

EDUCATING AND SUPPORTING GIRLS WITH ASPERGER'S AND AUTISM

A resource for education and
health professionals

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This book would not have been possible without the willingness of so many females with autism spectrum conditions to contribute their experiences, ideas and opinions. To those girls and women I would like to say a huge thank you – together they have helped to produce a resource which will hopefully raise awareness of females on the autism spectrum and help to ensure that they are able to thrive during their educational experiences.

About the author

Victoria Honeybourne is a senior advisory teacher for speech, language and communication needs. She has previously worked as a teacher within a communication centre, as a teacher of special educational needs and as a mainstream teacher. She is author of *The Sky's The Limit: A mental wellbeing workbook for young people with SEN* (Speechmark, 2016) and co-author of the *Speech, Language and Communication Pocketbook* (Teachers' Pocketbooks, 2014). She has also spoken at national events about SEN and has written articles on SEN for national publications. Victoria has a diagnosis of Asperger's Syndrome and has developed a particular interest in working with other females on the autism spectrum.



Part 1

About this book

Aims of this book

This book focuses on girls and young women on the autism spectrum in relation to their educational experiences: at school, college, and the transition to further education establishments and employment.

The aims of this resource are:

- To provide teachers, support staff, therapists, youth workers, social workers and other professionals with a greater insight into girls and young women on the autism spectrum: their strengths, difficulties and interpretations of the world.
- To provide professionals working with females on the autism spectrum with a range of resources and activities to use with girls and young women to support them in developing strengths and overcoming difficulties.
- To support educational establishments in creating environments which enable females on the autism spectrum to fulfil their potential.
- To provide resources for girls and young women on the autism spectrum to help them to gain greater self-understanding and self-acceptance empowering them to be able to make the most of their educational experiences.

Why education?

This resource focuses on education for a number of reasons. Young people today in the UK are expected to remain in education until they are at least 18. Those who go on to higher education are likely to spend at least another three years in education. Our time in education coincides with our childhood and teenage years, often the formative years of our lives, which provide the opportunity to learn, discover, explore and grow, not only academically but also emotionally, socially, psychologically and spiritually. Our school days are often referred to as 'the best time of our lives'; a time of fun and freedom, of exploration and enjoyment.

However, for females on the autism spectrum, this is unfortunately often not the case. Many females with autism report negative experiences of school and further education: feeling misunderstood, invisible, isolated and left-out; reporting bullying; feeling their needs were unmet and having difficulties with friendships and getting on with others. In the worst cases, negative experiences of school for females on the autism spectrum can lead to school refusal, unnecessary educational failure and serious long-lasting mental health difficulties. The impact of these negative school experiences can influence not only future study and employment opportunities, but also future levels of self-esteem, wellbeing and happiness. The importance of our time in



- SENCOs
- Specialist teachers
- Trainee teachers
- Pastoral staff
- School counsellors
- Therapists
- Youth workers
- Speech and language therapists
- Social workers
- School nurses
- Family support workers
- Further and higher education staff
- Disability officers
- Support workers and advocates
- Employers
- Parents and carers
- Individuals on the autism spectrum

The resources and activities in this book are designed to be used with females on the autism spectrum roughly between the ages of nine and 19. Some of the resources, such as those focussing on the transition to secondary school, are designed for the younger end of this age group, while others, such as those looking at preparing for university and employment, are designed for the older end. The resources can also be used with younger or older females if appropriate.

These resources are aimed at girls from roughly age nine upwards as females are often diagnosed with autism spectrum conditions slightly later than their male counterparts (Idring, 2012). Many women with autism, looking back, also recognised that their difficulties and differences became more apparent following their transition to secondary school and after going through puberty, due to the many social and emotional issues at this time. Although this resource focuses on the nine to 19 age group, it is envisaged that the information will also be useful to those working with younger and older age groups.

Individuals are likely to benefit from using these resources and activities at different times. Some individuals do not receive a diagnosis of autism until they are in their teens or beyond while others may have had a diagnosis from a very young age. There may be some individuals who do not meet all of the criteria for a diagnosis of autism but who will still benefit from using some



these resources, as they may experience difficulties in similar areas. Some resources may also be useful to use with an entire class or group, including those individuals who are not on the autism spectrum. Indeed, using some of the resources with a whole class, can support girls with autism to feel less 'different' and can help to encourage self-esteem and learning in all pupils. Students will also vary in their level of understanding and their ability and willingness to engage in reflective activities. Therefore, not all activities may be suitable for all individuals. All of the factsheets and resources have been written in an easy-to-read style in order to be accessible to as wide a group as possible.

How to use this book

Part 2 of this resource is 'An Introduction to Autism' which gives a brief overview of what is meant by autism spectrum conditions, the major theories and research surrounding autism, and the typical difficulties that individuals experience.

Part 3 covers 'the school experience for girls and young women on the autism spectrum'. This section looks specifically at the educational experiences of girls and young women with autism spectrum conditions. Over 70 women on the autism spectrum contributed their experiences, insights and quotes. This section also contains advice to professionals and educational establishments about how they can adapt their environments, policies and practices to ensure that females with autism can feel safe, accepted and fulfil their potential.

These sections are followed by 'workbook' style sections covering the following topics:

- Self-awareness and wellbeing
- Learning in the classroom
- Wider school life
- Preparing for future study
- Preparing for employment

Each of these sections contains an overview for professionals about the difficulties that those on the autism spectrum may experience in these areas. This is followed by resources and activities to use with girls and young women on the autism spectrum, and notes for professionals about how to use these activities. Some completed examples are provided to demonstrate how these resources could be used, but there are no right or wrong answers as the activities aim to encourage each individual to come up with their own insights and solutions. Each section also contains 'factsheets' aimed at females on the autism spectrum themselves. These cover a number of topics and will appeal to those who prefer to learn independently. The factsheets cover various aspects of autism and school-related topics.



Limitations of this resource

Information for this resource was gathered from over 70 women with a diagnosis of an autism spectrum condition. However, it is important to note that the majority of the women interviewed had been educated in mainstream settings and many had a diagnosis of Asperger's Syndrome or High Functioning Autism. This resource is, therefore, aimed mainly at those females who are educated in mainstream settings. Girls on the autism spectrum who have co-occurring learning difficulties and more severe forms of autism are likely to experience some of the difficulties mentioned in this book, but will also have more noticeable significant difficulties in communicating with others and communicating their needs. Some may be non-verbal and need specialist support across their lifetime. This resource does not cover look in detail at this group of individuals with more complex needs.

It is also important to note that autism in females has only become more recognised very recently. Some of the women interviewed for this book did not have a diagnosis of autism when they were in school, but only received one when they were older. Therefore, some of their educational experiences reflect that fact that they were undiagnosed at the time. Some women interviewed were now in the 40s or older so some of their experiences at school may reflect educational policies and practices that are no longer current. Research and understanding in the fields of special educational needs and child psychology has developed enormously over the past thirty years and good practice is constantly evolving.

It should also be noted that the resources and activities in this book act more as a means of self-discovery and future planning, rather than covering specific issues in detail. Some students, for example, might need more extensive support with their study skills, friendships or preparing for transition, and there are resources and books available which look at each of these areas in more detail. What this resource can do, however, is enable improved self-awareness in students and a better understanding in professionals of individual's needs, highlighting which areas might need further support.

Theories underpinning this book

There are a number of ideas which underpin this resource.

'When you've met one person with autism, you've met one person with autism'

This is an oft-repeated saying in the autism community. The autism spectrum covers a huge range of abilities and autism affects each person very differently. Each female on the autism spectrum is likely to have a different combination of strengths, difficulties and life experiences. It is recognised that not every aspect of this resource will be relevant to every girl or young women. The activities are designed to be as open-ended as possible and to be used in a variety of ways



which can be adapted to individuals. Some girls and young women on the autism spectrum may need more in-depth work on certain areas and some will need support to complete the activities, while others will prefer to work independently.

Biopsychosocial approach

This resource sees autism very much as a difference rather than a disability. This resource sees autism as an equally valid way of being, merely different to the majority. Unlike the medical model of disability which sees a disability as an impairment located within the individual, the social model of disability sees disability as being caused by the way society is organised. In the social model of disability, barriers to equality (physical barriers, attitudes, social expectations) need to be removed so that 'disabled' people can live equal and independent lives (Scope, 2015).

The biopsychosocial approach (suggested by George Engel, 1977) goes a step further and suggests that biological, social (environmental, cultural, socio-economic) and psychological (thoughts, feelings, attitudes) factors all play a significant role when it comes to human health and disease. This resource is based on the fact that these three aspects (the biological, social and psychological) are all factors when it comes to the wellbeing of those on the autism spectrum.

It is particularly important for females on the autism spectrum that they grow up feeling accepted, rather than feeling that there is something 'wrong' with them that needs 'fixing', as this is likely to accentuate feelings of low self-esteem and mental health difficulties. It is also important on a much wider societal and cultural level that difference is accepted and embraced rather than labelled and therefore marginalised. By creating a more inclusive and supportive environment, we can eliminate many of the feelings of being 'different, odd, invisible, lonely, depressed and anxious' which often accompany living on the autism spectrum.

It is also often reported by individuals on the autism spectrum that it is the response of others which can cause the greatest difficulties. Carol Gray (2000) maintains that 'we (families, professionals, the wider community) hold more than half the solution' to the difficulties faced by an individual on the autism spectrum. Gray suggests that changing the language used, the style of interaction, the physical and sensory environment, and social or cultural expectations can make a big difference.

'To be yourself in a world that is constantly trying to make you something else is the greatest accomplishment' (Ralph Waldo Emerson)

This resource does not focus on trying to 'fix' or 'cure' autism, but on providing girls and young women with strategies and skills that will empower them to gain self-esteem, confidence and independence. The book focuses on the importance of self-awareness and self-acceptance and encourages girls and young women to accept and express who they are, rather than trying to pretend to be something that they are not.



Person-centred approaches

A person-centred approach is used throughout this resource. Person-centred approaches developed out of the work of Dr Carl Rogers (1902-1987) and moved away from the concept that the professional is the expert, to viewing the client as the expert on themselves (BAPCA, 2015). Person-centred approaches begin from the individual in question, looking at the world from their point of view and what is important to them. This is particularly important to those on the autism spectrum who see and interpret the world differently. Often, neuro-typical (non-autistic) values may not be so important to those on the autism spectrum and it is important that professionals and family members do not try to impose neuro-typical values on those with autism, as these may be meaningless or unimportant to the individual in question. Findings of a research report commissioned by the Autism Education Trust (2009), for example, suggest that more studies are needed on the views of young people on the autism spectrum and that the views of children and young people with autism are as important as the opinions of others, yet not always taken into account as much as they could be.

Positive Psychology

“Where attention goes, energy flows” (Well-known saying)

This resource uses ideas and strategies from the field of positive psychology. Positive psychology can be described as ‘the scientific study of human strengths and positive emotions’ and seeks to promote wellbeing, rather than remediate deficits. The movement is based on the work of Martin Seligman who proposed that happiness, meaning and lasting fulfilment can be cultivated. The positive psychology movement also seeks to help people acquire the skills to be able to deal with everyday life in positive ways (Seligman, 2002).

In the field of autism, traditionally more attention has been paid to the negative aspects of the condition, rather than the positives, such as how to increase wellbeing and happiness of those on the autism spectrum (Vermeulen, 2014). A recent report by Pellicano et al (2014), for example, indicates that more than half of all research and funding on autism in the UK is spent on investigating the biological causes of autism, with relatively little investigating how the lives of those with autism can be improved. Peter Vermeulen (2014) suggests the approach to autism research needs to change, with the aim being not to make people with autism less autistic, but to enable them to become ‘more autistically happy’.

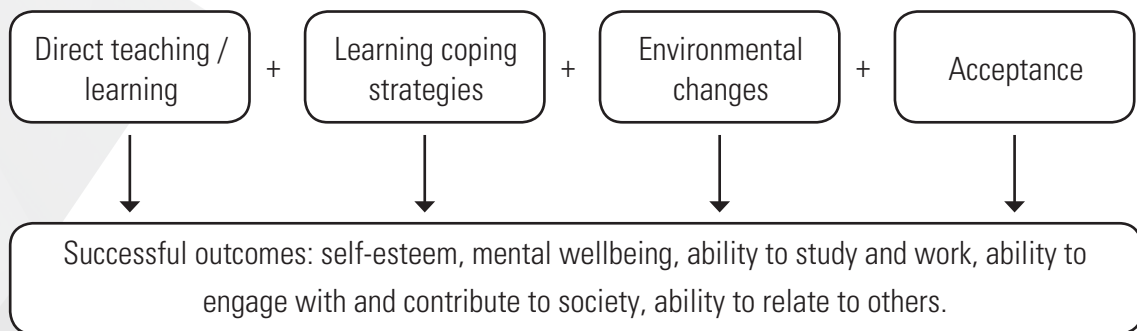
Indeed, there is growing evidence about the importance of promoting positive emotions. Research indicates that positive emotions can lead to an upwards spiral of wellbeing and happiness (Fredrickson and Joiner, 2002), with positive emotions meaning that individuals are more able to utilise better coping strategies and to think more creatively and flexibly, leading in turn to more positive emotions.



This book, therefore, focuses on promoting wellbeing, encouraging strengths and seeking positive solutions, rather than remedying deficits. That is not to say that the considerable difficulties that those on the autism spectrum can experience are overlooked or ignored, but simply that a more positive approach is taken, rather than dwelling on negatives and difficulties. This is based on the premise that 'energy flows where attention goes'. If we, as either those on the autism spectrum or those working with people on the autism spectrum, focus on the negative aspects, then these negatives are likely to fill our thoughts. If, however, we adopt a more positive approach and focus on our strengths, progress and achievements, then this is where attention will be, thus leading to happier, more positive thoughts and feelings. As Paul Dolan (2014) summarises, 'the key to being happier is to pay more attention to what makes you happy and less attention to what does not'.

A model for living successfully with autism

The model below suggests four strategies that can combine to support those on the autism spectrum to live happily and successfully:



- Direct teaching / learning: Many people with Asperger's and autism will be able to learn some things through direct teaching (whether in school, college, support groups, 1:1 work, or through self-study). This may include learning things such as social skills, independent living skills, problem solving skills, communication skills, or methods of promoting wellbeing.
- Learning coping strategies: At times those on the autism spectrum will need to develop coping strategies to cope with their differences, allowing them to participate in activities and events. These may include coping strategies such as wearing earplugs / tinted lenses to overcome sensory sensitivities, or using planning techniques to cope with change.
- Environmental changes to the physical environment or to policies and practices will be needed, which can benefit individuals on the autism spectrum and enable them to achieve their potential.
- Acceptance: This includes self-acceptance and acceptance from others. An individual on the autism spectrum needs to accept their differences and uniqueness, as do friends, family and colleagues, in order for them to thrive.



It is likely that combination of these four things will be needed to ensure the most successful outcomes for individuals on the autism spectrum. This resource brings together these four strands, including some 'direct teaching' of skills and strategies, ideas for developing coping strategies, ways of managing the environment, and activities to work on self-esteem and self-acceptance.

Particular importance throughout this resource is placed on promoting self-esteem and self-acceptance. Self-esteem can be defined as how we see ourselves, often especially in relation to the ideal self we would like to be. Low self-esteem is often commonplace in females (and, indeed, males) with autism spectrum conditions. Low self-esteem is often associated with an increased risk of loneliness, resentment, depression, anxiety, irritability, eating disorders and negative risk-taking behaviours such as substance abuse (Jellineck et al, 2002). There is also evidence that positive self-esteem (gained through doing things you are proud of, making a contribution to society, working and keeping busy) can promote happiness in individuals with autism (Vermeulen, 2014).

Note from the author:

My own educational experiences were mixed. I was a child who excelled academically but struggled socially and emotionally. I was an enigma to my family, my teachers and myself. How was it that a girl apparently reasonably intelligent and healthy always somehow failed to reach her potential? Why did this girl cope during the school day but then go home and explode into total meltdown? Why did this girl want to spend all of her time alone? Why could this teenager cope with reading about philosophical debates but not cope when certain foods or textures were placed near her? Just why was this girl not just a normal teenager, why was she on a slightly different wavelength to those around her and why didn't she 'get' how to get on with people?

I had known for as long as I could remember that I was somehow different. I'd never quite met anybody like myself before, until, that is, I started teaching pupils who had Asperger's and autism. Some things started to seem eerily familiar. Whereas other staff would be seemingly perplexed by students' apparently irrational behaviour and thoughts, to me it seemed a perfectly normal way of interpreting the world. I fitted in very well with this type of person but there was a problem: autism was just a male problem, right?

Wrong! Having spent my childhood and teenage years undiagnosed and living in a fog of confusion and pretence, getting a diagnosis of Asperger's syndrome enabled me for the first time to shed light on my life experiences; suddenly everything made perfect sense! I realised that my experiences were, in fact, quite common amongst other women with Asperger's, and often quite different to those experienced by males.



As I began my teaching career I realised that something didn't feel right, especially when working with pupils with autism. I was doing all of the things I had been taught to do, all of the things a teacher was meant to do, all of the things I had seen others do, yet I knew these things were not necessarily what would work the best with girls on the autism spectrum. I put myself into their shoes (yes, even us aspies can do that from time to time) and thought back to my younger self. School hadn't always been a pleasant experience for me, so why was I expecting the same thing to work for children who shared my diagnosis?

In my ideal world there would be no need for a label of 'Asperger's syndrome' (nor many other named conditions). Not because we would have found a 'cure' or treatment, but because neurodiversity would simply be accepted and celebrated. Schools, workplaces, services and individuals would expect and support difference rather than be confused and challenged by it. We have not yet reached that ideal state but it certainly isn't an impossible dream.

The activities in this book focus on the idea of wellbeing, of teaching girls on the autism spectrum that it is ok to be who they are. It looks at how to improve self-esteem and confidence, how to promote positive emotions and how to accelerate and promote strengths. This is not a resource which aims to make anybody less autistic (as that in the long run will only lead to depression and exhaustion), but to help the next generation of women become more 'autistically happy and confident'. It is a resource which encourages educational establishments to be open to difference and diversity.

It took me quite some time to discover who I am, to realise what is important to me and to enjoy being me. I hope that this book can support other girls and young women with Asperger's and autism during their own journeys.

I have written other books and articles about special educational needs; this one, however, is different. This is the book I wish my teachers had had when I was at school, and the activities I wish somebody had worked through with me.

Victoria Honeybourne

November 2015



Part 2

An introduction to the autism spectrum

