



The prevention and reduction of violence committed by children and young people with autism



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Guides for the protection of children with autism and the prevention of aggressive or violent behaviour



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What is SPEAK UP?

SPEAK UP (System for the Protection and Empowerment of Autistic Children as victims of abuse or as Unintentional Perpetrators) is a European project involving Autism Europe, F.M. Regina Association, CIRENEO, The National Autistic Society, Autismo Burgos, Alpha Foundation and Progetti Sociali.

SPEAK UP intends to improve the current knowledge and awareness in relation to safeguarding children and young people with autism at a European level, both as victims of abuse, but also in the reduction and prevention of abuse and violence by children with autism to others. This work involves the development of this guide and another guide relating to the protection of children and young people with autism from violence and abuse, the development of a programme to reduce the risk of abuse for children and young people with autism and an information resource.

As this is a guide for professionals across Europe, there is no mention of the legislative frameworks around this area of work, as they differ from country to country. However, the guide should complement existing legislation and practices.

Who is this guide for?

This guide is aimed at practitioners working with children and young people with autism. It may also be useful for parents/carers and family members.

What is autism?

Autism is a lifelong, developmental disability which affects the way a person sees and understands the world around them. It is described as a spectrum condition as it affects people to varying degrees, however all people with autism will have difficulties in social communication, social interaction and social imagination. Many people with autism will also have sensory sensitivities.

Throughout this guide, the term 'autism' will be used. This will cover the range of diagnoses that people with autism may receive, such as autism spectrum disorder (ASD), autism spectrum condition (ASC), Asperger syndrome (AS), childhood autism, pervasive developmental disorder (PDD) and so on.

Social communication

Some people with autism have no or limited speech. Others have good language skills, but still find aspects of communication difficult, such as turn-taking, talking incessantly about their special interest, whilst not recognising that the other person may not be interested.

People with autism struggle with non-verbal communication and therefore find interpreting facial expressions and body language very difficult. They may also take things literally and think that people mean exactly what they say, such as 'like banging your head against a brick wall'. Sarcasm and jokes can also be difficult to understand for this reason.



Some people with autism will repeat sentences or phrases that they have heard or may repeat the last thing that you say to them. This is called 'echolalia'. The sentences or phrases may come from anywhere; a family member, a teacher, a TV advert or their favourite programme.

Social interaction

People with autism find it very difficult to recognise and understand other people's feelings and emotions, often described as 'Theory of Mind' deficits. Because of this, some people with autism may appear insensitive and cold; odd and peculiar in manner. They may appear to lack empathy. They may also struggle to express or even understand their own emotions and may react differently to others without autism in certain situations, for example, laughing at a funeral.

They may not understand the unwritten rules that people without autism pick up instinctively. They may stand too close to people or speak about things that are inappropriate in that particular circumstance. Many people with autism want to have friendships and relationships, but because they struggle with social interaction, they may go about it in an odd or inappropriate way. Theory of Mind is thought to emerge during early childhood and to remain a constant ability throughout our lives¹. People with autism, including Asperger syndrome consistently show impairments in Theory of Mind.

They may prefer to spend time on their own and not seek the company of others. Some children with autism don't appear to be very affectionate and others will be very affectionate, even overly affectionate but on their terms, ie when they want to be affectionate rather than when a parent for example might want them to be.



Social imagination

People with autism struggle to predict things outside of their daily lives and routine. They also find it hard to predict the behaviour and intentions of others, which can make them incredibly vulnerable. Change and coping with new or unfamiliar settings and situations can be incredibly difficult.

Due to these areas of difficulty, people with autism also struggle with executive functioning, meaning that they may be focused on detail and not see the whole picture. This makes organising, sequencing and prioritising difficult. In terms of reporting an incident, this can be very problematic. Difficulty with social imagination should not be confused with a lack of imagination. Many people with autism have incredible imaginations, with great creative skills.

Sensory issues

We have seven senses; sight, sound, touch, taste, smell, balance (vestibular) and body awareness (proprioception). Many people with autism have sensitivity issues with some or all of the senses and can be over- or under- sensitive. This can have a massive impact on the child themselves, but also on their family.

Sensory sensitivities in children with autism may be displayed in the following ways:

- › poor depth perception leading to problems with throwing and catching

- › possible clumsiness
- › finding it easier to focus on detail rather than the whole thing
- › wanting to hear certain music very loud, but finding other loud noises distressing
- › difficulty in drowning out background noise leading to poor concentration
- › they may have a high pain threshold and not say or be aware if they have injured themselves – touch may feel painful to them, even light touch
- › they may insist on wearing certain fabrics as others are too painful or uncomfortable, they may not like wearing clothes at all
- › they may only eat very bland food or food of a certain colour or texture
- › some people may be underweight due to a very limited diet
- › places like supermarkets can be incredibly overpowering for some people with the competing smells on every aisle
- › they may be unable to judge personal space



- and therefore stand too close to people
- › some will seek sensory stimulation by self-harming
- › some may have very sparse bedrooms or sleep on the floor because of their sensory difficulties.

These things should all be taken in to account with any safeguarding investigation.

Intellect 'vs' social understanding

It cannot be assumed that for people with autism their level of social understanding matches their intellect. Many people with autism who have average or above average intelligence still struggle to understand the intentions of others and still struggle to predict the consequences of their actions. This is due to their theory of mind difficulties and is not in any way related to their level of intelligence. This means that some children and young people with autism may put themselves into incredibly dangerous situations and, despite their level of intelligence, be unaware of that danger.

Many young people with autism just want to 'fit in' and to be seen the same as everyone else, so will try to hide their level of difficulty and instead portray an image that they think people want to see or expect from them. Again this can put them in vulnerable situations if they misread what they think is expected of them or if people assume that they are understanding everything that is being said or asked of them.

What autism is not

Autism is neither a learning disability nor a mental health condition, however people with autism can and do have additional learning disabilities and mental health issues.

Around 55 per cent of people with autism will have a learning disability² and around 66 per cent of children and young people with autism develop mental health problems³. However, there are many people with autism who do not have a learning disability or a mental health condition and for this reason, can often fall between the two services. Despite being unable to meet eligibility criteria for learning disability or mental health services, they and their family may still have unmet and perhaps unrecognised needs. This in itself can lead to families feeling isolated and that they have to manage on their own without professional support. It is imperative that the needs of children and young people with autism are assessed by professionals with a good knowledge and understanding of autism and how it impacts on the child. It is also crucial that these services work together to provide the best support possible for children and young people with autism.

Diagnosis

Getting a diagnosis of autism may take several years for some families, therefore there will be many families that you come into contact with who do not have a diagnosis for their child. As some families have to wait such a long time for a diagnosis, the pursuit of it can become all-consuming. It is important to have an understanding of what that agonising wait can do to a family.

The purpose of anger and aggression in all of us

Anger is a normal human reaction which we all experience and its purpose stems from a survival instinct. When something is a threat, we have a 'fight or flight' response. However, it reduces our capacity for cognitive reasoning. This is the same for those with and without autism.



It is important to recognise the stages and the physiological changes in the body that relate to the feeling of anger in order to know how to control it. For most of us, we can easily recognise these changes in our bodies when we are getting angry, but for many children with autism, they may not recognise or understand them. Some children with autism can be taught to recognise the stages of anger and how to manage their feelings, if taught in a way which makes sense to them.

Anger can show itself in verbal as well as physical responses. It can have many causes including frustration, fear and confusion.

Why might anger and violence be more prevalent in children and young people with autism?

Many people with autism experience high levels of anxiety all of the time. The unpredictability of life can be incredibly stressful for them and it may not take much for that to tip over.

The nature of autism may cause some people to present with behaviour which is challenging to others. Finding communication and social interaction confusing and stressful can lead to people with autism feeling frustrated and angry. Difficulties with understanding and predicting the intentions of others and with recognising and expressing their own feelings and emotions can also make those feelings of anger and frustration worse. The anger can sometimes appear to come from nowhere, but there is usually a trigger. Sometimes there can be more than one. These triggers don't always happen immediately before the outburst. Philip Whitaker suggests that you should think of the behaviour as an iceberg, ie, whatever the behaviour you're actually seeing, there's a lot more going on under the surface (Whitaker, 2001).

Understanding how the areas of difficulty associated with autism impact on behaviour, including sensory issues, is crucial for anyone working with children and young people with autism.

'Finding communication confusing can lead to people with autism feeling angry.'

Understanding behaviour as a form of communication

It is estimated that 93 per cent of communication is non-verbal. If this is the case, then for people with autism who struggle to understand non-verbal communication, they are clearly missing out on the majority of information that others are providing them with. This in turn can lead to real confusion and frustration on both sides.

Some children with autism will struggle to understand and communicate their feelings and emotions and may instead display them in their behaviour. It is important to recognise that children with autism will at times communicate through their behaviour and to consider what message they may be trying to get across when dealing with the behaviour.

Communication is a crucial part of being human, and being able to communicate is something that most of us take for granted. For most people who do not have autism, if our form of communication was taken away, we would feel incredibly angry and frustrated. We would need to find an alternative way to communicate. For children and young people with autism, they may experience the added frustration that they have a form of communication, but it isn't being understood by others. They may not be getting the expected response as a result of what they are trying to communicate.

For some children and young people with autism, when they are feeling particularly stressed and anxious, their ability to understand verbal information from others will be impaired. Their own ability to communicate with others will also be affected, which may

mean that they use alternative modes of communication. These could involve hitting, biting, spitting etc.

It is also worth considering whether the aggressive or violent behaviour the child is displaying is as a result of them being the victim of some form of abuse. If this is the case, they may not fully understand that the abuse has taken place or they may not be able to communicate in any other way that the abuse has occurred.

Having clear, accurate and regularly updated information about a child and their communication style is crucial. This should also include information about how a child may communicate when stressed, anxious or frustrated and how others should respond at these times.

Understanding and managing the triggers

Triggers for anger are very specific and unique to each child. The only way that you can understand the triggers is to get to know the child or young person well, observe and record.

Keeping diaries and 'STAR' or 'ABC' charts can often be helpful. The STAR model looks at:

- > settings (recording details such as the time of day, the environment, who else was around etc.)
- > triggers
- > actions (What was the behaviour that was observed?)
- > results (What was the outcome of the behaviour?).

ABC charts are similar in that they record:

- > the Antecedent (what happened before the behaviour began)
- > the Behaviour itself
- > the Consequences (what happened afterwards, how was the behaviour calmed down and ended, what was the result of the behaviour, how did the child feel afterwards).

Sharing this information with others will also prove helpful. Others may have identified potential triggers or similar behaviour as a result of other things. Putting everything together will give you a better understanding



of what is going on. Identifying the triggers of the behaviour, understanding the whole picture, and recording the information, will allow you to put strategies in place to manage that behaviour.

'Keeping good written information about the child's behaviour in order to identify patterns and assist in looking for clues is crucially important.'

Keeping good written information about the child's behaviour in order to identify patterns and assist in looking for clues is crucially important. To change the behaviour, you have to understand the behaviour. To understand the behaviour, you have to understand how autism impacts on that particular child.

Learnt behaviour?

Many issues need to be taken in to account when dealing with any safeguarding incident. Questioning whether the behaviour that the child is displaying has been learnt elsewhere also needs to be taken into account. Many children with autism will copy the behaviour of others or will use certain behaviours to get a specific reaction. This also links to behaviour as a form of communication and what the young person may be trying to impart.

If the behaviour has been seen elsewhere and the child is copying what they have seen, where has the child seen this behaviour? What were the circumstances? Again are there potential signs of the child being a victim of violence themselves? If the behaviour is being used as a form of communication, what are they trying to communicate? Has the child learnt that if they kick or punch, people leave them alone or they don't need to do a certain task?

Victims of abuse becoming perpetrators

Most people with autism are law abiding and have an incredible sense of justice. For some people with autism who have been the victim of abuse and who do not feel that justice has been served, the consequences can be catastrophic. There is clearly the potential for the child or young person to develop mental health issues as a result of this experience or for them to become the perpetrators of violence themselves as the anger and frustration at their lack of justice takes hold.

Where it is known that a child or young person with autism has been the victim of a crime and is now displaying violent and aggressive behaviour, it is crucial that the child receives appropriate support to deal with, not only the crime itself, but also the outcome of any investigation. This support must take into account the child's autism and their level of social understanding. Other sources of support available to victims of crime may not be appropriate for many people with autism.

Tools and strategies to prevent or reduce violent behaviour

As highlighted early on in this guide, we all experience anger and most of us can recognise and understand the physiological changes in our bodies and the progression of those changes as our anger increases. This can help us find alternative solutions to being in that particular situation and feeling those changes in our bodies. For some children and young people with autism they

may need help with not only recognising these changes, but also being able to express and manage those feelings. There are some excellent resources available to assist with this and they are detailed on page 11.

Training should also be provided to the child in relation to body awareness and sex education, in a way that is meaningful for them. Some children and young people with autism may commit sexual offences due to a lack of knowledge or understanding about boundaries and what is acceptable. Some behaviour which is acceptable at age two or three may be very inappropriate at age 12 or 13. There are limited resources available which have been specifically developed for children and young people with autism, but some of the ones which are available are listed on page 11.

Introducing relaxation techniques or understanding things that can help the child or young person relax can really help. Some children benefit from deep pressure, such as



weighted blankets. Teaching deep breathing can help. Many children with autism find that trampolining is a great stress reliever, others may benefit from some limited time on computer games or the internet, without distraction, to calm down. The ways of releasing stress, anxiety and anger will be different for every child with autism, as they are for every one of us. As with learning and understanding the triggers, learning the relaxation techniques and ways to calm down that work for each child is also imperative.

'The ways of releasing stress, anxiety and anger will be different for every child with autism, as they are for every one of us.'

Resources

This is a suggested, but not exhaustive list of useful books and resources

Clements, J. and Zarkowska, E. (2000). *Behavioural concerns and autistic spectrum disorders: explanations and strategies for change*. London: Jessica Kingsley Publishers

Whitaker, P. et al (2002). *Challenging behaviour and autism: making sense – making progress: a guide to preventing and managing behaviour for parents and teachers*. Kansas: Autism Asperger Publishing Co

Clements, J. (2005). *People with autism behaving badly: helping people with ASD move on from emotional and behavioural challenges*. London: Jessica Kingsley Publishers

Dunn Buron, K. (2007). *A 5 is against the law*. Kansas: Autism Asperger Publishing Co.

Al-Ghani, K. and Al-Ghani, H. (2008). *The red beast: controlling anger in children with Asperger syndrome*. London: Jessica Kingsley Publishers

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²Baird, G. et al. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *The Lancet*, 368 (9531), pp210-215

Gray, C. (2010). *The new Social Story book*. Arlington, Texas: Future Horizons Incorporated

Powell, A. (2011). *Autism: understanding and managing anger*. London: The National Autistic Society

Dunn Buron, K. and Curtis, M. (2012). *The incredible 5 point scale: assisting students in understanding social interactions and controlling their emotional responses*. Kansas: Autism Asperger Publishing Co.

Dunn Buron, K (2013). *When my worries get too big: a relaxation book for children who live with anxiety*. Kansas: AAPC Publishing

Hartman, D. (2013). *Sexuality and relationship education for children and adolescents with autism spectrum disorders: a professional's guide to understanding, preventing issues, supporting sexuality and responding to inappropriate behaviours*. London: Jessica Kingsley Publishers

³Simonoff, E. et al (2008). Psychiatric disorders in children with autism spectrum disorders, comorbidity and associated factors in a population-derived sample. *Journal of American Academy of Child and Adolescent Psychiatry*, 47(4), pp921-929

⁴Whitaker, P. et al (2002). *Challenging behaviour and autism: making sense – making progress: a guide to preventing and managing behaviour for parents and teachers*. Kansas: Autism Asperger Publishing Co.

About The National Autistic Society

We are the leading UK charity for people with autism (including Asperger syndrome) and their families. With the help of our members, supporters and volunteers we provide information, support and pioneering services, and campaign for a better world for people with autism.

Around 700,000 people in the UK have autism. Together with their families they make up around 2.8 million people whose lives are touched by autism every single day. From good times to challenging times, The National Autistic Society is there at every stage, to help transform the lives of everyone living with autism.

We are proud of the difference we make.

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