

**Towards Best Practice in Supporting
People with Asperger Syndrome**

**A Guide to Key Principles and Practice
from The Kingwood Trust**

Written and edited by members of an Expert Group

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FOREWORD

“Suddenly all the years of bullying, being picked on, being left out of teams, never being asked to parties, feeling different, made sense”.

Gail Tomlinson wrote this after being diagnosed with Asperger syndrome.

It is our mission at Kingwood to pioneer best practice in the support of people with autism. However, whilst we attempt to do this across the whole of the autistic spectrum we have found that people with Asperger syndrome, which is a part of the spectrum, have particular needs and difficulties that require a different kind of support. In recent years we have taken on more people with this syndrome but looked in vain for the advice we needed. In the absence of a practical guide we decided to research and write one ourselves.

On the 20th September 2011 we brought together a group of experts at the Royal Society of Medicine to pool their knowledge on what practical initiatives were found to be working that improved life for people with the condition.

Foremost among the experts were people with Asperger syndrome of different ages, gender and ethnicity. We also invited leading national and international experts with research and practical experience, providers of services and parents. Papers were written, discussions were held and finally we brought all the contributors together for a seminar. What struck me most as I was chairing the seminar was how much evidence we heard of good practice, of people with Asperger syndrome going to University and holding down jobs, thanks to intensive training and ongoing support, which has not been widely shared. The challenge is to enable many more people with Asperger syndrome to realise their potential.

Above all will be the need to listen carefully to what people with Asperger syndrome themselves say

Not all people with ASD wanted friends, or aspired to independent living. Some expressed the view that they wished neurotypicals would stop imposing their views on what constitutes a good life.

Dr Kerstin Witteney
University of Birmingham Survey of People with Autism

We make no claims to have produced a definitive guide to best practice in the support of people with Asperger syndrome. Much more research is needed. At Kingwood we simply set out to learn all we could in a short time in order to better support the people entrusted to us. We shall be closely monitoring their progress and plan to publish some case studies in a year's time. Meanwhile we hope that this guide will be helpful to those who have a responsibility to commission or provide support for people with Asperger syndrome and we are grateful to all who have contributed to it.

Lady Hornby
Chairman, Kingwood
November 2011

INTRODUCTION

During the last two years there has been an explosion of national interest in Autism Spectrum Disorder (ASD) exemplified by the passing of legislation for a specific condition for the first time in the UK with the Autism Act (2010). National Strategies have been written and advice on good practice promised (DH2010). The National Institute of Clinical Excellence (NICE) plans to publish clinical guidelines in 2012.

In searching for guidance to support change at Kingwood it was found that:

- Specific research evidence of effectiveness of initiatives and interventions in adults with Asperger syndrome (AS) is weak.
- Publications mainly concern themselves with issues facing the whole spectrum. Kingwood feels that a dedicated focus on Asperger syndrome is needed to ensure this group does not get lost in the overall consideration of Autism Spectrum Disorder and to ensure their specific needs are addressed.

The guide will be used by Kingwood and will be disseminated widely to Local Authority and G.P. Commissioning Consortia as well as to providers in the field. Together with the expert papers commissioned as part of the research for this guide, it will be available on the organisation's website.

1. CHARACTERISTICS OF ASPERGER SYNDROME

Asperger syndrome is a form of Autism. Autism is a lifelong condition that affects how a person makes sense of the world, processes information and relates to other people.

Whilst there are similarities with autism, people with Asperger syndrome are often of average or above average intelligence with few speech problems, whereas other people on the spectrum will often have an accompanying learning disability.

Every person with Asperger syndrome has a unique set of strengths and needs. However the difficulties encountered can be extremely debilitating and distressing. People with AS at the meeting all described how they were bullied at school, at University and in work situations.

Since the early age of 5 - 10 years old I remember not fitting in with the other kids even though I was trying hard to belong to a group.....even kids throwing stones at me. Sometimes I was punched by a group of kids from school or other neighbourhoods.

Joel Letort – Diagnosed with AS at age 44

The main areas of difficulty people with AS relate to social communication, social interaction and social imagination. Lack of eye contact is a characteristic of some people with AS and may be misinterpreted.

He suddenly snapped at me that I was very rude, that I never made eye contact, never looked at his face, just looked at his lapel pin or his tie or around the room. He said it was rude and that I should look at him in the face, when speaking to him.

Gail Tomlinson – Diagnosed with AS at age 33
describing a meeting with her Dean of Studies

People with Asperger syndrome may develop strong special interests and routines which can become obsessive but which can also lead to exceptional ability in their field

People with Asperger syndrome may also have difficulty understanding gestures, facial expressions and tone of voice, body language and may choose an inappropriate topic of conversation. They may be highly intelligent and computer literate but be unable to negotiate public transport or find supermarkets overwhelming to the senses, and often misjudge social situations.

I've lost count of the jobs I've lost because colleagues have taken a dislike to me, or because I initially found the job too difficult or couldn't do it quickly enough. I somehow or other give people the wrong signals.

Jean Tee - Was over 50 before being diagnosed with AS

Depression and anxiety are common mental health problems for people with AS.

2. PREVALENCE

Latest research indicates that approximately 10 in 1000 people in the population have Autism Spectrum Disorder (Brugha et al 2011)

Using the figures from Dr Wing's 1979 study, a General Practitioner with an average list size of 2,200 patients would expect to have 20 patients with ASD of which 8 may have Asperger syndrome. Despite this fact a survey commissioned by the National Audit Office found that many GPs reported that they do not have any patients with autism as part of their practice list, highlighting the scale of under or misdiagnosis. Researchers at the University of Leicester conducting the first ever, general population survey of autism in adulthood reported in May 2011 that not a single person they surveyed that met the criteria of autism or Asperger syndrome actually knew they had the condition, despite the importance for individuals of having an accurate diagnosis (Brugha et 2011).

The impact of receiving a delayed diagnosis, was described in the Sunday Observer by the British actor Paddy Considine -

"All my life, I've felt why, other than you're going mad, you're depressed, you've got anxiety, would you like us to hospitalise you. But I am grateful because now I know I can name my condition as something other than selfishness and anger."

3. VALUES AND PRINCIPLES

Three important **themes** emerged throughout the Expert Group Meeting.

Firstly, the values of the leaders in their fields shone out from their contributions and guided their practice.

“Knowledge about the condition and an attitude that is positive, respectful, curious, and optimistic, an attitude that embraces and celebrates difference”

Dr Michelle Garnett –Minds and Hearts Clinic –Brisbane Australia (2011)

Secondly, that collaboration between the service and the person, with extended time to develop trust and confidence together with a reflective approach were key attributes for the delivery of a successful service.

Thirdly that due to the dearth of research in the area, clinicians’ and support workers’ practice used established clinical or social care techniques adjusted specifically to the needs of people with Asperger syndrome. They are, however, working assiduously to develop novel approaches as additional knowledge of the condition emerges.

Representatives of services present at the meeting all referred to **sets of principles** that guided their approach – **empathy, respect, engagement, commitment and enthusiasm**.

“Anyone working with Asperger syndrome needs to have the ability and curiosity to investigate how the person views the world”

Melissa McAuliffe – Specialist, East London (2011)

“We respect and celebrate people on the autistic spectrum. Our commitment is born of a passion to understand, enhance and assist.”

Dr Michelle Garnett –Minds and Hearts Clinic –Brisbane Australia (2011)

“The steer from people with AS who helped us develop the service was that they didn’t want a social worker, they wanted to keep the majority of their lives private, but just needed support to resolve certain issues”.

Simon Veasey - Team Leader, Warwickshire (2011)

“Service users have told us that what is important to them is that staff seem interested in you as a person”

Christine Austin – Team Manager, Liverpool (2011)

4. SERVICE APPROACHES

4.1 Ways of working

This section of the guide provides examples of ways of working that have been found to be helpful in practice by members of the Expert Group. They include both therapeutic and social care examples. A consensus emerged on the elements of service that could be made available to be drawn on by people with AS, families and carers, and professionals as needed.

The elements are:

A dedicated team

Only 10% of areas have commissioned specific support for people with AS (NAO 2009). No single model predominates, although the majority of services, which have been established, are team based. The teams comprise a range of disciplines, such as psychiatrists, psychologists, speech and language therapists, and Social Care Professionals.

“Best Practice shows that where outcomes for adults have improved, this has been the result of the development of local teams.”

NAO 2009

A clearly defined pathway to assessment, diagnosis and follow up

Expert group members endorsed the need for a clearly defined pathway to include access to assessment, diagnosis, pre and post diagnostic counselling. NICE have been commissioned to produce guidance on this in 2012. Current examples include Bristol and Liverpool.

In 2003, I was diagnosed with Asperger syndrome.

When I asked what this was the description was like looking in a mirror. So that is what all the people who said I was strange thought. It was a heavy weight lifted from my shoulders.

Joel Letort (2011)

Person Centred Planning and Personal Budgets

There was consensus that Person Centred Planning following diagnosis, based around the agreed individual needs of the person, should be used with clear goals set. Specialists stressed the need to develop individualised plans and to keep the number of goals manageable to avoid creating a sense of failure.

The success of Personal Budgets, which are giving adults more control over the care services they receive in line with their assessed needs, was highlighted. Examples were given of how people with AS are using their Personal Budgets to

purchase personal assistants which are providing them with help with for example, in budgeting, support for appointments and coping strategies. However it was stressed that use of direct payments may not be universally appropriate as some people with AS find the responsibility too onerous.

3 examples of the use of 'creative' Personal Budgets (PB) for Adults with AS from Nottinghamshire

- One young man used part of his PB to buy an electric voice recorder, which provides prompts for up to 3 months in advance. This creative solution assisted him to structure his days at a cost of £110 saving £63 per week when compared to the more traditional ways of providing support to meet this outcome
- Another used his PB to employ a cleaner as he could not manage to keep his house clean himself. This 5 hour per week package met his needs, increasing his confidence and self-esteem
- One young man used his PB to include access to his special interest in Emergency Services. He has subsequently become a civilian volunteer with the Police

Chris Mitchell – Team Manager

Direct person centred support

Research indicates that the most important factors for a good prognosis are development of daily living skills, family support and emotion management (Cederlund, Hagber, and Gillberg, 2010; Farley, McMahon, et al., 2009; Howlin, 2011; Lord, 2011).

Members of the group believed the following issues should be discussed when establishing a service:

Individual needs

The importance of accurate diagnosis and needs assessment is emphasised earlier in this Guide. It is important to recognise that girls and women may present differently (Attwood 2006). Also adults may have experienced many years of frustration from the impact of their condition and the response of local services (Tee 2011).

Case Loads

Social Care representatives concurred that caseloads of around 40 are a maximum number of clients per worker.

Range of Support

Support mostly centres on assistance with daily activities and routines, such as form filling, shopping, budgeting, lifestyle advice, and personal safety strategies such as self-defence for women, accompanying and preparing for health appointments, leisure activities such as joining a gym, or social activities. Such support did, however, need to be extended to providing assistance for attendance at, for example, police interviews and court diversion schemes, environments that increase anxiety and the risk of challenging behaviours. In addition the importance of support in developing personal social networks was noted. Creating links to local support groups such as those provided by the National Autistic Society could be valuable, as is helping people with AS to establish regular social events such as pub nights. An example of this can be found in Hackney where a regular pub night with live music has proved popular with the people with AS who attend.

Rapid Response

As Asperger syndrome is a lifelong condition with needs often changing significantly over time (McGovern, Sigman 2005), difficulties have been experienced in closing cases. Most of the services offer open access on a drop-in basis, or by email or telephone, as they believe from experience that a rapid response system can assist in successfully addressing these changing needs and can often prevent a crisis situation developing. This however has inevitably led to the creation of waiting lists, as it is not possible to discharge anyone from the system. An on-line service directory specifically for people with AS has been developed in Nottinghamshire, and has found to assist in reducing workloads. Advice on AS is also available through specialist websites and Apps for iPhones or android devices such as SOSH, Quickcues, and Tip Sheets.

Advocacy

People with AS often have difficulty in navigating their way through official systems. Supporting access to and providing advocacy in relation to the following has been found to be valuable in particular:

Diagnosis and assessment from health and social care for individuals and their carers, particularly where there is no identified pathway

Social care assessors on Fair Access to Care criteria

Benefits entitlement and the benefits system particularly in the assessment process carried out by ATOS for eligibility for Employment and Support Allowance, appeals and in support-to-work programmes.

Extended Support

The importance of providing support to families as well as the person with AS to prevent breakdown, during times of bereavement, with suicide prevention, and mental health crises was emphasised

Housing

Obtaining, setting up home and retaining accommodation is a critical element of the workload of support staff. There are a number of models of housing available such as Supported Living, Supervised Living and living in a Community, or remaining in the home, which provide varying levels of support and a range of types of environments. Due to the complexity of successfully securing appropriate accommodations, organisations such as Housing Options (www.housingoptions.org.uk), can be approached for assistance.

Professional staff can have very different responsibilities including helping the individual to select housemates and moving home. The team in Warwickshire for example recently helped a person they support to furnish a new flat by using a Freecycle, an organisation which matches people who want to dispose of goods with those that need them.

“When I first moved in I did not have the confidence. Now I will try anything”

Kingwood Case Studies (2010)

In addition to assisting in securing accommodation, significant support is often required in maintaining a tenancy. The issues that emerged were:

- Being a good neighbour and integrating with the local community.
- Property maintenance, such as keeping gardens to an appropriate standard and boundaries in good repair
- Health and safety risks. The team in Liverpool is developing a ‘hoarding’ pathway to deal with such situations, which are relatively common in people with AS, where it has become debilitating and a potential risk.

Support into and during Further and Higher Education

Increasing numbers of people with a diagnosis of AS are successfully gaining entry to Higher Education. In the UK such students are entitled under the Disability Act to financial support and reasonable adjustment of the learning environment to enable the student to have a successful academic career. Support through year long introductory preparatory programmes to master study and living skills, the use of peer group buddy programmes and on line study programmes have been introduced into universities in the USA, although it is too early to comment on their effectiveness (Ratto & Mesibov2011). In the UK useful guidance is available through 'Best Resources for Achievement and Interventions re Neurodisability in HE' (BRAIN.HE) and the NAS website "University: How to Support Students with Asperger syndrome." The educational experience can also be enhanced through the provision of supported vocational placements.

It has been demonstrated that positive vocational outcomes occur through individually tailored vocational placements and support and that cognitive and psychosocial functioning improve with appropriate and successful placements.

Keel, Mesibov & Woods, 1997

Support into and during meaningful activity including employment

The unemployment rate for people with ASD is over 85%. The voluntary sector project ASpire has reported that although 40% of their Asperger syndrome clients had degrees or high qualifications, less than 10% were employed in any way at all. The impact on the economy and loss of earning power within families of fewer than 15% of people with ASC in employment has been well documented (Knapp et al 2007).

Particular barriers to undertaking employment that commonly apply not just to the general population but doubly so for people with AS are the lack of jobs in the current financial climate, lack of awareness of employers about the potential skill levels, lack of willingness to undertake reasonable adjustments to enable someone to work, the benefits system which does not react quickly enough to changes in circumstances when an individual may be unable to attend for a period and the loss of benefit if someone works above the maximum number of hours allowed, even if for a short time. There was a consensus that there was considerable potential in enabling far more people with AS to obtain work. There are examples of successful schemes such as the provision of individualised support through the establishment of job coaches and employment specialists that

can identify the person's specific interests and match them to particular jobs, and through sensitive work design by for example job carving and the provision of work placements. It was noted that there had been particular success in the fields of horticulture and agriculture, and the establishment of small businesses, particularly those that can be managed from home such as in the area of Information technology. However there was also caution expressed that for some people with AS, their difficulties in social communication or repetitive routines are too disabling to permit them to participate in existing workplaces. The resources required to maintain them in traditional work are so high that an approach to support a programme of meaningful activities might be more realistic.

All teams present had success stories which relied on marrying closely the interests of the individual with continuing support to the place of employment.
Kingwood Expert Group 2011

"I can remember the first time I went to Prospects to discuss the Transitions project. It was a decision that would change my life. 3 years ago the prospects of finding a permanent job were very bleak. I would never have guessed that in the near future I would be working at Goldman Sachs, the world's leading investment bank."

Graduate testimonial (Povey 2011)

A family local to me successfully set up their very bright and verbal daughter with Asperger syndrome in an old-fashioned hardware shop. She knows exactly which sized nail is where, has learnt to stocktake, to smile at customers. The parents are still there in the background but are clearly grooming this eccentric young woman to take her place in the town, which has always known her.

Dame Stephanie Shirley (2011)

Training and Development of a wide range of across different staff agencies

A broad general level of understanding and awareness of the specific needs of people with AS needs to be built in to the core training of a range of disciplines across the agencies involved in delivering services. Teams represented at the meeting all provided local training for colleagues where resources allowed.

At a national level, following the commitment in the national strategy to increase awareness, the Department of Health (DH) has commissioned a new E learning course via the Royal College of General Practitioners entitled Autism in General Practice. Modules include access to early and accessible diagnosis; post diagnostic support and follow up; collection of data and commissioning of services, and making primary care more accessible. The DH also commissioned

training for Psychiatrists with the Royal College of Psychiatry on Diagnostic Interviews for Adults and People who know them well, and the British Psychology Society has developed 3 E based modules and SSCIE and the Royal College of Nursing are producing Education Guides.

A report prepared for the National Audit Office on a survey of General Practitioners in England on the subject of autism showed that 69% reported they had no patients with autism. 18% said they kept a register of high functioning autism and Asperger syndrome. 80% said they needed additional guidance and training. NAO 2009

The national investment urgently needs to be matched with local implementation.

Staff management

Members stressed the need to recruit experienced staff, who are able to operate on the same intellectual level as the people they are supporting, preferably with a mental health or social care employment background. When setting up a team a phased, carefully planned start-up period with induction for staff and clear referral criteria and operational policies were felt to be essential. It was highlighted that referrals should be discussed on a team basis; caseloads individually supervised; training opportunities provided and with accessible management.

A therapeutic environment

A number of strategies have been found to be useful in increasing the likelihood of attendance and to provide consistency and predictability in service delivery such as provision of a visual schedule of appointments; scheduling appointments at the same time of day, and on the same day each week, being desirable. Engaging the same clinician over time per therapeutic goal, in the same room, with minimal changes to furniture arrangement and care over seating plan e.g. side-by-side positioning has been found to be helpful. Asking the client about the treatment room and creating an environment in the clinic and therapy room that is not overly intrusive to the senses, for example with low lighting, minimal use of perfume or aftershave, minimal noise, and moderate ambient temperature, has been found to improve success, as has creating a visual agenda with the person at the outset of each session, and use of the agenda to give structure throughout the session.

Therapeutic approaches

Expert group members identified a number of useful approaches. Some have been subject to evaluation by Research Autism and found to be helpful in specific cohorts, mainly children. Where there is research backing for an intervention this has been referred to or referenced from Professor Mesibov's overview paper available on the Kingwood website (Ratto, Mesibov 2011).

Animals

Anecdotal reports are available of the transformative effect of contact with animals, particularly dogs, and were referred to by attendees at the Expert Group. Two projects led by the charity 'Dogs for the Disabled' in collaboration with the NAS and Kingwood respectively, are currently being researched and evaluated by the Professor of Veterinary Behavioural Medicine at University of Lincolnshire.

Art Therapy

This is a form of psychotherapy that uses art as its primary mode of communication. People who are referred need not have previous experience or skill. The aim is to enable the person to effect change on a personal level through the use of art materials in a safe and facilitating environment. Research Autism is currently evaluating this intervention but it has been found to be very helpful by those attending the meeting.

Cognitive Behavioural Therapy (CBT)

Is a short term talking therapy that aims to change patterns of thinking or behaviours that lie behind people's difficulties. Developed as a combined therapy in the 1970s, it builds on traditional behaviour approaches developed in 1920s and combines it with cognitive approaches developed in 1960s. CBT has been evaluated positively by Research Autism and is used by clinicians in the teams in Liverpool and Brisbane. Dr Tony Attwood has published a paper outlining modifications to CBT to accommodate the cognitive profile of AS (Attwood 2009).

More recently several professionals have introduced Positive Psychology as a fruitful source of strategies for improving the quality of life for adolescents and adults with AS. Among the areas that have been suggested as potentially useful for individuals with AS are the teaching of optimism, self efficacy, gratitude, humour, and kindness (Ratto & Mesibov 2011).

Group work

This is a process whereby the skilled practitioner creates an environment where a number of people experiencing similar problems can share their experiences, form supportive relationships and help each other develop solutions.

Warwickshire are planning to use this approach for young people with AS starting university. Group work is used with varying success. There is no research evidence as yet to support the efficacy of group over individual interventions (Duncan & Klinger, 2010). Whilst some social activities are thriving e.g. a gaming group to bring together people who love specific computer games (East London), representatives stressed the need to work one-to-one prior to a group setting and one team had stopped group sessions as it has been found to be too time intensive due to a need to prioritise their resources on individual sessions. (Nottinghamshire)

Support, which is highly valued by the participants, has also been provided to family carers, partners or children individually where resources allowed, but several services ran group support sessions. For example, Brisbane runs spouses meeting to discuss issues arising from living with someone with AS.

Learning styles inventory

In 1978 David Kolb developed a questionnaire method of assessing people and their preferences for assimilating information. This self knowledge and knowledge by the practitioner can help improve retention, learning speed and enjoyment. Examples of different modes are those who learn by doing, in fieldwork or laboratories, those who prefer written reports and lectures, and those who like to record their learning in log books. As people with AS tend to have asymmetrical abilities in verbal and visual reasoning, understanding the preferred method of assimilating information can enhance learning potential.

Mind Reading

An interactive CD / DVD ROM has been developed by Professor Simon Baron Cohen at Cambridge University, comprising a unique reference work covering over 400 emotions, which is designed for children and adults who have difficulties recognising emotions in others.

Mood Gym

Professionals have suggested more specific emphasis is needed on the two biggest mental health issues for adults with AS, anxiety and depression, with a major goal of creating coping strategies for these two significant mental health issues (Ghaziuddin, et al., 2007).

Mood Gym is a free self-help internet based programme developed by Dr Helen Christensen and Dr Kathy Griffiths in 2001 at the Centre for Mental Health Research at the Australian National University to teach Cognitive Behaviour Therapy (CBT) for people vulnerable to depression and anxiety.

Physical Exercise

Research has confirmed that physical exercise can be helpful in reducing depression in the general population. The Brisbane Clinic has also found it helpful in people with AS. The term energy management is used to describe the

intervention, which is also used as a means of channelling emotion. There is a preference for using a personal trainer rather than gym attendance but walking, running, the use of a trampoline, fencing, weight lifting, golf, dancing, surfing, drumming were all cited, that is, individual rather than team sports, as helpful.

Relaxation techniques

This includes relaxation training, meditation, yoga, music, solitude, massage, comedy, repetition, sleep and routines. Stress management techniques relating to the area of difficulty can include wallet sized cards to act as reminders. (Brisbane)

Social Stories

This is a tool for teaching social skills, which provide the person with explanations about situations that people find difficult or confusing. Carol Grey developed the tool for children in 1991. Research Autism has found good evidence in some children of an associated reduction of unwanted behaviours and some negative aspects of social interaction. Services have customised the techniques to become “drama classes” for social situations and relationships e.g. How to ask someone out (Garnett - Brisbane).

Task Analysis

A feature of several approaches ABA, TEACCH, Active Support.

ABA Applied Behavioural Analysis is an approach in which behavioural interventions are used to build positive behaviours and skills and to suppress unwanted behaviours. Applied to autism in the 1960s in the USA, one of the characteristics is to break down goals into small steps. An example of this is described by Veasey (2011), where a young man with AS was referred to them for advocacy for employment but was found to have been housebound for two years. There was therefore a need to work towards the goal by identifying interim steps such as getting up at a certain time, wearing appropriate clothing, using public transport, etc which can take many months to achieve.

TEACCH Treatment and Education of Autistic and cognitively handicapped Children.

Developed in North Carolina in the mid 60s, this approach aims to improve adaptation to everyday life by improving skills in a very structured way often using visual methods. One such method is to break down a task such as going to the dentist into a series of small steps to acclimatise to location, waiting room, dental surgery, dental staff, noise, lighting, duration, etc.

Active Support

Developed in the 1980s and in the UK led by the Universities of Bangor and Kent, its approach is to support active involvement and

engagement in meaningful activities and relationships. It involves a very structured approach including breaking down daily living skills or socialising into small steps.

Use of Language

Members spoke of the need to use logic in discussion about issues e.g. going into great detail about biological hazards of lack of attention to personal care to support the promotion of good hygiene. Mantras such as “Remember, Remind, Consequences” are being successfully employed. Self Talk, whilst not evaluated as yet, is used in Brisbane to support positive behaviours.

DRAFT

4.2 What is not working

The group identified a number of **obstacles** to delivery of effective services for people with Asperger syndrome:

Poor access to services. There is often no clear pathway to diagnosis or post diagnostic clinical support. Other teams such as those in Learning Disabilities services have access to Speech and Occupational Therapy, Supported Living Coordinators, Adult Placement Scheme workers and Family Carer workers. The absence of this support in most of the existing AS services, increases pressure on the AS team members and limits access to the full range of essential services.

Inappropriate assessment processes. Incorrect assessment against Local Authority Fair Access to Care criteria results in weeks and months of delays if inexperienced assessors fail to pick up the needs of people with AS. Many areas have reduced access to support only to those people defined as having 'Critical' or 'Substantial' need, without having introduced autism friendly assessment processes, which give appropriate weighting to the difficulties people with AS experience. Useful advice is contained in GAP Magazine October 2011 edition "How can adults with Asperger syndrome contribute most effectively to their community care assessments."

Understanding Asperger syndrome. Support planning requires a different approach when working with this group compared to others. Asking people to imagine what their future might look like is not a technique that works and goals need to be broken down into small, manageable stages.

Inadequate resources. A shortage of accommodation and support solutions for young people in transition who would like to leave home but cannot, leave families unsupported, with services only becoming involved when crisis situations occur. This leads to avoidable distress and significant unnecessary additional costs for Local Authorities.

Rigid commissioning systems. Difficulties are experienced in Local Authorities commissioning very small packages of support, for example, when some people may only need 2 hours a week or short-term assistance at irregular intervals.

Inappropriate service structure. Mixing people with AS with services for people with learning disabilities were felt by the people with Asperger syndrome present and the existing teams to be extremely unhelpful often leading to alienation and withdrawal from services.

Lack of continuity of support. Closing cases were problematic. Various strategies to offer continuing support were identified although teams were struggling with caseloads. In practice people who may appear to have resolved their difficulties will often need immediate access to support on an irregular basis, as a means of crisis prevention.

5. NAVIGATING RISK

Many people with AS experience particular vulnerability due to their condition in relation to understanding risk. This could include daily activities such as crossing the road or cooking safely, to the inability to judge the intentions of others or the impact of their actions on others.

Safety

“Many people with AS can be oblivious to dangers that lurk in every community and must be trained to avoid dangerous situations where possible and cope with them when necessary”

Petersilia,2001.

Training programmes are needed for situations such as getting lost, seeking privacy in public toilets, in understanding the difference between strangers and friends and learning how to interact with each. For people with Asperger syndrome who drive dealing with emergencies, accidents, and possible confrontations with other drivers are important priorities (Ratto & Mesibov 2011). Personal safety such as self defence classes and ad hoc advice needs to be given, such as during the recent disturbances in London where clients were alerted to stay in their homes. Investment in Autism Alert Cards schemes in Local Authorities has also proved to be valuable.

Use of computers

Whilst many young people with AS find the Internet a comfortable environment to operate in as they feel in control of their world, it also presents significant risks. Online gambling, excessive spending, child pornography, hacking, dating sites, extremist groups, and online bullying were all issues that the teams were grappling with.

One word of warning

It's quite possible with my condition to be taken over by some extremist political group (right or left) or even some extremist religious group who will use you as a cipher repeating everything they tell you. Asperger people want to be accepted so much that even when they know they are being used, they go along with it

Jean Tee (2011)

Sexual Issues

Better sex education and a better understanding of sexuality have often been cited as important unmet need (Stokes and Kaur, 2005). The limited studies available on sexuality have found that the majority of individuals with AS express interest in dating and physical intimacy and are engaged in sexual behavior (most commonly masturbation), but often lack basic factual knowledge about anatomy and sexuality (Ousley & Mesibov, 1991). Sexual education for individuals with AS should address the topics of privacy, personal hygiene, appropriate forms of physical contact with others, anatomy, and comprehensive sexual education tailored to the needs, interests, and cognitive ability of each individual (Koller,2000). Although little research is available on the efficacy of intervention strategies, behavioral programmes have been generally effective in treating inappropriate sexual behaviors in public (Ratto & Mesibov 2011). Teams found this a difficult area where people were often both victim and perpetrator. It was felt important that there was joint work with Safeguarding Adults Lead Practitioners so that the risks are understood. (Veasey 2011)

The criminal justice system

Individuals with AS are more likely to be victims of crime and abuse than typical individuals. They also have more difficulty reporting their victimisation (Petersilia, 2001). Teams reported an increase in 'Hate and Mate' crime where behaviour from so called 'mates' could more accurately be described as abusive and exploitative. There is increasing evidence that individuals with AS might be overrepresented in the criminal justice system (Cashin & Newman, 2009). They suggest that the majority of offenders with AS have co-morbid psychiatric and/or substance abuse disorders. Child pornography is another crime for which they are more and more frequently convicted. Murrie et al (2002) reported that the majority of people with AS are "scrupulously law abiding" but a subset who do offend are disproportionately difficult to treat, and challenging and expensive to support. Difficulties in communication, empathy, and social understanding, as well as the tendency toward preoccupations and repetitive behaviours may put individuals with ASD a greater risk of perpetrating crimes, often without full comprehension of the nature and implications of their acts (Mayes, 2003).

6. OUTCOMES

Demonstrating effective outcomes to Commissioners is essential for continued funding. Research shows that whilst improvements in language, communication, conversational skills and responsiveness, and social integration can be made, social functioning and quality of relationships remain significantly impaired. (Ratto & Mesibov 2011).

At a national level the Mental Health Outcomes framework was developed in 2009 by the Social Inclusion Unit and this provides a useful tool. At a local level the Liverpool team has piloted a self assessment framework exemplified below. The initial results were shared at the meeting and had been found to be helpful in demonstrating value.

	Much better	A little bit better	There's been no change	A little bit worse	Much worse	Responses
Having basic needs met - such as food, sleep and keeping warm	25%	25%	50%	0%	0%	12
*Your risk of being hurt by other people	8%	33%	58%	0%	0%	12
*Your risk of hurting other people	33%	0%	67%	0%	0%	12
*Your risk of deliberately hurting yourself, including suicide	67%	8%	17%	8%	0%	12
Your employment situation	8%	0%	75%	8%	8%	12
Your housing situation	25%	8%	67%	0%	0%	12
Your physical health	17%	17%	50%	8%	8%	12
Getting on with your family	17%	33%	33%	17%	0%	12
Making and keeping friends	8%	50%	25%	17%	0%	12
Feeling accepted by your family	8%	33%	50%	8%	0%	12
Sexual/intimate relationships	8%	17%	75%	0%	0%	12
Your self-esteem	50%	25%	8%	17%	0%	12
Your confidence	33%	33%	17%	17%	0%	12
Achieving your goals	8%	42%	33%	17%	0%	12
Feeling respected by other people	8%	58%	33%	0%	0%	12
Respecting other people	8%	50%	33%	8%	0%	12
Having a purpose in your life	17%	42%	33%	0%	8%	12
Accepting who you are	25%	42%	17%	8%	8%	12
Fulfilling your potential	8%	50%	25%	8%	8%	12

CONCLUSION

Whatever method is chosen to evaluate the many varied approaches in use, the key measurable, as noted at the beginning of the document is whether the needs and aspirations of the person with Asperger syndrome are being met.

7. MEMBERSHIP OF EXPERT GROUP

In alphabetical order

Kandasamy Abarjitha	Person with Asperger syndrome
Kate Allen	The Kingwood Trust
Chris Austin	Liverpool Asperger Team
Anne Clothier	Person with Asperger syndrome
Adam Feinstein	Looking Up and Awareness (Autism Cymru)
Dr Michelle Garnett	Minds and Hearts Clinic, Brisbane (AUS)
Hilary Gilfoy	Previously - Autistica
Countess Guerrini-Maraldi	Parent
Eileen Hopkins	Autistica
Lady Hornby	The Kingwood Trust
Paul Lamdin	Person with Asperger syndrome
Joel Letort	Person with Asperger syndrome
Dr Jenny Longmore	NeuroKnowledge
Melissa McAuliffe	East London NHS Trust
Professor Gary Mesibov	UNC School of Medicine (USA)
Chris Mitchell	Adults with Asperger syndrome Team Nottinghamshire
Sue Osborn	The Kingwood Trust
Becky Pinniger	Parent
David Pinniger	Parent
Carol Povey	National Autistic Society
Dame Stephanie Shirley	The Shirley Foundation
Jean Tee	Person with Asperger syndrome
Gail Tomlinson	Person with Asperger syndrome
Simon Veasey	Warwickshire Adult Autism and Asperger Services
Susan Williams	Independent Consultant
Dr Lorna Wing	Consultant Psychiatrist

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