

Minimising distressed and disturbed behaviours through the care or education environment

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WHY IS IT IMPORTANT TO CONSIDER THE ENVIRONMENT WHEN PLANNING THE CARE OR EDUCATION OF PEOPLE WITH AUTISM AND RELATED DISORDERS?

We all respond to our environment. If we are content with our surroundings, we can be content in ourselves. If we are not content, we will try to reorganise them, rearrange things, change them or dispose of them. We might even move away and choose somewhere else to be. Most of us have the power to make such changes, the power to choose. We are in control of our lives and, to a certain extent, are able to exercise choice to ensure our comfort and security. We can negotiate with the social world and find our niche.

People with autism do not tend to have such power of negotiation and self-determination. They are to a great extent dependent on the good will and judgement of others. They do not tend to understand their position in the social hierarchy and may try to influence their surroundings by behaving in ways that make change necessary. Using behaviour to comment on one's circumstances can of course lead to a reduction of those circumstances. People with autism need help to negotiate for favourable circumstances and the opportunity for contentment. They need help with making their environment suitable for their special needs.

The environment is not just the bricks and mortar, plants and inanimate objects that we are surrounded with, but more importantly it includes the human beings we have to interact with. Bricks, mortar and objects tend to be

predictable and reliable. A wall tends to stay where it is built; a piece of furniture tends to stay where it is put; an ornament will not move by itself. The weather changes of course and the seasons progress, and both are important environmental factors that can have profound effects on people with autism in particular. However, the most unpredictable and disconcerting factors in the environment are people.

People are not always predictable. They move around with a will of their own; they look different from day to day; they make noises, some familiar, some not; they are sometimes animated, with their mouth turned up at the corners, sometimes quiet, with their mouth turned down. People make demands of you, but it is often hard to know what it is they want. Sometimes they let you do certain things; sometimes they try to stop you. Sometimes they are encouraging and sometimes they get angry and criticise. They seem to change the rules from day to day.

From the point of view of a person with autism or Asperger's disorder, people are a conundrum. Sometimes they even appear threatening and are to be feared. People with autism tend to have less power than the rest of us and we are all wise to be wary of those who can exercise power over us.

People with autism or Asperger's disorder lack many skills that we take for granted and have many difficulties that are hard to comprehend. The most obvious difficulties are with the social use of language. Even the most verbally able, literate people with these disorders, who may have a wide vocabulary, find it impossible to engage in a mutually rewarding conversation with another person. The ability to accommodate the thoughts, ideas and feelings of another is missing. This inability to exchange thoughts, ideas and feelings means that they cannot exert influence or engage in debate or negotiate for themselves. It is left to the carer or educator to anticipate their needs and even to advocate for them. People with autism, no matter how intelligent, are left in a powerless position in the social world, at the mercy of others. It is little wonder, then, that they sometimes act out of fear and frustration.

People with autism and Asperger's disorder tend to have great difficulty in generalising concepts and have a literal understanding of what they see and hear. They have difficulty with anticipating the behaviour of others, being unable to use theory of mind, the ability to imagine how others think and feel. They tend to lack the ability to plan ahead, to anticipate how to organise a series of actions to achieve a desired outcome. They depend on others to make desirable things happen and to preserve the familiar. They depend on others to maintain an environment that is sympathetic to them and their changing needs.

This inability to understand the world they live in and in particular the social world goes some way to explaining their love for the familiar, for order

and routine. Bricks and mortar and objects are predictable and therefore safe, provided they are not interfered with by the human element, which inevitably introduces incomprehensible demands, change and uncertainty.

Without the power that comes from the use of language, without the ability to understand why things happen and especially the motives of people who cause them to happen, and without the control over the environment that we take for granted, people with autism are forever at the mercy of events. They have little understanding of the people they depend on and little ability to influence them in a constructive way. All too often those who can exercise such powers reciprocate this lack of understanding. People with autism and Asperger's disorder are often seen as incomprehensible folk who live in a world of their own and choose not to engage with others. They may be regarded as malign beings who deliberately behave badly. It is little wonder then that they sometimes have to resort to difficult behaviours to influence the world around them.

Of course, drugs may be used to reduce the undesirable behaviours. This course of treatment is often indicated by the medical model, which seeks to treat what may be seen as underlying anxiety or psychosis. However, there are costs to be paid for using drugs. Apart from the financial ones, there are the side-effects of major tranquillisers, addiction, reducing effects over time and the even more undesirable behaviours and conditions that can result from cocktails of powerful drugs.

Experience has shown that by paying proper attention to the environment, the use of tranquillising drugs can be reduced to very low levels indeed and even stopped altogether. The development of specialist homes and schools for people with autism and related disorders in the UK over the past two decades has improved their lives and prospects considerably. By concentrating on getting the environment right in the first place, the factors that cause the behaviour that leads to the prescription of tranquillisers have been to a large extent eliminated. Those of us who are engaged in social care in these more enlightened times are much less reliant on psychiatric interventions than we were in the not too distant past.

WHAT CAN WE DO TO IMPROVE THE ENVIRONMENT FOR PEOPLE WITH AUTISM AND RELATED DISORDERS?

Educators and carers can start by accepting that people with autism and Asperger's disorder do not choose to have their disability. It is not their choice to be isolated from pleasurable and rewarding social interaction with the people around them. People with autism and related disorders have many needs and

desires and rights that ought to be expressed, negotiated for and defended. It is up to carers and educators to recognise that the inability to communicate effectively and mutually beneficially is a shared one that both parties need to work at. People with autism do not have the ability to help themselves, but those charged with the responsibility of caring for them certainly should help.

There are particular areas we can be careful to address. These are the social aspects of the environment, where we know that people with autism and Asperger's disorder are particularly disadvantaged, and the physical aspects, over which we exercise such control.

Social interaction

Social interaction is usually stressful, sometimes even painful, for people with autism or Asperger's disorder, and so our behaviour and expectations must take account of this.

For most of us, social interaction is not only pleasurable but also very necessary for our mental health and well-being. Social exclusion is one of the most hurtful ways of treating somebody. One of the favourite tools of punitive or oppressive regimes is isolation, which is also often used as a punishment in prisons. The thought of social exclusion or isolation is so abhorrent to most professionals and carers that they will put pressure on people with autism or Asperger's disorder to engage with others and to join in activities. This can have an extremely detrimental effect. Great sensitivity has to be exercised in encouraging them to join in what they might enjoy, while at the same time recognising those activities they do not. They do not learn social behaviour merely from exposure to a sociable peer group.

People with these disorders should neither be forced to join in nor excluded. They need opportunity and gentle encouragement over time. Try to judge whether a particular social activity would be rewarding for an individual or if that person might benefit from something different. Many people with autism or Asperger's disorder would not be happy with a noisy, unstructured activity, but would prefer a more structured one in quiet surroundings, perhaps with less direct interaction with people.

Social communication problems are normal for people with autism or Asperger's disorder and to be expected; carers and educators must learn to understand and communicate with each individual.

Understanding the difficulties that people with autism and related disorders have with language and communication, carers and educators must learn to communicate effectively. People with autism all share similar problems, but they are still individuals and we must learn to adapt effective practices and

principles to the individual. Generally speaking, we must learn to use fewer words, to emphasise key words and to avoid ambiguity, especially metaphors, similes and irony. Making jokes is probably best avoided altogether unless you know the individual extremely well.

Their behaviour may well cause stress and anxiety to those with whom they live.

People with autism often have to live in mixed communities of people with disabilities and their behaviour can cause distress to others. This in turn may lead to them being ostracised or, even worse, to the detriment of all concerned. Social mixing must be carefully planned to minimise distress. To avoid social problems it is advisable to be very careful about placing people with autism and related disorders with others. Behavioural characteristics that are accepted by one individual may cause severe problems for another. It is not reasonable to blame people with autism for behaving the way they do – they are merely responding to their environment and the difficulties they are experiencing. Neither is it profitable to blame the one who cannot tolerate the other. It is better to mix people together who do not antagonise each other.

Physical environment

Privacy and personal space are important, but this must be balanced by adequate supervision of people who are often unaware of common dangers.

- Safety aspects of furniture and fittings are important. Equipment is likely to be misused, so the potential to cause injury must be assessed and minimised.
- Robust furniture and fittings will reduce pressure on staff. Equipment should not be so vulnerable to misuse that carers and educators have to be overly protective of it. This will reduce the potential for conflict.
- Levels of physical security, both inside and out, must be considered. How easy is it for people to absent themselves unnoticed? Is there a degree of surveillance outside? Are there procedures for attending to someone who is leaving the site, and are all staff aware of what they should do?
- Noise levels should be considered – hypersensitive hearing is common in autism and Asperger's disorder. The radio or television is often left on not for the benefit of those being cared for or educated but for the sake of the employees. Loud music or voices are at the very least distracting to people who have difficulty in discriminating between what they should attend to and that which they need not. At worst, loud noises (and, for some people, even the tone or pitch of a noise) can be physically painful and cause considerable distress.

- Boundaries must be clearly defined. Although it is usually unacceptable to lock doors, especially those to the outside, which are usually fire exits, it is nevertheless important to reinforce physical limits. Even a token barrier will often be respected if it is reinforced by clear and firm explanation.

Daily programme

- The daily programme must be structured and highly organised, with a timetable that is not subject to sudden arbitrary changes, and a staff rota that presents familiar staff in predictable patterns.
- The timetable should be made readily available and presented pictorially for those who cannot read. A daily programme of activities in book form (pocket photo albums are useful) is also helpful, again presented pictorially if necessary.
- Changes should always be planned in advance and carefully explained with reassurance. Sudden, arbitrary changes of plan should always be avoided.
- New activities should be introduced gradually and sensitively in small steps, by negotiation. Always have a contingency plan (or fallback position) in case of refusal.
- The significance and importance of repetitive behaviours should be recognised but effective strategies must be devised for limiting them and addressing the harmful ones. Such behaviours are often an indicator of anxiety, the cause of which must be addressed in the first instance.
- Information should be presented in visual terms as much as possible.
- The atmosphere should at all times be calm and safe.
- Psychiatric support may provide help with medication to reduce anxiety or to treat illness such as depression, which can particularly affect people with Asperger's disorder.
- A range of vigorous physical activities should be made available and the individual consistently encouraged to join in.
- An individual's skills and interests should be reflected in the programme of activities. Activities that an individual particularly enjoys may act as a reward for participating in the less attractive ones.
- Agreed and appropriate strategies must be devised for coping with disturbed or distressed behaviour. Everybody must follow these in a consistent manner.

The behaviour of carers and educators

Probably the most important environmental factor is the human one. It is often forgotten that those interacting with the individual have the most

significant environmental impact upon them. Carers, teachers and others have the power to make an intolerable situation tolerable or vice versa. The behaviour of these people is crucial to the well-being of the person with autism or Asperger's disorder and their training is of paramount importance to those charged with responsibility for them.

People with autism and related disorders have very great difficulty in understanding the behaviour, speech and body language of other people. They are often completely unaware of how their own behaviour patterns affect others. Those charged with caring for and educating them need to anticipate these difficulties and behave in ways that are helpful to their client rather than causing them difficulties.

Body language

Body language must be non-threatening; avoid getting too close and unnecessary touching. Remember that people with autism have great difficulty using and understanding gestures, eye contact and facial expressions. It is important to give out a resolute and confident impression, which will inspire the confidence of the individual. Be aware of the effect that your presence is having on a client and be prepared to adjust the distance between you or to withdraw an attempt to touch.

Demeanour

It is important to be polite but also to be firm and consistent. Avoid letting your personal feelings affect your behaviour towards the individual; try to maintain the same approach at every interaction. Avoid behaving in a playful or irreverent manner or allowing strong emotions to colour your behaviour. Pace yourself to be steady, maintain a take-it-as-it-comes, matter-of-fact demeanour, while consistently reinforcing the message you are trying to get across.

Voice

Develop a calm voice, even and without dramatic intonation – confident with a tone that is persistent but does not betray irritation and does not hector. Ensure that your voice demonstrates patience, tolerance and acceptance, while showing conviction.

Words

Use as few words as possible. Avoid long, chatty sentences. Get to the point as quickly as possible using key words that the individual can relate to. People

with autism and Asperger's disorder tend not to appreciate the pleasures of social intercourse and quickly become confused in conversation. Speak in the future conditional, for example 'When you have finished what you are doing, then you may start the something else'.

Acceptance

Show that you respect the individual as a person and that you accept the client as he or she is. It is often necessary to tolerate a preoccupation with a particular topic or interest. Avoid being judgemental at all costs. You might set a time limit on how long you will listen to it, after which you will thank them for the information and move on. If you have to point out some bad behaviour, ensure that it is the behaviour that you judge to be unacceptable, not the client.