



The protection of children and young people with autism from violence and abuse



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European Commission



European Commission - Justice



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



Contents

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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 prevention or reduction of anger and violence in children with autism, 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 in the respective countries.

Who is this guide for?

This guide has been developed to assist those responsible for the protection and safeguarding of children and young people with autism. This guide aims to complement existing policies and procedures and will provide specific information and guidance in relation to children and young people with autism.

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 have difficulties in social communication, social interaction and social imagination. Many people with autism 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, or 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.

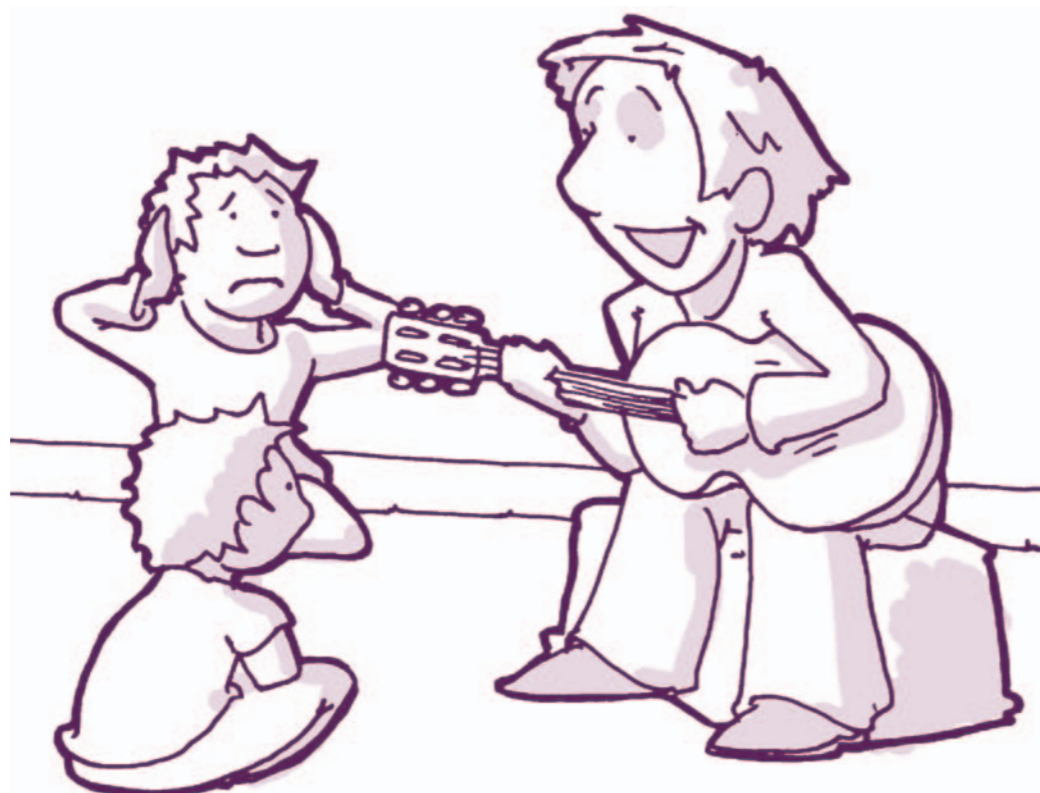
Difficulty with social imagination should not be confused with a lack of imagination. Many people with autism have incredible imaginations, with great creative skills.

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 person with autism, and 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 into 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 difficult 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.



For one family, their pursuit of a diagnosis for their son led to a safeguarding investigation. A community paediatrician accused the parents of having a 'fabricated and induced illness' as he felt it was impossible for their son to have autism. The paediatrician claimed that their son's symptoms were caused by emotional abuse inflicted by the parents.

Their son did indeed receive a diagnosis of autism by a clinical psychologist working for the NHS and their GP, who was asked for his opinion said he thought it unlikely that they were fabricating their son's symptoms. This led to the case against the family being dropped and support being put in place to support their son.

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Safeguarding children and young people with autism

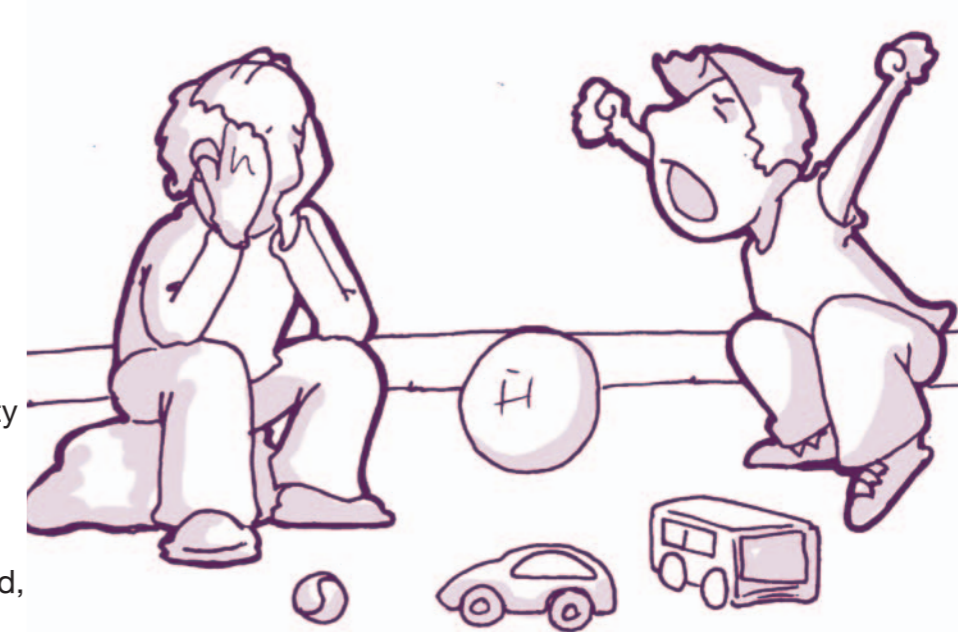
What additional issues need to be considered when dealing with safeguarding investigations involving children with autism?

As people with autism have difficulty with social communication and social interaction, their ability to be able to understand or report potential signs of abuse will be affected, to varying degrees. Again, despite levels of intelligence, if their social understanding is in any way impaired, how they process and understand certain situations will undoubtedly be affected.

Difficulty in being able to 'read' other people and therefore understand and interpret their intentions makes children with autism incredibly vulnerable to abuse.

The misconception that a child with autism of average or above-average IQ will be less vulnerable due to having better understanding of what is happening also puts children with autism at further risk.

The nature of autism itself can put people at risk. High levels of stress and anxiety are common, as are self-injurious behaviour, the desire to be alone, behaviour which can be perceived as challenging to others and finding physical contact uncomfortable. This requires an incredibly difficult balance between what is due to autism and how it presents uniquely in each individual and what is a potential sign of abuse.



Some families may feel that they accept their child for who they are and allow them to withdraw from the world. Is that neglect? Many people with autism need to have structure and routine in their lives to cope with an unpredictable world. Some parents may allow this to take over and dictate the lives of the whole family, others may rally against it, believing it's in the child's best interest for them not to give way to the structure. Is this abuse?

There are many different therapies and interventions available which claim to cure autism. Some of these practices can in themselves 'appear' abusive. Some parents pursue these out of desperation and when the claims for some of these therapies and interventions are far from clear, it can be difficult for parents to know what to believe. (For further information about the different therapies and interventions, please see www.autism.org.uk/interventions.)

Sensory factors can have an impact on the child's behaviour. Seeking sensory stimulation can result in behaviour that is self-injurious.

Children with autism sometimes display behaviour that challenges those around them and can therefore be vulnerable to experiencing interventions that are inappropriate, disproportionate or abusive.

Children with autism often share environments with other children who may display behaviour which challenges and the child with autism may copy this behaviour.

There is an increased risk of professionals becoming overfamiliar with the behaviour that a child with autism exhibits. They are then at risk of failing to pick up other concerns, or seeing new behaviour as an extension of behaviour they have already observed. A clear understanding of autism and its impact on a child is imperative, as is the ability to recognise subtle changes or other indicators, and remaining open to the possibility of abuse or neglect. A clear understanding of how autism impacts upon each individual child is crucial in determining an appropriate response to indicators of abuse.

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We teach children from an early age to comply with parents and other adults, but there are a number of situations and certain adults where we wouldn't want them to comply. Children are taught to do as they are told and to listen to adults and do as they say, but the 'grey areas' to these rules can be incredibly confusing for some people with autism. This learned compliance can put them in incredibly vulnerable situations in relation to abuse by adults. For many children and young people with autism, they may be aware of situations they are in, when they feel that they shouldn't comply and do as an adult has told them. They may instinctively feel a sense of danger. This may not happen instinctively for some children and young people with autism. It is important to explain what those grey areas are and find ways that they may be able to assess the risk themselves. It is also crucial that they are given a script or a process to follow when they have assessed that a situation may be putting them in a vulnerable position. They need to know what to say or do to get out of that situation.

Identifying potential signs of abuse in children with autism

It is essential to avoid making the assumption that all signs and indicators are attributable to abuse or that all are attributable to the child's autism. The best outcomes are achieved when designated persons and safeguarding professionals consider both possibilities and explore these carefully and thoroughly.

It is imperative that those working with children with autism have good-quality, detailed information which is gathered and reviewed regularly, so that changes can be identified and updated. Information about the child should be sourced and shared with those who come into contact with them in order to ensure a consistent approach, considering data protection requirements. This will help to indicate how autism affects them and the 'typical' behaviours that the child displays, as well as identifying any changes in behaviour, however subtle. There may, however, be other reasons for these changes and every eventuality should be explored. It is also essential that information is shared about the child as they go through the various stages of transition in their life; from primary to secondary school, from child to adult services.

Sleep issues are incredibly common in children and young people with autism and like any parent with a child that won't sleep, parents of children with autism will look for various ways to try and solve the problem. Many parents of babies and small children



with or without autism may resort to having the child in bed with them as a way of just getting some sleep. Breaking this habit for any parent is difficult. However, for some parents of children with autism this can be more problematic. It may have become a routine for the child, this is what they are used to and they may well be loath to give it up. This may be something that the parents desperately struggle to get the child to give up, but as the child gets older and bigger, it may feel less appropriate for this to continue, but parents may be concerned about raising this with professionals for fear of what they may think and whether they may see something sinister in it.

Many children with autism, because of their sensory difficulties, find it incredibly uncomfortable to wear clothes. Parents may have allowed them at an early age to remove clothing when they are in the house for this reason. This is quite acceptable when the child is young, but may well be frowned upon as the child gets older. As with the example of sharing a bed with the child, parents may

also be concerned about how they may be judged if they ask for help to manage this.

Dietary issues are incredibly common in children and young people with autism. Again, parents may have concerns about raising issues relating to their child's diet in case of repercussions. It can't be assumed that the child has a poor diet because the parents only give the child the same limited diet. Many parents of children will go to all kinds of lengths to get their child to eat a more varied diet.

Signs of abuse, or possible self-harm? Self-injurious behaviour serves a purpose for everyone that displays it. Changing and

breaking that behaviour isn't easy for anyone. It is important to understand why the person displays this and what purpose it serves. It's also important to be alert to changes in that behaviour and identify possible reasons for those changes.

As with all of these examples, it is important not to assume that concerns are solely related to the child's autism. Although all of these issues are very real and frequent for children with autism, they could all also point to signs of abuse. The knowledge of the child, accurately recorded information and questioning early signs of concern are all imperative.

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Eliciting information from people with communication difficulties

It's important to record accurate information about how a child communicates with others and how the child understands and interprets language. Communication with children with autism will clearly vary from child to child. Therefore having an understanding of how to best engage in reciprocal communication for that particular child is crucial. How best to communicate at different times needs to be identified, for example when the child is happy, sad, anxious, ill, in different settings etc. This information should also be recorded. If the child uses echolalia, this should also be recorded, particularly if the source of the sentences or phrases that the child is repeating are known.

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. This may involve hitting, biting, spitting etc. It's important to consider this at the time when you speak to the child.

We know that children with autism are visual thinkers, regardless of where they are on the autism spectrum. Therefore the use of visual communication support will be beneficial. Again this will depend on the child and their level of understanding. Visual supports don't have to necessarily be pictures or symbols; for some people having something that is written down can be incredibly helpful.

A child with autism who used echolalia would repeat scenes from his favourite television programme that was featuring a story line around domestic abuse. When repeating what he had heard on the programme, he replaced the names of characters with those of his family members, creating concern for the professionals in contact with him. Gathering information of this kind is vital to ensure that the correct decisions are made.



The following points should be considered when trying to elicit information from children with autism:

- › If possible, involve someone that knows the child well, who can help communicate with the child and also identify the child's level of understanding.
- › Consider the environment. If it is somewhere the child is unfamiliar with, this will create added distraction and/or anxiety.
- › Allow enough time for the child to process the questions or information.
- › Don't rush them.
- › Don't re-phrase the question. If necessary, repeat the question in the same way.
- › Be led by the child and go at their pace.
- › Be clear and specific with the questions or phrases that you use.
- › Reinforce what you are saying with visual supports, whether PECS (Picture Exchange Communication System), symbols, pictures or writing, communication passports, etc. or other tools that child uses to communicate.
- › Build in breaks. As communication is going to be something that the child finds difficult, at whatever level, it's important to allow them to have plenty of time in which no demands are placed on them.



Hate and mate crime

Over recent years, there have been more reports of hate crime incidents. A hate crime is a crime committed against a person because of their disability, ethnicity, transgender status, faith or sexual orientation.

Mate crime is when someone takes advantage or exploits the vulnerability of someone while pretending to be their friend. Many people with autism desperately want to have friends, but may struggle to know the best ways of starting and maintaining friendships. They can therefore be particularly vulnerable to mate crime. In addition to this, as they would struggle to understand the intentions of others, they may struggle to see the relationship as anything other than friendship, even if this involves the person with autism getting involved with activities that they may have concerns about.

As children get older, they become more aware of the social vulnerability and potential pliability of children with autism and some may take advantage of that. Some young people with autism can blend and mimic the language and behaviour of others as a way of fitting in. Despite the fact that the child with autism might say that these people are their friends and use the same language as them, it doesn't necessarily mean that they have been accepted by that group of people or that the person with autism feels altogether comfortable in that environment. It's incredibly important for professionals to observe these relationships and question the nature of some friendships which may appear unusual.



Professionals working with children with autism should always be alert to all signs of bullying, mate or hate crime and take action if they suspect a child is experiencing any form of harassment. Preventive strategies at school often include teaching children to identify safe places and people who can help them.

Support for the child

Clearly if the child is unable to understand that any form of abuse has occurred, this will have a major impact on the reporting of that abuse and also the support needed to help the child deal with it.

As part of the process of eliciting information about the incident, the child's knowledge and understanding of what has occurred should be explored. Gathering this information will also be beneficial for helping the child deal with the incident and ensuring, as much as possible, they don't become the victim of this

kind of abuse again. However, it is essential that any information given to the child in terms of safeguarding themselves takes their autism and individual needs into account. Providing generic support to the child with autism may mean that they miss out on some of the more subtle messages that you are trying to help them understand.

As for anyone who has experienced any form of abuse, people with autism need help to deal with that experience. However this support has to take into account their autism and as such their communication difficulties, as well as the fact that they may well deal with and process the experience in a different way.

As with all victims of abuse, the potential for mental health issues to arise following an incident is incredibly high. Providing the right kind of support for that child in a way that they understand, that takes account of their communication needs, social understanding and intellect is incredibly important. This will help to prevent other issues further down the line, such as becoming a perpetrator of violence themselves.

It is also important to give children and young people the skills and training to deal with situations in which they might be vulnerable.

It may be necessary to give the child a script with which to respond if someone says something or touches them in a way they are uncomfortable with, but they may also need to be prepared for a number of different

responses that they may receive and how then to respond. It is imperative that children with autism are taught how to keep themselves safe.

Support for the family

Having a child with autism can be very difficult and isolating at times. Many families battle for years to get a diagnosis for their child. Following the diagnosis, they may have to continue the fight to get the support they need for their child. As a family, they may also need to fight for the right education, or for financial help, while trying to keep the family together and give enough support to their partner and siblings. The experience of all of this can, at times, be seen negatively by professionals, who may not know about any of this and who may judge the family as being aggressive, obstructive or difficult.



It is important that parents receive information about what autism is and how it impacts on their child. In particular information about understanding communication and behaviour and general strategies for how to manage behaviour. It's important that professionals are non-judgemental. If the family has asked for help and support it is likely that it has come after trying a number of ways of dealing with issues by themselves. If you appear to judge them based on the decisions they have made, that may mean that families do not seek support, perhaps until it is too late. It's important to encourage parents to have open dialogue with professionals involved in their child's life. Many parents have a fear of their child being taken from them and therefore may be concerned about raising any issues.

It's useful for teachers and support staff to encourage parents to tell them about changes at home which may all have an impact on the child's behaviour, for example moving house, a sibling or a parent leaving home, a sick relative which may mean one parent is away from the home more frequently than before, etc. All of these things can have an effect on the child's behaviour and are therefore important to take into account when considering any changes.

Although we still don't know the exact causes of autism, we know that in some

cases there is a genetic link. It is important to consider this when looking into potential safeguarding incidents, as what may appear to be signs of neglect or abuse, may be the parent's difficulties in relation to social interaction because of possibly undiagnosed, or even diagnosed, autism. This will clearly not be the case for all parents with a child with autism, but it is important to consider, particularly in relation to bonding and attachment concerns that professionals may have.

Many people with autism make excellent parents and it should in no way be assumed that they are any more likely to have issues with bonding with their child than any other parent, but it is worth considering if their parenting style is different or not what you would expect. Due to the difficulties with being able to 'read' or understand the feelings and emotions of others, this is unlikely to come naturally to a parent with autism and may therefore be something that they need to learn.

It's important to understand that for parents with autism, the way they parent their child may be different to our ideas of how to parent a child, but that doesn't necessarily mean that the way they do it is wrong. However, there may need to be additional support given to those parents who have autism, whether they have a diagnosis or not.

'It's important to encourage parents to have open dialogue with professionals involved in their child's life. Many parents have a fear of their child being taken from them and therefore may be concerned about raising any issues.'

Resources

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

Csóti, M. (2001). *Social awareness skills for children*. London: Jessica Kingsley Publishers

Wrobel, M. (2003). *Taking care of myself: a hygiene, puberty and personal curriculum for young people with autism*. Arlington, Texas: Future Horizons Incorporated

Kerr-Edwards, L. and Scott, L. (2003). *Talking together... about sex and relationships: a practical resource for schools and parents of children with learning disabilities*. London: Family Planning Association

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

McMaster, C. (2011). *The choices game: staying safe in social situations*. London: Jessica Kingsley Publishers

Holliday Willey, L. (2011). *Safety skills for Asperger women*. London: Jessica Kingsley Publishers

Brown, D. (2012). *The Aspie girl's guide to being safe with men: the unwritten safety rules no one is telling you*. London: Jessica Kingsley Publishers

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

Steward, R. (2013). *The independent woman's handbook for super safe living on the autistic spectrum*. 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

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

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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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