

Meeting the needs of adults with Aspergers Syndrome to access work and employment

A Local Information Resource

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Introduction and Acknowledgements

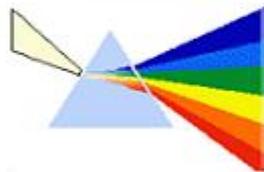
This booklet has been compiled by D.A.S.H. – Discovering Autistic Spectrum Happiness – to raise awareness of Aspergers Syndrome in adults and to offer practical information to local service providers about meeting the needs of their clients.

Acknowledgements

Much of the information contained in this booklet has been sourced from a one day awareness raising conference held in Swindon in June 2005 with the kind permission of the Adults with Autistic Spectrum Disorder Assessment and Diagnostic Service in Swindon (AASDADSS) – forerunner of the NHS Assessment and Diagnostic Service.

DASH

Discovering Autistic Spectrum Happiness
Reg charity no: 1116852



DASH is an independent local charity whose mission is to improve the quality of life of adults of working age with Aspergers and other high functioning Autistic Spectrum Conditions living in Swindon.

Our primary aims are to:

- Raise awareness of Aspergers;
- Promote and enhance access to assessment and diagnosis, post diagnosis support, welfare and care, housing, education and employment;
- Research, promote and help to deliver a local model of support and services.

In this way we will help people with Aspergers Syndrome to enjoy safer, healthier, more sociable, more productive and happier lives.

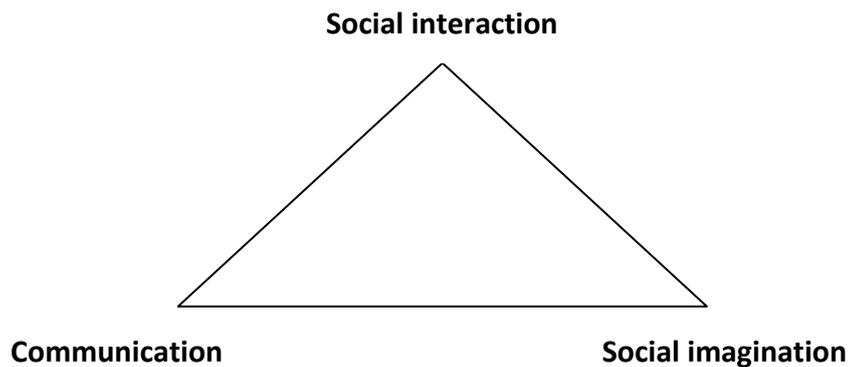


Reg. Office: 284 Marlborough Road, Swindon, SN3 1NR
Email: info@dashswindon.com
www.dashswindon.com www.swindonwildflowernursery.com

Autistic Spectrum Disorders in Adults

Autistic Spectrum Disorders are lifelong developmental disorders. They can be accompanied by mental health problems but are not in themselves a mental illness.

Autistic Spectrum Disorders are often described in terms of 3 main 'impairments' – namely social interaction, communication and social imagination.



Aspergers Syndrome

Aspergers Syndrome falls in the range of Autistic Spectrum Disorders but people with Aspergers Syndrome don't exhibit the classic features of autism. People with Aspergers syndrome usually have:

- Fewer problems with language and can tell us their experiences, inner feelings and states;
- Are often very intelligent and do not usually have accompanying learning disabilities often associated with autism;
- Many adults with Aspergers Syndrome can and do go on to further education and employment, although sustaining these can be problematic unless employers and colleagues are well-informed and supportive.

Aspergers Syndrome has an estimated incidence of 39 people per 10,000 head of population and affects mostly men.

So in a population of 220,000 as in Swindon, there might be 858 people at any one time – some of whom may be leading happy, fulfilling, if idiosyncratic lives with manageable difficulties and some of whom are likely to be entrenched in mental health services, unable to cope with the misery and frustration of their 'hidden' disorder and with, for example, a diagnosis of depression, schizophrenia or schizoid personality disorder.

Characteristics

Adults with undiagnosed Aspergers Syndrome may present with some or all of the following characteristics:

- Difficulty with social relationships – lack of empathy, naive, inappropriate, one-sided interaction, little or no ability to sustain friendships even whilst wanting to be sociable and enjoy human contact;
- Difficulty with communication – in some situations the person with Aspergers Syndrome can communicate very well – sharing matter of fact information can be excellent but they may still have poor non-verbal communication. People with Aspergers Syndrome find it hard to understand non-verbal signals and can be unaware of the needs of other people. People with Aspergers Syndrome may speak fluently but they may not take much notice of the reaction of people listening to them. Despite having good language skills they may sound pedantic or over literal;
- Limitations in imagination. Whilst they often excel at learning facts and figures, people with Aspergers Syndrome may find it hard to think in abstract ways. They may appear to be remarkably creative but it can be a perfect duplication of an original source;
- Special interests – intense absorption in certain subjects can be usefully utilized in study or work. Some interests may help a person to develop social skills. On the other hand, if an obsession develops, this can be very distressing and counter productive;
- Love of routines. People with Aspergers Syndrome often find change upsetting. They may try to inappropriately impose their routines or set patterns for the day on others. They may not be able to recognise what may be necessary in a situation;
- Cognitive flexibility. Thinking may be rigid and not adapt to change or failure. A person may have difficulty learning from mistakes;
- Attention. People with Aspergers Syndrome may have difficulty dividing their attention, such as following more than one conversation at a time;
- Sensory sensitivity – some ordinary sensations may be perceived as unbearable intense, such as TV. The mere anticipation of the experience can lead to intense anxiety or panic;
- Clumsy and ill-coordinated movements and odd postures.

Why diagnose?

Not all people with Aspergers Syndrome will request or require mental health services but those that do may be diagnosed with obsessive compulsive disorder, schizophrenia, depression or anxiety. Quite simply, without assessment and diagnosis people with Aspergers Syndrome are at risk of receiving the wrong treatment!

A common downward spiral (National Autistic Society 2001)



The distress of people with undiagnosed or even diagnosed Aspergers Syndrome cannot be over-estimated, especially if their needs are not acknowledged or are misunderstood. Assessment and diagnosis can provide the framework for better understanding of their problems, inform their care plan and facilitate access to appropriate resources – hopefully leading to a better quality of life! It can also limit blame and guilt.

Assessment

Swindon NHS first commissioned an Assessment and Diagnostic Service as a pilot scheme in Oct 2010. This is now provided by SEQOL and is accessible to any adult who suspects they may have and ASC via their GP.

When people are referred to this service they are initially offered a self reporting questionnaire that acts as a screening tool for assessment. There is a threshold above which people are put forward for a full assessment.

Assessment itself examines specific aspects of social skills, language skills, cognitive abilities, movement skills, specific interests and obtains a developmental history.

It involves client interview, questionnaires and tests; family member interviews and questionnaire, other professional reports and observations to reach a conclusion.

Resources are currently needed for this service to meet demand and reduce waiting time. But even so demand may currently be suppressed by lack of information and understanding on the part of potential referrers eg CPNs and GPs.

Taking Responsibility

The needs of adults diagnosed with Aspergers Syndrome have been well documented in a report by the National Autistic Society in 2002 called "Taking Responsibility". It highlights the need for;

- A training and awareness programme to increase professional understanding;
- A clear support pathway for families to request diagnostic assessment;
- A clear support pathway for families to request Care Act assessment;
- Improvement of employment opportunities and support;
- Interventions to reduce social isolation;
- Interventions to reduce clinical mental health difficulties;
- Interventions to develop independent living skills and relationships;
- Better post-diagnosis emotional support, information and advice for people with Aspergers Syndrome;
- A range of appropriate supported housing options;
- Better social and learning opportunities (and academic support) within education;
- Carers needs to be assessed and met;
- More appropriate service provision e.g. appropriate placement;
- Access to advocacy services;
- Sensitive Crisis Services

The Harsh Reality

People with Aspergers Syndrome are often very intelligent and know what it is that they want. It can be very traumatic for them if they are aware that they are either not being heard or they can't get what it is that they want, for reasons that don't appear to them to be rational. Occasionally, long term frustrations can eventually v themselves in angry outbursts or other behaviour that is unacceptable to others.

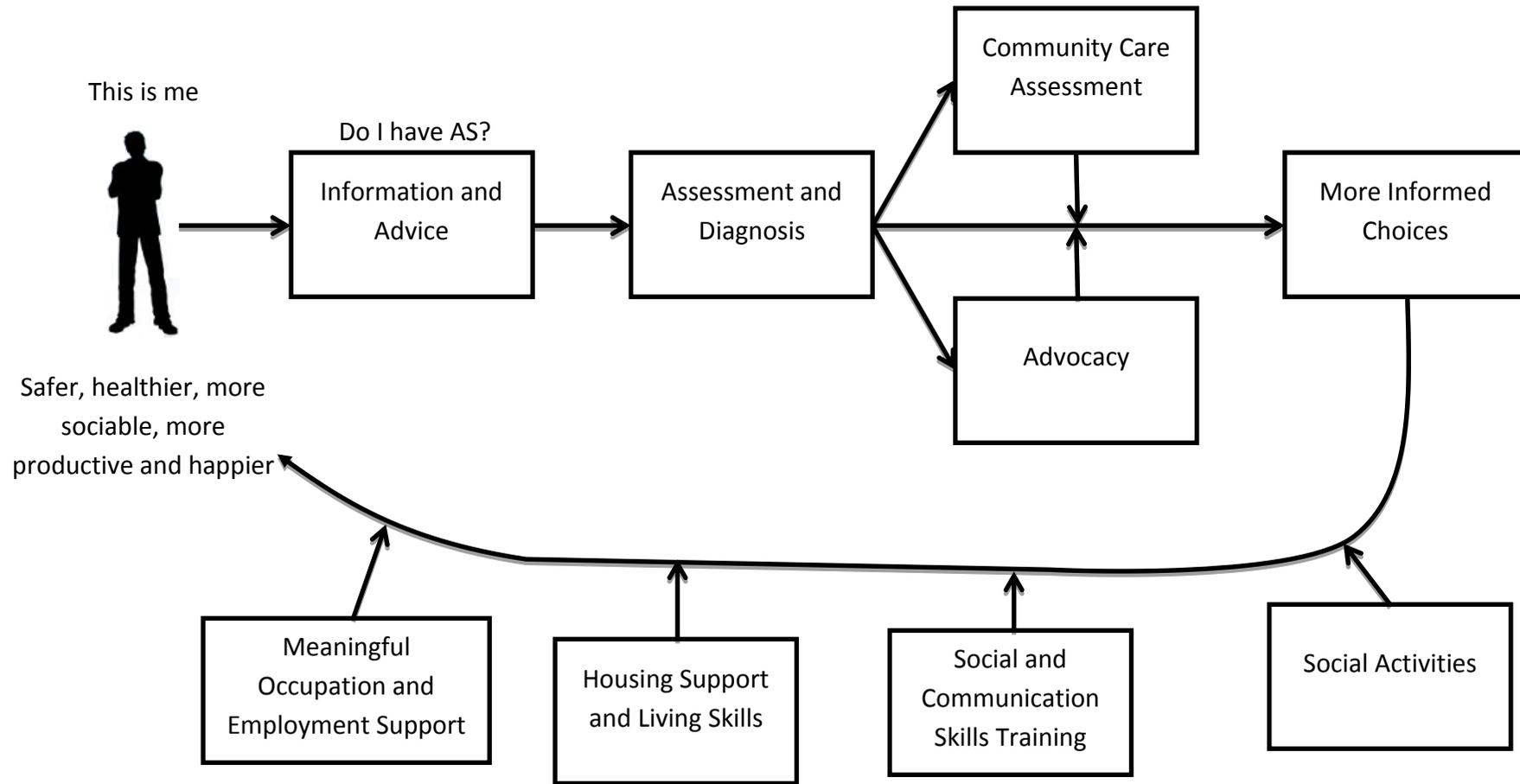
Even in mental health services, without appropriate on-going, regular support including an opportunity to talk regularly about their fears and interpretation of events, a crisis may not be far away and without resolution of these fears and anxieties, people with Aspergers Syndrome often become stuck and unable to move on.

On the other hand, if they are diagnosed with Aspergers Syndrome and their mental health problems are sufficiently resolved, they may face discharge from mental health services and no ongoing support to help them cope with daily life.

If there are no family members who can offer support, profound social isolation may result as the means of avoiding difficulties and conflict. This is often the case for people with Aspergers Syndrome despite desperately wanting to be part of the community and to use their intelligence and special aptitudes to contribute to society.

Young people moving from dependence to independence and the world of work, adults with the additional burden of poor mental health and adults leaving mental health services, **all** require the same package of integrated support around housing, daily living activities, social interaction, therapy, skills training, work and employment.

'This is Me'



Support and Therapy

Social Support to combat social isolation:

- Existing community activities
- Befriending schemes
- Social groups – general or Aspergers Syndrome
- Discussion groups
- Interest groups
- Physical activities

Practical support:

- Help with accommodation
- Financial/benefits
- Routines, home skills, safety
- Personal care, diet, sleep, illness
- Community skills such as using; bus, going to pubs, GP etc

Skills Training:

- Social skills – listening, turn taking, questioning, personal space
- Assertiveness training – rights and responsibilities, boundaries, dealing with criticism, passivity and aggression

Therapy:

- Individual
- Non-interpretive
- Non-anxiety provoking
- Clear structure
- Routine e.g. time place duration
- Concrete, intellectual, rational
- CBT

CBT:

- Increases awareness of behaviours and thought patterns
- Sets behavioural goals collaboratively
- Looks at “automatic” versus “rational” thinking patterns
- Encourages self-monitoring and self sufficiency
- Relaxation training

Handy Hints – Social Skills Support

Suggestions for meeting the needs of people with Aspergers Syndrome who use your services.

Think about The Stress Factor!

- How does stress affect the way you function?
- Does it mean you make mistakes more easily?
- Distracted, so not reading signals?
- Maybe more awkward than normal?

These all need to be considered in relation to clients we support with Aspergers.

What might help?

- Understand what triggers anxiety and stress
- Keep stress levels down
- Clear instructions on key tasks – think carefully about jokes/inference/sarcasm, use visual aids ie pictures/charts
- Honest and supportive feedback

Social Behaviour

- Emotional pleas don't work
- Neither does subtlety
- Talk about one thing at a time
- Be specific in giving instructions
- Allow space
- Don't expect mind, emotion or behaviour reading
- Never force someone to socialize
- People with Aspergers Syndrome are happy to be by themselves and do their own thing
- Going out to meet others or having them round for social occasions makes them nervous
- Crowds are not fun
- Help people with Aspergers Syndrome observe other people in social situations
- Use social stories to understand cues and actions for specific social situations
- Develop empathy with poetry
- Practice reading and using body language
- Use safety phrases when confused e.g. "I did not mean to upset you"
- Research emotions one at a time

- Expressing emotions; video role play to provide subtle or precise expression of emotions
- Read Jackson (2002, p.175) for advice on dating

Language

- Pragmatics; social stories and role play
- Literal interpretation; predict misinterpretation, explain metaphors
- Pedantic speech; keep concrete and precise
- Idiosyncratic word; genuinely creative
- Vocalising thoughts; 'think don't say'
- Auditory discrimination; check understanding pause

Interests and routine

- Special interests; talk about them, acknowledge expertise
- Constructive application
- Routines are imposed to make like predictable
- Try compromise, scheduling
- Reduce anxiety

Thinking

- Theory of mind; role play and learning perspective taking
- Stop and think how the person will feel
- Use memory strategies
- Learn to ask for help
- Imaginary worlds can be a form of enjoyment
- Practice visualisation

Sensory Sensitivity

- Auditory; avoid some sounds, music can camouflage, minimize background noise, consider ear plugs
- Tactile; duplicate tolerated garments, sensory integration therapy
- Visual; avoid intense light, use sunglasses/visor

Employment Support

Typical job attributes of people with Aspergers Syndrome

- Conscientious
- Punctual
- Get on with the task, less social chit-chat
- Honest
- Direct
- Reliable on routine tasks
- Able to spot errors
- Interesting viewpoints
- Areas of expertise

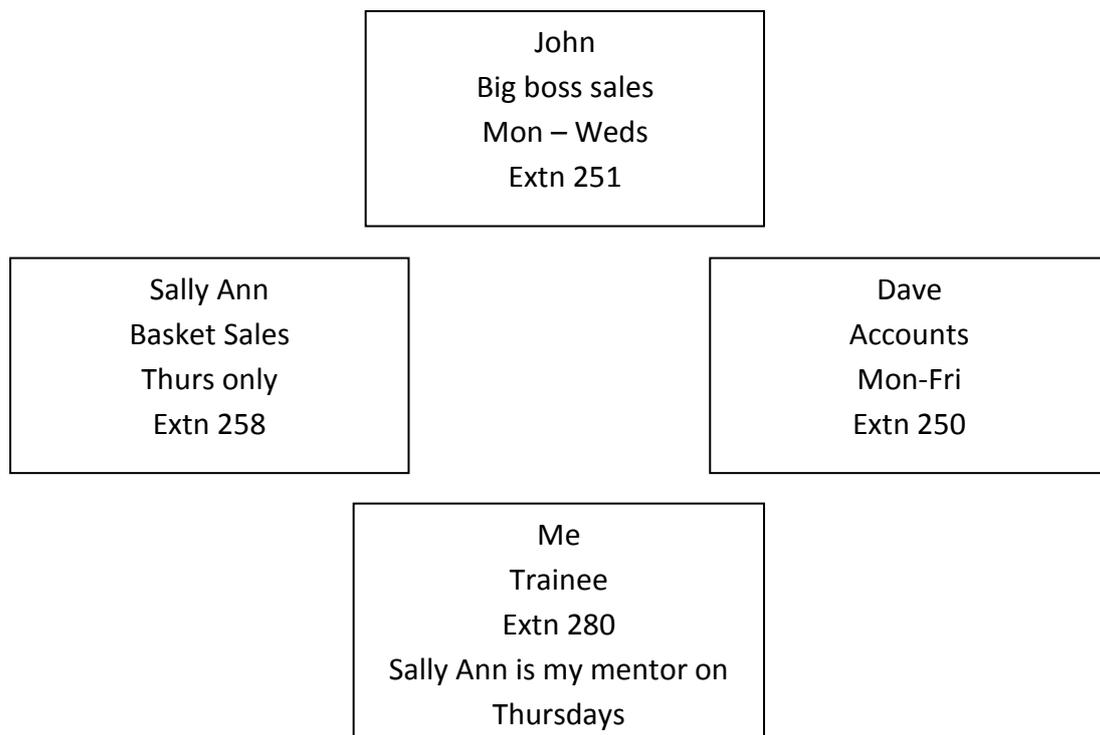
The most suitable jobs for someone with Aspergers Syndrome tends to

- Involve attention to detail
- Be fairly predictable
- Be guided by systems, procedures and processes
- Allow the person to work alone quite a bit
- Use any ability in memory for facts
- Not be in highly pressured 'deadline' environment
- Not involve lots of complicated social contact, or supervising of others

Basic Guidelines

- Anything merely implied will probably not be understood by a person with Aspergers Syndrome.
- Be clear!
- Always provide a type of work that is going to match the person's particular strengths and talents.
- Contingency plans for dealing with unbearable stress e.g. a place to go for a break, and contact with someone who will give support.
- Immediate clear and open feedback about the standard of work done.
- Who will supervise or manage if you are not in?
- Clear line management and an informed supervisor or mentor, who can be available to give rapid advice.
- Do be aware that asking for help may be difficult for the person, you may need to 'teach' him to do this.

For example – in such an organisational network:



Too much Stress?

If I am feeling too stressed to work properly I can:

- Go to quiet room
- Go to the canteen

If I still feel stressed I can:

- Go and discuss with John (extn 251)

If I get stuck or need advice:

- Everyone in the office gets stuck with work sometimes
- It is important to ask someone for advice if I get stuck
- I can speak to Sally-Ann if the problem relates to basket sales
- I can speak to John if the problem relates to accounts
- If it is Thursday I will go to Dave for all problems NOT John

Basic Guidelines

- Clear specific job tasks which are put in written form to the employee
- Diagrammatic or pictorial instructions of job tasks should be considered

Daily Work Structure Sheet

Date	Work to complete	Reminders to myself
07/06/13		
9am		
10am	Check post room	Coffee break
10:30am		Check with John how work is going
11am	Start filing or finish photocopying	Canteen if not too busy at 11:30
12pm		
1pm Lunch		Take time out – do not stay at desk

Work Request From

Date	Name	Work Request	Completion Date	Any other information
Monday 7 June	Fred	Filing new data	Friday 11 June	See Fred on Thursday pm to update

Carers Support Groups

SCAAS Support for carers of Adults on the Autistic Spectrum

This is a group for anyone who cares for a person (Over the age of 16) who has autism or Aspergers Syndrome. The aim is to provide support and information for each other. Professionals are invited to speak on various topics at some meetings.

We meet on the last Wednesday of the month, except July and January when, instead, social events take place for members and their families (usually a barbecue and a skittles evening). We do not meet in August and December, as many people are unavailable due to holiday preparations.

Meetings take place at Farleigh College base room (which is located on the North Star Site, by Swindon college) starting at 7.30p.m. and usually go on for an hour or two, with tea, coffee and biscuits being provided.

Contact Nicola Brownless Email: nocola.brownless@ntlworld.com tel: 01793 524410

Parent 2 Parent

Are you a parent or carer of a child with Autism, ASD, Asperger Syndrome, PDD NOS or any associated condition? If so would you like to chat to others who really understand the challenges because they too are parenting a child with these conditions?

Come and join us for a chat and a cuppa!

We meet on a Tuesday from 1-2.30pm at Ruskin school, Wordsworth Drive, Stratton

And on Tuesdays 1.15-2.30 at Drove Children's Centre, Plymouth St

Accompanying children welcome

Contact Hazel Clarke email: hazelclark0@gmail.com Tel: 01793 702528

Wednesday Evening Meetings

This is an Evening group (8pm start) for anyone who cares for a child/young person who has Autism or Aspergers Syndrome. The group provides mutual support, information and signposting.

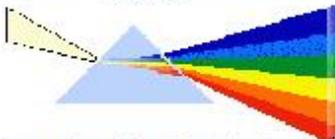
We meet on the first Wednesday of the month, during term time.

Contact: Christine Rogers email: rogersc@ntlworld.com Tel 639442

Local Information and Advice Services

DASH

Discovering Autistic Spectrum Happiness



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Registered charity no: 1116832

in partnership with
Swindon & District Branch



The National Autistic Society

Other facilities available at
Pinetrees Community Centre

- CAB: Mon, Wed & Thurs: 10 – 12; over 55s on Thurs only.
- Library with internet access: opening times variable. For info: 07785 454 357
- Café: 9am – 2pm
Mon – Fri. Hot lunches
Tues & Thurs



Swindon Autism Information and Advice Service

For everyone on the autistic spectrum of all ages and their families, and those employing, working with or supporting people on the autistic spectrum.

Where:
Office 2, 1st Floor (lift available)
Pinetrees Community Centre,
The Circle,
Pinehurst SN2 1RF

When:
Tuesdays: 2 – 4
Wednesdays: 10 - 12 and 5 - 7
Thursdays: 2 – 4
Saturdays: 10 - 12

How:
The above are 'drop in' sessions with no need for an appointment. If we can't meet your need for information & advice in the 'drop in' we will offer you a 1: 1 follow up meeting.

Parking & public transport:
A large free car park & bicycle shelter is available at back of building. Bus no 11 stops just before the circle coming from the town centre just 50m from the building.

How to contact us:
Email: info@dashswindon.com
Mobile: 07554 665 715 (Tuesday – Thursday inclusive & Saturday 10 – 12)



Further Information

An excellent source of information is:

National Autistic Society (NAS)
393 City Road
London
Telephone: 020 7833 2299
Email: nas@nas.org.uk
Website: www.autism.org.uk

Autism Helpline:
0845 070 4004