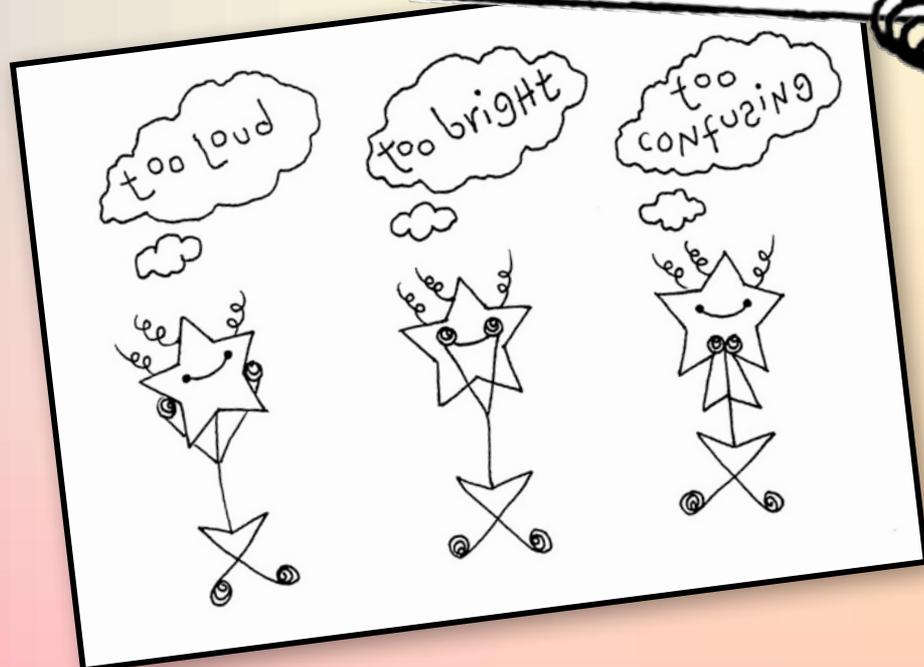# Understanding Autism

## A training pack for support staff and professionals based on 'Postcards from Aspie World'



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Pavilion

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Set of 'Postcards from Aspie World', including accompanying life stories booklet and information on how to use the postcard set.

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# Introduction

Dan Redfearn

## The need for a training resource on effective support for people on the autism spectrum

The fundamental idea underpinning this resource is that the lived experience of marginalised people is a powerful learning tool. In this case, the words and experiences of people with autism will aid participants to develop strategies to reduce the impact of the negative, and enhance the impact of the positive implications. By using the *Postcards from Aspie World* resource and by supporting participants to use examples of learning from their own experiences, this resource will encourage a consideration of what life is like for people on the autism spectrum and their families, and as a practitioner what they can do about it.

There are a significant number of drivers that support the need for such a training pack focused on the needs of people with autism. Prevalence studies identify that approximately one in 100 people are on the autism spectrum (Brugha *et al*, 2009), yet a series of governmental and charity reports (Department of Health, 2006; 2010; Rosenblatt, 2008) concur that people with autism are one of the most marginalised groups in society, whether that be in terms of societal awareness and community inclusion, access to services, or being able to live an independent life, which includes employment opportunities.

The above evidence emphasises the need for a greater awareness and understanding of the needs of people with autism generally, but specifically in health, social care, education and other services such as employment and the criminal justice system. The Government's vision formalised in the Autism Act (2009) and *Fulfilling and Rewarding Lives* strategy (Department of Health, 2010) for adults with autism in England, was to ensure that: *'All adults with autism are able to live within a society that accepts and understands them. They can get a diagnosis and access support if they need it and they can depend on mainstream public services to treat them fairly as individuals, helping them to make the most of their talents'* (Department of Health, 2010). This vision was underpinned by a recognition that services needed to respond better to individuals' needs and that a greater level of awareness and understanding was required to achieve this.

The official review of the strategy (Department of Health, 2014a) accepted that while some progress was demonstrated more needed to be done, and identified 15 priority challenges for action. Three of these directly relate to the need for a better understanding of autism, how it might impact on individuals and how practitioners and services can respond to their needs.

*'I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am. I want the staff who work in them to be aware and accepting of who I am.'*

*'I want staff in health and social care services to understand that I have autism and how this affects me.'*

*'I want people to recognise my autism and adapt the support they give me if I have additional needs such as a mental health problem, a learning disability or if I sometimes communicate through behaviours which others may find challenging.'*

(Department of Health, 2014a)

The need for a better understanding of autism is also implicit in the other 12 challenges and is suggested in some of the more detailed actions required to achieve them.

If people (and services) that support individuals with autism are going to fulfil these identified priorities, they will require a level of knowledge and understanding not only about the condition, but also about how it impacts individuals. One way of supporting this development is through training. This resource aims to achieve this by providing materials that can be delivered to participants to give them a good understanding of autism, how it might impact on individuals and how they can be supported effectively. Only by having this knowledge and approaching their support in a person-centred way, will they be able to develop effective strategies and ways of working that will ultimately improve the experience of people on the autism spectrum.

The Equality Act (2010) requires services to make reasonable adjustments in order to deliver equal treatment to all users of that service. It is all too easy to think of such adjustments as physical alterations to environments, but they also include considerations relating to the adaptation of working practices, and both can be required when considering the needs of someone with autism. In order for people to make reasonable adjustments to their services and practices, they must first be able to recognise and understand the need for them and then think about what and how they can be implemented. This resource will support learners in both these areas, as it follows a very practical approach to learning. It is deliberately practice focused and avoids major discussion of theoretical approaches to understanding and intervention for autism, instead preferring to emphasise and explore how people with autism can be supported effectively, with specific attention to the individuals that participants are currently working with, as well as how more general services can respond to individual need.

Central to this resource is the promotion of a person-centred approach to the support of individuals with autism. Person-centred approaches are rooted in the belief that people with disabilities are entitled to the same rights, opportunities and choices as other members of the community. They are concerned with the whole of someone's life, not just their need for services (Sanderson *et al*, 1997). They also challenge the traditional notion of independence by seeing it in terms of choice and control, rather than physical capacity to carry out particular tasks. Person-centred approaches go beyond 'needs' to consider people's aspirations, are not limited by entitlement to services and are not necessarily dependent upon professional involvement.

While the term 'person-centred approaches' is relatively new, it relates to a set of values and ways of working that have roots within much wider historical movements that have challenged the way that people with disabilities are included in society (O'Brien & O'Brien, 2002). These include the social model of disability, the inclusion movement and the development of self-advocacy, all of which seek to challenge the way that disabled people are viewed in society and provide frameworks for inclusion, rights and independence.

The term 'person-centred planning' has often been used as a way of describing a collection of tools or strategies that can be utilised by individuals who use services (Sanderson *et al*, 1997). However, while tools and templates may help to prompt ways of supporting people in a more person-centred way, unless they are utilised within a person-centred way of thinking and working, they will not have the desired impact. They must be used with the intention of giving people who have disabilities more positive control over their lives and making sure that services do a better job of listening to what people who use them really want, and then making sure it happens. Person-centred planning is a process for continual listening and learning, focusing on what is important to someone now and in the future, and acting upon this in alliance with their family and friends.

In response to the autism strategy and the recognition of the need to raise awareness and develop knowledge in relation to understanding needs, a number of online training resources have been developed – some of which are freely available. While acknowledging that these learning tools have their place and are helpful for some people, this pack has been developed with recognition of the importance of collective learning. The central philosophy is that participants are supported to reflect and learn from their own practice and experiences in light of new knowledge, and thereby consider new approaches and ways of working that are relevant to their own areas of work and the individuals they support. This course therefore provides significant opportunities for shared learning, and the resource is based around using the lived experiences of an individual on the autism spectrum as well as reflections on current practice, to develop better understanding and shape future support. This should help to enhance the skills of the participants in their work place, rather than just giving them knowledge in the classroom.

## A note about terminology

There is much confusion and debate around the terminology associated with the autism spectrum and it is easy to allow this to detract from more important aspects of ensuring that people are given rights and support to be full and active citizens in society. It is not the place of this resource to give an opinion on what or how we should use terminologies, but it will follow the principle of using a consistent approach that encapsulates all labels and diagnoses associated with the autism spectrum including Asperger Syndrome.

'Autism' and 'the autism spectrum' will therefore be used throughout the training materials.

# Who might benefit from this training?

This training pack will be useful to a wide range of practitioners and any staff working with individuals with a diagnosis of autism, those suspected of having autism and those who may come across individuals with autism in the course of their work. This will include both clinical and support staff across health and social care services as well as in other settings, such as employment services and the criminal justice system. This may include:

- Personal assistants
- Support workers
- Service providers and managers
- Nurses (in all fields and specialisms)
- Social workers
- Speech and language therapists
- Occupational therapists
- Psychologists
- Doctors (including GPs and psychiatrists)
- Reception staff
- Porters
- Security staff
- Advocates
- Volunteers
- Legal representatives
- Police
- Job centre staff

Please note that this list is not exhaustive but provides examples to indicate the breadth of people who would benefit from the training, as they are likely to need to provide support to an individual in the course of their work.

The training will be of particular benefit to those who regularly support individuals with autism and who want to develop their knowledge and apply it to their support of a specific individual or practice area.

It may also be useful for parents and other family carers of people with autism.

The training pack does not require any prior training, knowledge or experience of autism and can be tailored to the individual learning needs of participants – please see the section on using the training resource on p16.

Some examples of settings and situations in which the training resource can be used:

- Community learning disability staff could use it to train colleagues and other professionals working in generic services such as a mental health ward, outpatients department or a GP practice.
- A manager of a residential learning disability service may use it to train the staff team who are supporting a person with autism.

- Local authorities and service providers could use it as part of their induction requirements or in-house training and staff development programme.
- A specialist practitioner in autism could use it to train family carers and personal assistants to enhance their knowledge and support of the individuals they are caring for.

While the training resource can be used as a chronological course lasting 1½ – 2 days, it can also be delivered in shorter sessions over a longer period of time, or with specific sessions targeted towards a specific need. For example:

- It may be that participants or a staff team have a good basic awareness of autism and so with a quick revision session may move directly to understanding the triad of impairment (**Session 3**) or any of the 'Supporting someone with…' sessions (**Sessions 4, 5 & 6**) or activities.
- Trainers may have been asked to provide some basic awareness training to hospital reception staff who may have only minimal contact with people with autism. This may focus on the 'Understanding Autism' session (**Session 1**) with a general exercise then used to focus on what that might mean for supporting someone in their department.
- A family supporting their teenage son/daughter with autism may request some support around sensory sensitivity and difficult behaviour and, on assessing their good overall knowledge, **Exercises 9, 11** and **12** may be felt to be most appropriate.

# About the trainer

This training pack is ideally suited for delivery by managers and trainers who have a working knowledge of autism, or by health and socialcare practitioners with knowledge and experience of supporting people with autism.

The training needs to be delivered by someone who has a good knowledge of autism and of supporting individuals in a person-centred way, however, specific information and illustrative material is also included. It is important for the trainer to familiarise themselves with the training resources and to identify any specific examples that they may wish to use, or additional resources they may wish to consult to enhance their knowledge.

# Involving people with autism as co-trainers

This training resource includes and is based upon the experiences of a particular individual with autism. In recognising that all people with autism are different and in order to explore the experience of a range of people, we encourage participants to think about and discuss the experiences of people that they work with or support. We would encourage a wider consideration of a range of individuals by involving people with autism and their families as co-trainers.

This resource could easily be delivered with people with autism and their explanation of points and examples of experiences can enhance the insight and understanding given to the participants. If you are thinking about co-facilitation, there are number of factors that you should consider.

With thanks to the Jane Forrest and the Greater Manchester Autism Consortium training sub-group for kindly allowing us to reproduce their protocol (with minor amendments) for involving people with autism and their families in training in the section that follows.

## Why involve people with autism and their families

The involvement of people with autism and their families in the design, delivery and evaluation of autism training is good practice. All recent guidance including the national strategy *Fulfilling and Rewarding Lives* (Department of Health, 2010) talks about the importance of involving people with autism in training. The Skills for Care/Skills for Health (2011a) publication *Autism Skills and Knowledge List for Workers in Generic Social Care and Health Services* also identifies that involvement and co-production and a person-centred approach are key to any training strategy.

There are a number of benefits to involving users and carers in training:

- By involving people with autism and their families as 'experts by experience' at all stages of the process, we get a much better result that really represents the views of people and tells their stories.
- Involving and consulting people from the start of the process sends out a strong message that people are valued and that their views and experiences should be at the centre of any training.
- Involving people can also build confidence and support the development of a positive self-image in people who may have experienced discrimination or felt that their views and opinions did not matter.
- People with autism are under-represented in the workforce. Involvement in the design, delivery and evaluation of training can enable people to develop skills and knowledge that may support them to enter the employment market.

## What do we need to consider before we involve people?

When considering involving people with autism and their families in the development, delivery and evaluation of training we need to consider the following:

'Where does involving people fit with our organisation's protocols and policies?'

In particular:

- **Gifts and payment –** do we have a protocol for paying expenses or offering payment to people who are 'experts by experience' and give their time, skills and knowledge?
- **Confidentiality –** how do we ensure that people with autism and their families are protected when they work with us to deliver training? Also how do we ensure the confidentiality of other people when staff are discussing their work on training courses?

- **Risk management/health and safety –** what do we need to be aware of when we are including people with autism as co-trainers? What are the basic minimum safeguards that we need to have in place? For example we might need to consider insurance, basic health and safety training, emergency contact details etc.
- **Values and attitudes –** when we involve people with autism and their families in developing and delivering training we are sending out a strong message that says we value what they have to say. It is important that any training around autism should be underpinned by a sound value base.
- **Representation –** how can we ensure that we are representing a wide range of people with autism, not just those who are delivering the training?

## How can we involve people?

People with autism and their families can be involved in many different ways, for example:

- **Generating ideas for training –** discussion groups, questionnaires, internet discussion sites.
- **Putting together training materials –** for example using technical expertise to put together training resources, collecting and editing people's stories, making DVDs for use in training.
- **Delivering training –** co-training with another person, getting involved in all parts of the delivery.
- **Inputting to training –** telling their story: in person, in writing, on video, giving permission to tell their story either anonymously or credited.
- **Giving feedback** on training materials and offering support with rewriting and updating training materials.

## How can we support people to be involved?

To get the best out of people and to ensure that their experience of involvement is positive, we need to consider how we can offer appropriate support. This will need to be tailored to the needs of the individual, and may include:

- Offering training and support to people who want to be involved in training delivery – a 'Train the Trainer' course may be appropriate for some people.
- On-going 1:1 support and mentoring for people – this will need to be negotiated with the individual.
- Offering people with autism and their families the opportunity to shadow other trainers, for example, sitting in on training to 'get a feel' for it.
- Offering people with autism and their family places on other training that will support the development of their knowledge.
- Ensuring that the ground rules and expectations of people involved in delivering training are clear and understood by everyone involved.
- Drawing up a written contract setting out clear expectations which both parties need to agree and sign up to.
- Making sure that we consider autism friendly environments when we choose training venues. For example paying attention to décor, noise levels, lighting, heating, access to breakout rooms etc.

- Making sure that participants are clear about the role of the person with autism who is involved in the training. Being clear with participants what the ground rules are e.g. around asking questions (clarity about what are appropriate and inappropriate questions).
- Making sure that training is structured to fit in with the needs of the person with autism e.g. start and finish times, breaks, breakout room, additional people for support, refreshments etc.

# Using the training resources

## Content of the resources

This training resource is based on a series of postcards and life stories called 'Postcards from Aspie World' that offer insight from critical moments of the life of a young woman with Asperger syndrome (or Asperger's syndrome). It is based on the premise that learning from the lived experience of someone on the autism spectrum can help those who support individuals to understand and adapt their approach to achieve better outcomes. The postcards and accompanying life stories form a central part of the training resource and the postcards should be printed off from the Adobe file on the CD-ROM. Participants will be directed to specific postcards during particular exercises to form the basis for discussion and consideration of the implications to practice or support.

The postcards are showcased within a more traditional training framework in the form of PowerPoint slides offering introduction to key concepts, specific learning points, or explanations of activities to supplement learning. Each exercise is focused around individual or small group activities that require participants to discuss materials given, but also draw on their own experiences and relate to their own practice in supporting people with autism.

## The training sessions

The training resource is divided into six sessions each between 1hr 15 and 1hr 45mins long. They are designed for delivery across three half day courses (two sessions per course) but can be flexibly delivered as standalone sessions, or over full days depending on which sessions are required. The sessions are titled:

- **Session 1: Understanding autism**
- **Session 2: Autism in a wider context**
- **Session 3: Supporting individuals with autism: the 'triad'**
- **Session 4: Supporting individuals with autism: sensory sensitivity, routines and special interests**
- **Session 5: Supporting individuals with autism: anxiety and difficult behaviours**
- **Session 6: Supporting individuals with autism: independence and equality**

Each session contains a number of individual exercises focusing on a particular aspect of autism support. It is possible to use individual exercises to tailor a course to your specific training needs, to use parts of the sessions identified, or as a whole course.

All the sessions and exercises include a comprehensive set of PowerPoint slides and accompanying directions and additional learning resources as required and identified in the notes. There is also a separate PowerPoint file of the postcards to show at the beginning of the first session. These are supplemented by the 'Postcards from Aspie World' pdf file of postcards and life stories, which should be printed out with the other learning resources, with direction to specific postcards and life stories as per the session and exercise guidance.

Each of the six sessions includes an introductory activity designed to put participants at ease, but which is also related to the content of that session. These may not be required if the sessions are run across a full day with time allocated to other activities. However, they do provide a more relaxed approach to the learning and so we would encourage these to be used where possible.

Rough timings have been given for all sessions and exercises, but these should be used as guide only and trainers may plan to spend more or less time on specific activities depending on their assessment of the learning needs of the participants.

## PowerPoint slides

The training relies on the use of the PowerPoint slides that are on the accompanying CD-ROM. These will need to be played through a laptop and projector (or other appropriate equipment) and so the trainer needs some level of knowledge of this equipment and the software used.

## Learning resources

A number of the exercises include activities that require further elaboration, or the participants to consider and write specific responses. Where relevant, learning resources are provided to facilitate this and these can also be found on the accompanying CD-ROM. A set of postcards and life stories can be found in the training pack for the trainer and the postcards and life stories should be printed off to distribute to each participant (Learning Resource 1.1). Please note that a printer that prints double sided is needed for this as the back of each postcard is on the back of each handout page. They could be cut up along the bottom of the images to make separate postcards.

# Planning and preparation

## Equipment

All training sessions require a computer connected to a projector. Any other resources required for included exercises and activities are listed in the notes for each session and each individual exercise. Additional equipment may be required for any additional activities the trainer may wish to include.

### Number of participants

It is anticipated that the training would be delivered to a group of around 16 participants, however smaller and larger groups are possible. There would be no minimum number suggested so long as there are enough to undertake the group activities. In our experience, delivering this type of training to more than 22-24 people proves challenging and can be problematic.

## Links to qualifications

The training pack meets the stated learning outcomes in the Skills for Care *Autism Skills and Knowledge List* (2011a) focusing particularly on the first three levels:

- Underpinning values and attitudes.
- Basic awareness.
- Intermediate knowledge and skills.

As such, it incorporates the requirements of the Qualifications and Credit Framework (QCF), with each session cross-referenced to the stated learning outcomes in the following autism specific knowledge units:

- LD210 – introductory awareness of autistic spectrum conditions.
- LD310 – understand how to support individuals with autistic spectrum conditions.
- LD510 – promote good practice in the support of individuals with autistic spectrum conditions.

These are complemented by other units such as:

- Support individuals undergoing healthcare activities.
- Contribute to supporting individuals with a learning disability to access healthcare.
- Working in partnership with family carers.

Further information on these frameworks and how they map together can be found in the documents:

*Autism Skills and Knowledge List for Workers in Generic Social and Health Services* (Skills for Care & Skills for Health, 2011a)

*Implementing the Autism Skills and Knowledge List Through Staff Training and Development* (Skills for Care & Skills for Health, 2011b).

All the units are available to view at www.skillsforcare.org.uk