



Fulfilling and rewarding lives for adults with Autistic Spectrum Conditions living in Wakefield District

A Joint Strategy for 2011 - 2014

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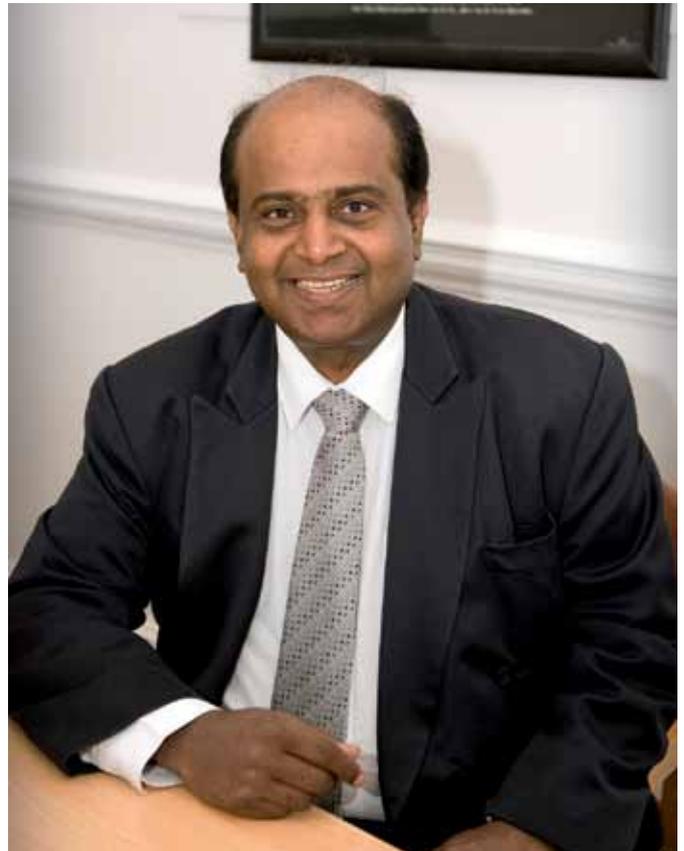
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INTRODUCTION

I am pleased to introduce Wakefield's first joint strategy for people with autistic spectrum conditions (autism), which demonstrates our commitment to ensuring that all adults with autism are able to live fulfilling and rewarding lives and that they are understood, accepted and helped to make the most of their talents. Together, we want to improve access to early diagnosis, provide support where people need it and ensure that there is fair access to universal services.

Autism affects people in different ways. Many people with autism also have a learning disability or severe social interaction problems and will require longer term support from health and social care services. Others may need short term support following diagnosis or when faced with difficult situations or decisions in life and will not need or want to become reliant on services. Through this strategy, we hope that together we can improve health and wellbeing through strengthened joint commissioning and leadership, greater partnership and co-production with people with autism and their families, and through building the capacity of communities to accept, respect and value the contribution that people with autism make.



Sam Pratheepan

Director of Adults Social Services - Family Services,
Wakefield Council

THE POLICY CONTEXT

The Autism Act 2009 is the first ever piece of legislation designed to meet the needs of one specific impairment group. It provides a statutory framework for policy development at both a national and local level for the provision of support for those affected by autism. As required by the Act, 'Fulfilling and Rewarding Lives: the strategy for adults with autism in England' (2010) was subsequently published. The main themes of the government strategy, which we have used to underpin Wakefield's strategy are:

- increasing awareness and understanding of autism
- developing a clear and consistent pathway for diagnosis of autism
- improving access for adults with autism to the services and support they need to live independently within the community
- helping adults with autism into work
- enabling local partners to develop relevant services for adults with autism to meet identified needs and priorities.

Statutory guidance for local councils and NHS organisations to support implementation of the strategy was published in December 2010, under Section 2 of the Autism Act 2009. In respect of Wakefield, this means that the Council, NHS Wakefield District and South West Yorkshire Partnership Foundation Trust have a statutory duty to follow the path chartered by the guidance, "without freedom to take a substantially different course". While there are clearly defined responsibilities for the Council and NHS organisations, the focus of this strategy is partnership and ensuring clear, integrated pathways for short and long term care and support. The appended delivery plan will cover all areas of statutory responsibility arising from the guidance.

For information on the statutory guidance relating to partner organisations, contact Sara Pearson, Partnerships Co-ordination - Family Services on 01924 303847 or email smpearson@wakefield.gov.uk.

There is a plethora of other national policy relevant to people with autism and their families, not least the government's personalisation agenda and 'Valuing People Now' - the learning disability strategy.

For a full review of the national policy context which shapes Wakefield's local autism strategy, contact Sara Pearson, Partnerships Co-ordination - Family Services on 01924 303847 or email smpearson@wakefield.gov.uk.

WHAT DO WE KNOW ABOUT AUTISM?

In developing this local strategy, account has been taken of national prevalence data, as well as a Local Needs Assessment commissioned by Wakefield Council to engage the local community and to ascertain the views of people with autism and their families.

The National Autistic Society estimates that over half a million people in the UK have an autistic spectrum condition (autism). This equates to one in every 100 people. It is a lifelong condition that affects the way a person communicates with, and relates to, people around them. While each person with autism is a unique individual with unique talents and needs; in respect of obstacles to leading a fulfilling and rewarding life, people with autism broadly share three areas of difficulty:

1. Social communication associated with problems using and understanding verbal and non verbal language, such as gestures, facial expressions and tone of voice.
2. Social interaction, with difficulties recognising and understanding other people's feelings and understanding or managing their own feelings.
3. Social imagination, such as problems in understanding and predicting other people's intentions and behaviour and coping with new or unfamiliar situations.

In addition, many people with autism have sensory difficulties, such as hyper-sensitivity to sounds. 'Fulfilling and Rewarding Lives', the national autism strategy, acknowledges that "despite the significant strides made over the last decade to increase equality and tackle exclusion, adults with autism are often not treated fairly." Wakefield Council, in line with the national strategy, wants to improve its understanding of those people in Wakefield district living with autism.

The information shown on table 1 in respect of predicted numbers of people with autism living in the Wakefield district is the best available from national prevalence data, and information collected at a local level. This indicates that there are 2,000 adults with autism living in the district, aged 18 to 65 years, with 85% male and 15% female, although some studies suggest an under reporting of incidence of autism in women.

There are 97 people with autism currently supported by Community learning disability teams, and 57 through secondary mental health services, and a further 91 people where there is an indication of autism but no clear diagnosis; there are also people with autism known to the Attention Deficit Hyperactivity (ADHD) service. Most of the adults known to these services will have a secondary diagnosis of autism.

From information available therefore, as many as 80% of adults with autism aged 18-64 are not receiving a service through the integrated adult teams. There will be people with autism receiving a service through housing related support or the homelessness service and through primary health care services, but this information is not routinely kept.

Of the people with autism not known to the above services, many will have overcome difficulties with communication and social interaction and found fulfilling employment that suits their particular talents. However, some people known to services may be very able intellectually, but have required the support of services because the degree of impairment of social interaction has hampered their chances of achieving independence. It is not possible at this stage to know how many people falling into the latter may need support in the future and to what level.

TABLE 1

NATIONAL AND LOCAL PICTURE	ESTIMATED NUMBER OF PEOPLE LIVING IN WAKEFIELD
People with Autism Spectrum Condition (ASC) - all ages (1 in 100)	Approximately 3,200, (local population)
Estimated prevalence of ASC -men is 1.4% whilst amongst women it is 0.2%.	Based on the Adult population locally -1736 males and 263 females. (2000 adults to 65 years of age)
People with ASC in Wakefield District known to learning disability teams	97 people known to the LD teams, whose secondary disability is ASC
People with ASC in Wakefield District known to mental health teams and ADHD team	91 with an indication of ASC 57 with confirmed diagnosis
People with ASC with Learning Disability (IQ below 70) estimated at 50% (Not felt to be reliable data)	Approximately 1,000 based on 50% of local population with ASC will also have a learning disability.
Long-term health outcomes of Adults with ASC and learning disabilities are poorer and are directly proportional to the IQ of individuals as above	Approximately 1,000 based on 50% of local Adult population with ASC will also have a learning disability and are likely to have poorer health outcomes
The mortality rate of people with moderate to severe learning disabilities are three times higher than in the general population (Emerson and Baines, 2010)	Estimate of Adults with moderate to severe Learning Disability in Wakefield = 1261-Therefore expected mortality rate for people with moderate to severe Learning Disability = 30 per 1,000 (3%)-Approximate deaths of people with moderate to severe per year = 3% x 1261 = 38
(NAS) estimates two thirds of adults with ASC do not get support they need. High prevalence of mental ill health is seen as an indicator	Two thirds of 1999 (Estimated prevalence locally of Adults with ASC) = 1333
15% of adults with ASC in the UK in full-time paid employment	15% of 1999 (Estimated prevalence locally of Adults with ASC) = 300
51% of adults with ASC in the UK have spent time with neither a job, nor access to benefits, 10% of those having been in this position for a decade or more 61% of those out of work say they want to work	51% of 1999 (Estimated prevalence locally of Adults with ASC) = 1019
79% of those on Incapacity Benefit say they want to work	61% of 1999 (Estimated prevalence locally of Adults with ASC) = 1219
Children with a prime diagnosis	251 with a PD and 52 on action plus

LOCAL INVOLVEMENT

An independent agency was commissioned by Wakefield Council to carry out a local needs assessment of people with autism to help inform the development of this strategy.

For the full report of Wakefield's Local Needs Assessment, contact Sara Pearson, Partnerships Co-ordination - Family Services on 01924 303847 or email smpearson@wakefield.gov.uk.

The purpose of the Local Needs Assessment was to engage as many people in Wakefield who are living with autism as possible, both those known to services and those not. The needs assessment included a desk based review, questionnaires to a range of professionals, focus groups to better understand what is and is not working for people and families and to gather ideas for the future. An invitation to participate in the consultation was made to over 100 community, health and religious groups across Wakefield district, in order to involve people with autism not known to services; unfortunately there was no response from the latter approach. It is difficult to know the reason for the lack of response; this needs to be considered as part of delivery on the strategy and in view of gaps in our knowledge about 80% of the population of people with autism living in the Wakefield district.



KEY ISSUES FROM CONSULTATION

WHAT'S WORKING WELL?

- Positive experiences regarding social worker help with housing arrangements and input from psychology and advocacy.
- Some good examples of joint working between health and social care professionals to secure housing.
- Big improvement in access to health care through Vulnerable Person's In-Patient Card - this includes improvements in A&E.
- Diagnosis is much better than it used to be particularly for children. WeSail has helped.
- GP and dental services have been better at supporting people with autism.
- The Patient Partnership Service gives good clear advice.
- Some Police Officers are quite knowledgeable about autism, but this is not consistent.
- Libraries have developed an understanding of autism and adapted accordingly.
- Getting the right health or social care worker who got to know the person and their family has been invaluable to some families.
- Connexions worker in WeSail Team provided good support for transition planning.
- Hidden Talents Service - Service supported people with autistic spectrum conditions and other hidden disabilities to gain and retain employment:
- For duration of service, 51 referrals received; 30 clients enrolled; 9 supported to undertake voluntary work/work placement and 10 supported to gain employment.
- Specialist advocacy for people with autism

WHAT'S NOT WORKING?

- Improvements could be made in relation to personal choice both about who works with a person with autism and their families and choice of respite environments.
- A need to listen to families more and a need to provide more information about what is available.
- Still lack of awareness about autism with some professionals, including emergency services.
- Not very many people with autism are in work, particularly those with additional disabilities.
- Some GPs still not aware of autism.
- Diagnosis for some adults still a battle.
- Some GPs and emergency services need to be more aware of autism and early diagnosis and follow up support should improve.
- Lack of public understanding of autism and judgements made by people lead to anxiety for people with autism, particularly generic services.
- Loneliness was an issue raised in discussion groups; 63% said they have difficulty in finding and making friends.
- Some teachers do not have a good understanding of autism.
- Some families worried about having social workers involved due to their perceived stigma.
- There are barriers in respect of signposting to appropriate services and accessing universal services for some people.

IDEAS FOR A BETTER FUTURE

- Sharing of success stories of people who have made the transition from home, into independent living.
- More opportunities for socialising for people with autism.
- Broaden use of the VIP card.
- Mentoring schemes suggested as a way forward and to provide information on a wide range of community, social and academic opportunities.
- Offering awareness training would be useful and services should take time to get to know the person with autism.
- We could make better use of existing services, for example providers offering unfilled training places.
- A 'one stop shop' for information would be helpful.
- A consistent point of contact person would be useful in maintaining contact when a person with autism reaches adulthood.
- Awareness training for GPs and other professionals in respect of autism.
- Make accessing a diagnosis easier, especially for adults.
- Should be media campaigns to increase awareness; TV, such as soap operas could tackle issues to raise awareness.
- Increased sensitivity to the needs of people with autism, such as shops, travel support and services which should adapt their responses accordingly-recent 'autism friendly' cinema events initiated by Dimensions could be replicated.
- Should be clarity about what makes good support, i.e. support designed specifically for the person.
- Parents to be encouraged to support their child to aspire to pursue employment and to make best use of their skills and talents.
- More information should be made available about employment support.
- Work more in partnership with people with autism and their families.



TIERED APPROACH TO CARE AND SUPPORT

The approach being developed by Wakefield Family Services for commissioning care and support, as depicted below, is ideal to meet the needs of people with autism, given the spectrum of need prevalent within the population of people with autism. It also fits well with the five key themes underpinning this strategy.

This model is set within the wider context of improving the health and well-being of citizens, in order to achieve our vision of supporting individuals to retain as much independence as possible, whilst preventing or delaying the need for on-going or extensive services.

For many people with autism, if they are able to access universal services and advice and information, they will not require other services. Others will require short term focussed support following diagnosis or during difficult times. Also, for those people with additional severe and enduring problems such as learning disabilities or a mental health condition, they will require ongoing care and support, which may be extensive in nature. For this latter group and their carers, the emphasis will be on personalised care and support and putting service users in control of arranging their own care and support.



PRIORITIES FOR CHANGE

Priorities for change are underpinned by the five areas identified within the national strategy as identified on page 4 of this document and within the delivery plan overleaf. The delivery plan also includes all areas that are required from statutory guidance. Additionally, development of the strategy, including needs assessment has identified other gaps that have also been built into the delivery plan. These are data collection, preventative support, sensory integration assessments and the needs of older people with autism.

Leadership for the delivery group will be provided by the lead commissioning manager appointed by the Council to lead on development and delivery of services and support for people with autism, and a person with autism will be invited to act as co-chair. This group will report to the Learning Disability Partnership Board and the Joint Strategic Commissioning Board.

The Health and Wellbeing Board and the Local Strategic Partnership will also need to satisfy themselves that information in respect of the needs of people with autism is being appropriately gathered and the needs of people with autism are being addressed by all partners.

LOCAL DELIVERY PLAN APPENDIX 1

(To be reviewed and revised in April 2012)

ACTION (for each action ensure we are aware of best practice elsewhere)	STATUTORY GUIDANCE/LOCAL PERFORMANCE REFERENCE	PERSON/S RESPONSIBLE
P1 Increasing awareness and understanding of autism		
1a Review commissioning arrangements and skills of providers in meeting the needs of people with autism (Should we adopt some minimum standards before providers are used/some kind of validation process), e.g. Autism aware organisation		Jayne Gilmour/Mark Wakefield
1b Improve training and autism awareness amongst front line public sector staff (should be included in general equality and diversity training across all public services) and provide specialist training for GPs and care managers	It is essential that autism awareness training is available to everyone working in health or social care and that it leads to changing the behaviour and attitudes of staff	Delivery Group and Partners
1c Raise public awareness of autism in Wakefield and throughout the Council and Partner Organisations. Consideration of a website developed by people with autism. Launch of new strategy		Delivery group and partners
P2 Developing a clear and consistent pathway for diagnosis of autism	Local areas should appoint a lead professional to develop diagnostic and assessment services for people with autism	
2a Develop a clear pathway for people with autism from diagnosis to social care assessment and support-consideration of a VIRTUAL TEAM for people who do not meet the Facs criteria. Appoint a lead professional to develop diagnostic and assessment services	Diagnosis of autism should be recognised as a reason for assessment	Philip Smedley/Jayne Gilmour/Ann Rutter
2b Consideration of a specialist care manager for access to services and signposting		Delivery Group

TARGET DATE	INFORMATION TO BE GATHERED FOR PERFORMANCE MONITORING	DATE ACHIEVED/PROGRESS/ COMMENTS
	Providers with specialist skills and service user satisfaction. Numbers	
Training plan in place by April 2012		A bespoke training course was developed and delivered in partnership with people with autism during 2010. The evaluation needs to be shared with the delivery group
September 2012		
		The pathway has been mapped and discussions about a virtual team are underway
November 2009	People accessing services/self reports of better access	This was piloted and whilst successful in supporting and signposting was not recommended as the way forward

ACTION (for each action ensure we are aware of best practice elsewhere)	STATUTORY GUIDANCE/LOCAL PERFORMANCE REFERENCE	PERSON/S RESPONSIBLE
<p>2c To undertake a local needs assessment, through engagement with people with autism and their families. This should identify numbers of people in Wakefield and their needs</p>		Rebecca Squirrell/Gillian Quinn
<p>P3 Improve access for adults to the services and support they need to live independently within the community</p>		
<p>Ensure we are aware of services and networks locally that people with autism can currently access</p>		Delivery Group
<p>To identify if people with ASC are accessing the ADHD service and outcomes from this to-date</p>	SAS/New Autism Strategy	Jayne Gilmour/Stuart Davis
<p>Establishment of a self-advocacy group for people with ASC-to inform future planning</p>		Jayne Gilmour/Delivery Group
<p>Consider the housing and support needs of people with autism (housing delivery group)-needs assessment</p>		Duncan Smith/Di Button
<p>Consider commissioning a low level befriending/support service for people with ASC (dependent on outcome of needs assessment) Broader action around social networks. People who do not meet the Council's Fair Access to Care Criteria could access this service</p>		Delivery Group
<p>To ensure that adult services are aware of services being developed/approaches being used for children and young people with ASC</p> <p>Identifying and meeting the needs of older people with autism</p>		Caroline Slater

TARGET DATE	INFORMATION TO BE GATHERED FOR PERFORMANCE MONITORING	DATE ACHIEVED/PROGRESS/ COMMENTS
1st April 2010	Information about numbers of people, including young people coming through, age groups and level of need. Perceptions of gaps in service and what we need to develop for the future Results of needs assessment to be presented to the PB and other relevant networks	This was undertaken by Paradigm with mixed results, particularly in reaching people with autism who do not use integrated services
1st December 2009	Map of services and ultimately information provided/take up of services	A mapping exercise was undertaken-this needs further work
1st December	Information presented to the group and data collected by SWYFPT	This information is awaited
TBA	Numbers of people attending and outcomes in respect of health and wellbeing	
		This was considered as part of the autism needs assessment
Before April 2010	To be identified if this is agreed as a priority/need	A specification has been developed. Funding needs to be identified
TBA	Information shared between services	

ACTION (for each action ensure we are aware of best practice elsewhere)	STATUTORY GUIDANCE/LOCAL PERFORMANCE REFERENCE	PERSON/S RESPONSIBLE
<p>P4 Helping adults with autism into work</p> <p>Commission an employment pathway for people with ASC and review its effectiveness (see employment sub-group) Travel training DWP initiatives</p>		Jayne Gilmour
<p>Ensure the new DWP work scheme considers the needs of people with ASC's</p>		
<p>P5 Enabling local partners to plan and develop appropriate services for adults with autism</p>		
<p>5a Ensure effective transition planning for children known to services. (Caroline to brief the group)</p>	Special Educational Needs Code of Practice	Caroline Slater/Jim Leyland
<p>5b Ensure the group keeps up to-date with progress with other delivery groups as it relates to people with autism, eg, getting a life health and safeguarding as it relates to the prison population. (training for criminal justice staff)</p>		Jayne Gilmour/chairs of other groups
<p>5c Liaison with the health group in respect of ensuring better access to health care, including psychological therapies for people with autism. Health delivery group needs amending-reasonable adjustments in NHS</p>	PCT blueprint	Ann Rutter/Marie Gibb
<p>5d Ensure the needs of people with autism are addressed through Hate Crime and Safeguarding initiatives</p>		Ian Holden/Lisa Willcox-Safeguarding Manager.
<p>5e Consider the specific needs of people with autism and Personalisation (at a glance briefing on personalisation)</p>		Jim Leyland
<p>5f Address the needs of Carers of people with autism and link to carers delivery group</p>		Duncan Smith

TARGET DATE	INFORMATION TO BE GATHERED FOR PERFORMANCE MONITORING	DATE ACHIEVED/PROGRESS/ COMMENTS
Achieved	Numbers of people referred and in paid work/case studies in respect of health and wellbeing	A service was commissioned with good outcomes and extended into 2011/12 through variation on the MHY contract. Outcomes for people with autism from the new Work Programme need to be carefully monitored
	TBA	
Quarterly basis	Progress reports from PB	
	Included in health delivery group	

ACTION (for each action ensure we are aware of best practice elsewhere)	STATUTORY GUIDANCE/LOCAL PERFORMANCE REFERENCE	PERSON/S RESPONSIBLE
5g Transition-consider the extent to which the steering group is addressing the needs of people with autism		Delivery and Transition groups
5h Consider the special needs of people with autistic spectrum, for example sensory equipment		Delivery Group
5i Further identification of people?		Delivery Group
5j Consider the needs of older people with autism		Delivery Group
6 Local Planning and Leadership	Equality Act and making reasonable adjustments Standard NHS contracts	
6a Development of a reliable data base/aligned to JSNA (see 5i)	See page 25 of stat guidance re: information to collect	Delivery group/Liz Blenkinsop
6b This may require further consultation with people with autism, particularly those not in receipt of services		
6c <ul style="list-style-type: none"> • Appoint lead Council Officer • Lead officers for all statutory partners • Commissioning plan 		Jayne Gilmour has been appointed as lead officer for the LA
6d Consideration of an elected member lead for autism		Jayne Gilmour/Sam Pratheepan
6e Partnership Board and Delivery group <ul style="list-style-type: none"> • Re-establish Delivery Group with appropriate membership • Identify co-chair - Role of Big Society 		Jayne Gilmour
6f Ensure the Health and Wellbeing Board is briefed on the autism strategy and is clear about leadership and commissioning implications		
6g Consider how we can build community capacity to support people with autism within their communities		

TARGET DATE	INFORMATION TO BE GATHERED FOR PERFORMANCE MONITORING	DATE ACHIEVED/PROGRESS/ COMMENTS
December 2011		Jayne Gilmour agreed as lead officer
Achieved End September 2011		Sam Pratheepan as Director of Adult Services and chair of the LDPB will have a key leadership role
End September 2011		
End September 2011		
October 2011		
April 2012		

The Department of Health has recently published good practice guidance for evaluating progress on implementing the autism strategy at a local level.

Wakefield will assess its own performance against this guidance and use outcomes to influence future planning.







