders, 230 of

whom are in special schools and the rest, who have good cognitive abilities, are, or will be, in mainstream schools. Not all these young people have Asperger's and, of those that do, not all will need social care services. However, the experience of Community Learning Disability Teams and Community Mental Health Teams suggests that the number of referrals is rising and that there are problems in providing a satisfactory service response.

Information gathered by the Nottinghamshire County Council children's support services shows a 150% rise in the number of children diagnosed with autistic spectrum disorders over the last six years. The majority of children are within the range 8 years to 14 years with a higher proportion of the children in special educational provision aged 11 to 15 years. These children require effective transitional arrangements to be in place to enable adult services to establish levels of individual need and appropriate service responses.

### 5.2.1 People supported by NHS secondary care services

Data derived from diagnostic episodes for people having a classification of F84 (Autistic disorder) from the Nottinghamshire Healthcare NHS Trust (March 2005) shows:

	internal	external	total
AMH acute	4	2	6
AMH Rehab	3	1	4
CAMHS	2	2	4
Learning Disability	43	21	64
Forensic		3	3
Total	52	29	81

### 5.2.2 People supported by the County Council

Current distribution of people supported by the County Council shows a high proportion of identified adults with Aspergers disorder in the conurbation area , with few individuals receiving services in the Mansfield, Ashfield and Newark areas of the county.

County District	Individuals known to services
Broxtowe	8 (13%)
Gedling	14 (23%)
Rushcliffe	12 (20%)
Newark & Sherwood	2 (3%)
Bassetlaw	14 (23%)
Ashfield	5 (8%)
Mansfield	6 (10%)

## **5.3 Inspections and Assessments**

The 2005 Commission for Social Care Inspection Report of Nottinghamshire County Council learning disability services made specific reference to the needs of people with Aspergers syndrome, which noted

*“There were some service gaps identified by front line staff: for people with mild learning disability, Asperger’s syndrome.....Work was underway to develop a joint strategy with health in response to the increasing numbers of people diagnosed with Asperger’s Syndrome.” P30.*

*“Interfaces between service areas did not always work effectively and there were no protocols in place to guide staff and managers. This was particularly an issue for mental health services and managers who identified a specific lack of clarity around meeting the needs of people with Asperger’s Syndrome” p39*

The development of this strategy and those of the joint learning disability and mental health strategies attempts to address the findings of the CSCI report and to assist in the better coordination of services to individuals and families.

## **6 FINANCE**

### **6.1 The current spend on people with Aspergers**

In 2007/08 the Council has provided £360,000 of development funding to support up to 25 people with Aspergers Disorder. Furthermore the Council’s Medium Term Financial Strategy has signalled the intention to increase the pace of development over the period 2008/09 and 2009/10 to support an additional 65 people.

## **7 COMMISSIONING INTENTIONS**

The specific commissioning intentions relating to people with Aspergers Disorder are outlined below. They are categorised to reflect the departments overall commissioning intention as described in chapter one, the departmental strategic overview.

### **7.1 Developing and sustaining partnerships**

**Establish a multi-agency team** including support from social services, psychology, psychiatry, forensic services, and community nursing and with links to probation and housing services. The commissioning of a multi-agency team for assessment and case management, and short term interventions may provide for clearer access to care and treatment, better outcomes for individuals and families and reduce reliance on out of area provisions.

#### Good Practice example – Liverpool Asperger Team

Jointly commissioned, Multi agency team providing assessment, diagnosis and interventions for individuals and families.

The team have developed specialist knowledge and expertise in working with people. Early indications show a favourable response to the service from commissioners, families and existing providers.

### **7.2 Developing Self Directed Care**

**Promote the use of direct payments** so that an individual service can be provided for people who do not fit easily into current provision. Individually tailored care packages which allow for a flexible provision of service are ideally suited to the needs of people with Asperger’s whose needs around psychological and social functioning can make ‘off the shelf’ services difficult to provide. The development of individual budgets should be considered as a flexible way to meet the diverse needs of people with Aspergers and their families.

### **7.3 Promoting Health and Well-being – engaging the community**

**Address the social exclusion faced by many people with Aspergers Disorder.** This is seen as a significant issue as many existing day services are not appropriate or desired by adults with Asperger's syndrome. Support required may relate more to accessing further and higher education, access to leisure activities, and employment.

## **7.4 From Exclusion to Inclusion**

**Develop appropriate housing solutions for people with Asperger's** which allow for the required level of support and care to enable people to live independently in the community. Ensure that the local housing strategy and supporting people strategy includes the needs of people with Aspergers syndrome.

**Residential / Nursing care should only be provided where absolutely necessary.**

Community alternatives promoting social engagement will always be the preferred option for most individuals. People who have been placed in specialist residential or nursing placement out of the local area should be reassessed to determine if their needs can be met locally.

## **7.5 Carers services**

**Audit existing carer support services to ascertain if these are adequately meeting the needs of families and carers.** Develop a carer support, information and consultation service to meet the needs of families and carers of people with Asperger's syndrome.

## **7.6 Advocacy and Involvement**

**Ensure that local advocacy services can meet the needs of families and individuals.**

Existing advocacy contracts do not specifically require providers to provide for the needs of people with Aspergers Disorder. Variations to contracts may be required.

## **7.7 Market Management**

**Commissioners need to develop a greater understanding of the demand** for services and the ability of current providers to meet individual need. Information from children and young peoples services should be utilised together with community care information and public health information sources to develop a comprehensive needs assessment for the county.

## **7.8 Diversity**

**Information should be available in a appropriate languages and formats** to ensure all sections of the community can access services.

## **7.9 Quality and Performance**

**The introduction and development of appropriate assessment tools for use locally,** such as the DISCO model should be considered and staff trained in its use.

Currently many individuals are assessed and diagnosed within existing mental health and learning disability services utilising tools which are not designed to adequately meet the needs of individuals.

**Training to increase staff awareness of the problems faced by people with Asperger's Disorder.** Work with National and local service providers to provide training for staff and to set up preventative services for those people who fall below our eligibility threshold.

## 7.10 Leadership

**A protocol needs to be established so that case management responsibility is clear.** The experience of transitions co-ordinators and vulnerable adults' workers is that people with Asperger's often fall between the remits of the Community Learning Disability Teams and Community Mental Health Teams and passing on responsibility for long term case management can be difficult.

## 8 COMMISSIONING PLANS

The commissioning plans for services for people with Aspergers Disorder are set out below. The layout reflects the strategic commissioning intentions of the Department set out in chapter one and the nine priority performance outcomes as defined by the Commission for Social Care Inspection (CSCI), which are also referred to in chapter one. They are also classified into three groups:

- A - intentions that have been funded with the Council's medium term financial strategy
- B – are those plans which the department will look to fund through efficiency savings, modernisation plans and within the existing departmental budget envelope
- C - are those plans which the department will wish to take forward with our partners in the longer term and may go beyond the life of this strategy

### 8.1 Developing and sustaining partnerships

	Commissioning intentions	Resource implications	Link to CSCI outcome
A	Multi-agency multi-disciplinary team be established to provide specialist assessment, care management and short term interventions. The exact make up and model of the service is to be determined	Based on the Liverpool model, this would require a Local authority contribution circa £140K to provide social work, transitions and family support staff. Funding for this service would be taken from existing budgets  A PCT contribution of circa £200K to provide medical, psychological, therapy services and community nursing Much of these resources would need to represent reinvestment of existing revenue costs, already present within MH and LD services.	Improved health and emotional well being

### 8.2 Developing self directed care

	Commissioning intentions	Resource implications	Link to CSCI outcome
A	Increased delivery of direct payments to an additional 5 people per year for three years	Potential local authority cost of £50K per year from additional council commitment in 2007	Increased choice and control
A	Development of individualised budgets pilot programme	Project work to be funded circa £15K from slippage contained within additional council commitment in 2007	Increased choice and control

### 8.3 Promoting Health and Well-being - engaging the community

	Commissioning intention	Resource implications	Link to CSCI outcome
A	<b>Information.</b> Produce public information on the needs of people with Aspergers Disorder and the services available to meet their needs	£ 5K Funding from slippage contained within additional council commitment in 2007 for purchase/ development and distribution of information.	Choice and control
A	<b>Supported employment:</b> Ensure people with Aspergers Disorder are included within the ready fro work teams business plan	To be undertaken within current resources	Economic wellbeing

### 8.4 From Exclusion to Inclusion

	Commissioning intention	Resource implications	Link to CSCI outcome
A	Develop range of housing and support solutions to provide for the needs of people with Aspergers syndrome	Funding applications required to the supporting people team Potential tender process required to test market	Improved quality of Life
A	Provision of community care services to an additional 20 people per year for the next three years	Local authority budget commitment of £ 200K	Improve health and emotional wellbeing
C	Assessment of people currently placed in residential/ nursing provision with a view to people being offered alternative packages of care together with a 'Bringing people back home' exercise to	Project work to be funded circa £15K . Will require development of locally economically viable alternatives	Improved quality of life

be undertaken

## 8.5 Carers services

	Commissioning intentions	Resource implications	Link to CSCI outcome
B	Develop Carers information and support service	Potential bid for carers grant funding £35K	Improved health and emotional wellbeing

## 8.6 Advocacy and involvement

	Commissioning intentions	Resource implications	Link to CSCI outcome
B	Ensure advocacy services are contracted to include the provision of service to people with Aspergers Disorder	Approximately £10K	Freedom from harassment and discrimination

## 8.7 Managing the market

	Commissioning intentions	Resource implications	Link to CSCI outcome
A	Comprehensive Needs assessment is required to determine the level of need and demand across Nottinghamshire	Within existing PCT and LA budgets	Commissioning and use of resources

## 8.8 Diversity

	Commissioning intentions	Resource implications	Link to CSCI outcome
A	Information. Provide information about needs and services in accessible formats and languages	£3K from slippage contained within additional council commitment in 2007 for translation and production	Making a positive contribution

## 8.9 Quality and performance

	Commissioning Intentions	Resource	Link to CSCI outcome
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		implications	
A	Protocols be established to identify and provide guidance for staff re the potential service overlaps and service interfaces	Dedicated commissioning officer resources.	Leadership
C	Introduction of assessment tools including T& D costs. Introduction of assessment tools including T& D costs	£ 30K joint training commitment	Making a positive contribution

### Financial consequence of commissioning plans

- A – developments we will do and can fund - £ 413,000
- B – developments we must do but where funding is not identified - £ 45,000
- C – developments we would wish to do in the longer term - £45,000

## 9 WORKFORCE IMPLICATIONS

The development of specific services for people with Aspergers Disorder will require a workforce able to demonstrate the skills, knowledge and capacity to deliver for the local population.

Although additional resources will be required to deliver the commissioning intentions contained within this strategy document, much of the resource requirements will be expected to be found within existing organisational commitments. There is therefore a need to review the current practice and structures which support people with Aspergers, autism, learning disabilities and mental illness to consider the potential for reconfiguration, redistribution and specialisation of staffing structures.

Statutory health and social care providers will need to develop discrete capacity to provide assessment, treatment and care management services. Alongside existing professional skills and knowledge, these staff will be required to develop a greater awareness and capacity to deliver specialised services to an increasing population of adults with Aspergers Disorder.

Independent, voluntary and private sector providers will be encouraged to provide local services, with an increasing emphasis on personalised care based in the community. This will require providers to develop care and support staffing who meet not only the standards established by regulation and inspection agencies but also an understanding of the needs of this client group.