

Key principles for autism interventions: additional information

We want to explain a bit more about the key principles for autism interventions and why we think they are important (page 14 of this book).

1. The intervention is based on a good understanding of autism

Some interventions are based on flawed theories of autism and the causes of autism. For example, some of the first interventions to be used were based on the incorrect belief that autism is caused by so-called 'refrigerator mothers': mothers whose denial of emotional warmth causes their babies to turn away from other human beings and become autistic. We now know that this theory is false. Most researchers believe that autism has a variety of causes, which are likely to be a complex mix of genetic and environmental factors that affect a number of different areas of the brain (1, 2).

Other interventions are designed to 'cure' autism, despite the fact that autism is not an illness or a disease. These interventions do not usually consider how different each person is from others on the spectrum, and none has been shown to work (3). Furthermore, the idea of curing autism goes against the views of some in the autism community who do not want to be cured and would rather that research funding be spent on helping with practical problems such as crossing the road safely, making friends, or finding a job (4).

2. The people who deliver the intervention know the person well and respect their feelings and views

People who deliver an intervention should know the person they are working with well – because every person on the autism spectrum is different. People who deliver an intervention should also respect the person’s feelings and views. For example, the National Institute for Health and Care Excellence recommended that:

‘All health and social care professionals providing care and support for adults with autism should:

- aim to foster the person’s autonomy, promote active participation in decisions about care and support self-management
- maintain continuity of individual relationships wherever possible
- ensure that comprehensive information about the nature of, and interventions and services for, their difficulties is available in an appropriate language or format including various visual, verbal and aural, easy-read, and different colour and font formats)
- consider whether the person may benefit from access to a trained advocate.

One study found that some support staff in some care settings can make assumptions about the people they care for. This could stop them from understanding their views and wishes (6).

When this happens, people with autism could potentially be subjected to abuse. The Winterbourne View scandal is an example of what can happen when this is allowed to continue (7).

3. The person’s capacity for consent is taken into account.

Some people on the autism spectrum lack the capacity to consent to interventions. However, they still have the right to be protected from interventions which are painful, hazardous or unduly distressing. That right is enshrined in various pieces of legislation such as the Age of Legal Capacity (Scotland) Act

(1991), the Children Act (1989), the Mental Capacity Act (2005) and the Mental Health Act (1983) (8, 9).

For example, the Mental Capacity Act (2005) applies to everyone who looks after, or cares for, individuals aged 16 and over who lack capacity to make particular decisions for themselves. This includes family carers, healthcare staff, social care staff, and a range of other people.

The Act states that adults who lack capacity have the right to be represented by an advocate during any discussions of interventions. The advocate must ensure their rights are upheld. Safeguarding procedures must be kept in mind if the intervention has known risks (10).

4. The intervention is adapted to the needs of the person receiving it

Interventions should be adapted to meet the needs of the individual on the autism spectrum because each person on the spectrum is so different.

For example, some people on the autism spectrum have over-sensitive senses. They may find certain sounds physically painful or they may not be able to wear certain clothing because they find the fabric uncomfortable. Some people on the autism spectrum have under-sensitivity. They may seek out strong flavours, as they are unable to taste bland food, or they may rock or spin to stimulate their senses of movement and balance.

So, an intervention designed to help someone on the autism spectrum deal with their sensory sensitivities would need to take into account the specific sensitivities of each individual (11).

Also, some interventions not originally designed for people on the autism spectrum can still be beneficial to them if they have been adapted to their needs.

For example, the National Institute for Health and Care Excellence recommended that cognitive behavioural therapy should be adapted for individuals with autism. This might include,

for example, using 'a more concrete and structured approach with a greater use of written and visual information (which may include worksheets, thought bubbles, images and "tool boxes")' and 'placing greater emphasis on changing behaviour, rather than [thoughts], and using the behaviour as the starting point for intervention' (5).

5. The intervention is based on a theory that is logical and scientifically feasible

A number of interventions for people on the autism spectrum are based on illogical and unfeasible theories. Sometimes these are flawed theories about the nature of autism (see principle 1) and sometimes these are flawed theories about how the intervention itself is supposed to work.

One intervention that is scientifically unfeasible is homeopathy. According to the NHS Choices website: 'There have been several reviews of the scientific evidence on the effectiveness of homeopathy. The House of Commons Science and Technology Committee said there is no evidence that homeopathy is effective as a treatment for any health condition.

'The ideas that underpin homeopathy are not accepted by mainstream science, and are not consistent with long-accepted principles on the way that the physical world works. The Committee's 2010 report on homeopathy said the "like cures like" principle [homeopathy's central principle] is "theoretically weak", and that this is the "settled view of medical science"' (12).

6. Research evidence shows the intervention can work for people on the autism spectrum

Evidence-based interventions are important as the evidence provides assurances that they have been tested, and that they have been assessed for risks. Remember: evidence in favour of an intervention does not guarantee that it works with every person with autism, but it does provide some reassurance to people who are thinking about using it.

Many interventions used with people on the autism spectrum (including many forms of adaptive and assistive technology such as computer apps, smart phones and visual schedules) have limited or no research evidence. This does not mean that they do not work; it may simply mean that more research is required to find out if they do work.

Also, remember that some interventions (often not evidence-based) are marketed to play on a person's guilt or anxieties to convince them to pay to use this provider of the intervention. These interventions may not be designed with the person specifically in mind, may not work and often risk people's time and money (13).

7. The intervention works in the real world, not just in a research laboratory

Interventions should work in the real world. Many autism interventions start off being tested in research settings – where as many variables as possible are controlled. However, in the real world, it is often not possible to control for things like the level of training and experience of the person giving the intervention, the room where the intervention takes place, how often it can take place, and who takes part in the intervention. Because of this, a number of interventions have been shown to be less effective in the real world compared to research settings. For example, some forms of theory of mind training have been shown to be effective in laboratory settings, but seem to be ineffective in real-life situations (13).

8. The intervention is delivered by, or supported by, appropriately qualified and experienced professionals

Where the intervention is delivered by professionals, it is important that they have the appropriate qualifications to deliver the intervention effectively. For example, in the UK, allied healthcare professionals (such as speech and language therapists) are regulated by the Health and Care Professions Council and may also be chartered with an appropriate professional association

(such as the Royal College of Speech and Language Therapists). These agencies try to ensure that allied health professionals follow best practice, such as using evidence-based interventions.

Please note: unfortunately there is no regulation for some 'professionals' such as homeopaths, and no evidence that some practices such as homeopathy work, so any advice from these 'professionals' should be treated with extreme caution (12).

It is important that, in addition to any professional training, professionals have an appropriate level of experience, that is, they have actually worked successfully with people on the autism spectrum. It is equally important that they have the right attitude, that is, they 'get' autism and they 'get' people on the autism spectrum.

Where the intervention is delivered by someone on the autism spectrum or by family members, it is important that they are supported by appropriately qualified professionals. For example, anyone thinking of following a special diet should seek advice from a paediatrician, GP or dietitian. This is because altering your diet can have significant, long-term effects. According to one review of special diets for people on the autism spectrum:

'The combination of food selectivity and restrictive diets can make it difficult to achieve an adequate diet, consequently resulting in an excessive intake of certain foods and/or deficiencies and malnutrition due to insufficient amounts of other foods. In turn, inadequate intakes may lead to the development of chronic and degenerative conditions that tend to appear in the third or fourth decade of life (cardiovascular disease, high blood pressure, diabetes, dyslipidemia [imbalance of fats], and osteoporosis [fragile bones], among others) or even earlier, in the case of menstrual disturbances, sleep apnea [pauses in breathing], and psychosocial disorders.' (15)

9. The people delivering the intervention follow established guidance

The people delivering the intervention should follow established guidance, especially when that guidance has been published by

relevant regulating bodies or is based on research evidence.

For example, in the UK, psychiatrists and paediatricians who prescribe antipsychotics for people on the autism spectrum are expected to follow guidance on their use published by the Medicines and Healthcare Products Regulatory Agency (16). Recommendations on specific dosages for specific antipsychotics are set out in publications such as the BNF (British National Formulary) (17).

Where interventions are not covered by regulating bodies, the people delivering those interventions should still follow established guidance, especially when that guidance is based on research evidence. For example, in the UK, the National Institute for Health and Care Excellence has published guidance on interventions for adults on the autism spectrum and for children and young people on the autism spectrum (15, 18). (Please see page 308).

It is also helpful if the people delivering a specific intervention follow any guidance (usually set out in the form of a manual of instructions) from the developers of the intervention. This guidance will normally explain the key principles behind the intervention and how it should be delivered. Following the guidance ensures that the intervention is actually delivered the way it is supposed to be.

10. The intervention is carefully monitored and reviewed on a regular basis

All interventions should be carefully monitored and reviewed on a regular basis to ensure that they are delivering real benefits, using robust outcome measures. If it becomes clear that there are no significant benefits, the intervention should be stopped or amended.

For example, the National Institute for Health and Care Excellence recommended that, if antipsychotic medication is prescribed to help children on the autism spectrum with challenging behaviours, the paediatrician or psychiatrist should:

- identify the target behaviour

- decide on an appropriate measure to monitor effectiveness, including frequency and severity of the behaviour and a measure of global impact
- review the effectiveness and any side effects of the medication after three-to-four weeks
- stop treatment if there is no indication of a clinically important response at six weeks.’ (18)

11. The intervention provides significant benefits

Interventions should provide significant benefits to the individual on the autism spectrum (and their family or carers). However, different people may have different views on what counts as a significant benefit.

For example, a recent study of weighted blankets reported that a weighted blanket ‘did not help children with ASD sleep for a longer period of time, fall asleep significantly faster, or wake less often. However, the weighted blanket was favoured by children and parents, and blankets were well tolerated over this period’. (19)

In other words, the researchers did not think that the weighted blankets provided any significant benefits but the parents did and wanted to keep them. This may be because the parents saw some changes in the child that the study was not measuring, such as making the child calmer. Or it could be that the parents thought they saw some benefits that were not actually there (19).

Some interventions have not yet shown long-lasting benefits. For example, some treatments (such as oxytocin, a hormone that is injected or inhaled) have shown improvements in behaviours and communication skills, but only for a brief period after the treatment was given. When the treatment is stopped, the measured improvements in behaviour are lost (20).

12. The intervention does not cause significant physical or emotional harm

Some interventions have a major risk of physical or emotional harm. For example, holding therapy is a type of attachment

therapy. It is forced holding by a therapist or parent, either until the child stops resisting or until a fixed period has elapsed. The carer does not usually release their hold until the child 'surrenders' and looks into the carer's eyes. The carer then returns the child's gaze and exchanges affection.

According to Mercer, 'Practitioners base its use on the assumption that rage resulting from early frustration and mistreatment must be provoked and released in order for the child to form an emotional attachment and become affectionate and obedient. Death and injury have resulted from attachment therapy.' (21)

Holding therapy is a good example of an intervention which can cause physical harm through the forced holding, as well as emotional harm through the act of forcing a child to 'surrender' and look into their parent's eyes.

13. The benefits outweigh any costs (including risks)

Weighing up any potential costs (including any risks) against any potential benefits for an intervention is likely to be up to each person to decide, as some may be willing to take on more risk than others.

Some interventions (including some medications) may present significant costs and side effects. For example, a significant amount of research evidence shows that the drug risperidone may be beneficial for the treatment of various problems faced by people on the autism spectrum, including irritability, repetition and hyperactivity.

However, the same research noted that risperidone has many potential side effects, especially weight gain and drowsiness which may have a significant impact on the person's quality of life (22).

14. The intervention is good value for money and time invested

Different people will have different ideas about what is and what is not good value for money. However, some interventions are extremely expensive and we would recommend that you try to

identify as many of the costs as you can before undertaking the intervention.

For example, a review of dolphin-assisted therapy (DAT) found that:

'The cost for two weeks of DAT varies a great deal and a variety of packages are available. Figures given by Humphries (2003) quote a typical price of around \$2,600 (approximately £1,370) for five 40-minute sessions, but it can cost a participant and one parent more than £3,300 for two weeks, including flights and accommodation. At the more expensive end of the market is the 'Dolphin Human Therapy', which during 2006 cost \$7,850 for two weeks, or \$11,800 for three weeks. These quoted prices are for the therapy only (fixed sessions per week) and do not include flights and accommodation.

'There are other hidden costs such as surcharges for health care, which should be taken into consideration. Families are generally encouraged to bring children for a minimum of two weeks of DAT. When flights, accommodation and loss of earnings are taken into account, such excursions can cost up to £10,000.' (23)

Further information

In this book: Please see How to use this book (page 11), Chapter 3 (page 38) for information about interventions, Chapter 4 (page 43) for information about how scientists evaluate those interventions, and Section 3 (page 284) for advice on making the decision about whether or not to use a specific intervention.

Website: Please see www.researchautism.net/key-principles for the latest version of these principles.

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