

## Information to guide you when choosing an intervention



Research Aware

## Choosing an Intervention\*: Information To Guide You

### Overview

- ◆ Interventions can be described as treatments, therapies, treatment programmes etc.
- ◆ The aim of interventions is to help with symptoms and behaviours associated with autism. They are not a 'cure' for autism itself.
- ◆ Some interventions have research evidence\* to show they can help people and families with autism.

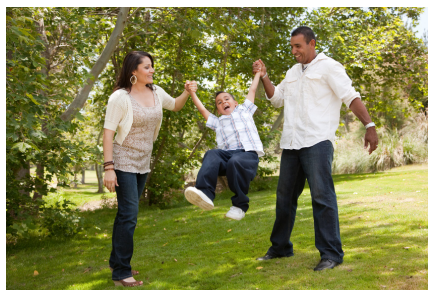
### Things to think about when selecting an intervention are:

1. Why should it work?
    - What are the aims of the intervention and what methods does it use?
  2. Where is the research evidence?
    - Is there published research on its effectiveness?
  3. Who is carrying out the intervention?
    - What are the qualifications, training and experience of the person delivering the intervention?
  4. What kind of involvement is needed from me and my child?
    - What are the costs to the family in terms of time and money?
  5. When can I expect to see changes?
    - What is the time-frame predicted for change, and when is the time to stop?
- ◆ Definitions of terms and words highlighted in BLUE in this document can be found in our glossary on page 9 - 10

\*You can find information about the research evidence for different interventions on the Research Autism website. (<http://www.researchautism.net/evaluations> )

## What are interventions?

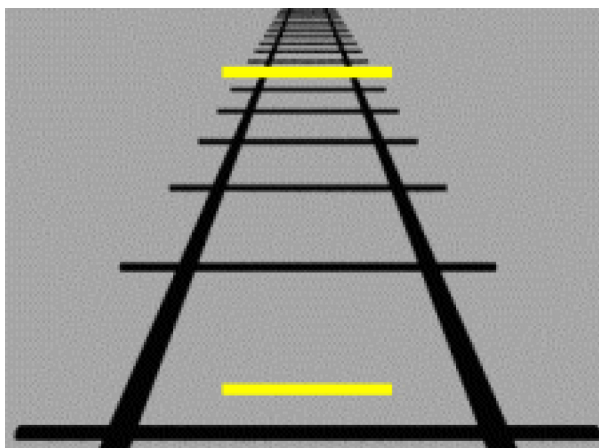
- ♦ **Interventions** are designed to 'target' symptoms rather than target the cause of autism. Contrary to some reports there is no 'cure' for autism.
- ♦ There is evidence that particular interventions are successful in helping both children and adults with autism.
- ♦ These interventions can help individuals with autism to develop social and communication skills and may target sensory and emotional issues.
- ♦ It is important to know that particular interventions can lead to significant improvements for individuals with autism and also their families.
- ♦ However, it is also important be aware that (i) not all of the currently advertised interventions are effective and (ii) not all interventions work for all children.
- ♦ Research has also shown that some interventions do not have any beneficial effects and some could potentially be harmful. Although this might sound worrying, this refers only to a handful of interventions.



## How do you choose an intervention for your child with ASD?

- ♦ Choosing an intervention is one of the most important decisions that parents of children with ASD have to make. In arriving at a decision, you will be guided by what you read and hear about different interventions. This information will come from intervention providers, from the web and from people you know. On hearing information about something new, it is natural for us to trust our impressions, and believe what we hear and see. But our impressions can also mislead us. To demonstrate this, here is an example of how our eyes can deceive us.





**Look at the figure above.**

**Q. Are the yellow lines the same or different lengths?**

**A.** They are the same.

Our brain is telling us they are different lengths because the top line appears further away. Our brains can fool us about simple sensory things like this. Therefore we should not just rely on our impressions or feelings about an intervention to decide if that intervention works. We need to always look for **objective evidence**. (Many thanks to Prof David Evans of Bucknall University, USA for this example)

- ◆ You should approach every new intervention with healthy caution no matter how well it is presented and no matter how convincing and well-known the people are behind it. In essence, you should view it like a scientist and avoid accepting any claim that is based on opinions, beliefs, and speculations; instead, ask questions and seek evidence.
- ◆ It is important to know that you can ask questions. You have the right to expect clear answers from people who offer interventions.
- ◆ Every claim made by the people who offer interventions should be supported by evidence. You should not feel you have to settle for anything less.
- ◆ It is important to gather as much information as possible about the intervention being offered.



- ◆ You should ask for a description of the intervention, either in the form of a detailed printed brochure or a website. Also look for 'peer-reviewed' scientific publications.

**When reading intervention descriptions it is important to think about some of the following questions. You should expect answers in line with the suggestions below:**

### **Q1. Why should the intervention work?**

The people who designed the intervention should explain why they think that their intervention should work with children with ASD. These explanations should not be based on personal stories and unverified personal reports. Often there will be a theory behind the intervention. The theory should provide an explanation as to why this particular intervention will change symptoms and how it will do that. You need to know what this theory is and whether it is based on [scientific research](#). The explanation should be clearly communicated. You should feel free to question the intervention provider if they use scientific jargon that is unclear.



Any intervention that is designed to help your child should have clear aims that are easy to understand. It should also have clear methods for achieving these aims. The main aim for a [behavioural intervention](#) is that the intervention should be responsible for making some kind of change to behaviour. It is important to find out what behaviour the intervention is aiming to change and how that behaviour might be expected to change. So, the aim of the intervention might be to reduce an undesired behaviour, increase a desired behaviour or skill, or even change a number of different symptoms of ASD at the same time.

If an intervention aims to change behaviour(s), the person delivering the intervention must use a reputable method that is clear to you. The method should include ways of measuring the change in behaviour. For an intervention to be successful, the therapist must have a clear and accurate picture of the behaviour(s) that will be targeted before the intervention starts. The therapist also needs to assess the behaviour(s) after the intervention. Look for information that states how the therapist will measure the behaviour(s). The method that they use must be accurate, reputable and clearly communicated.

### Questions you might ask

1. What is the theory behind the intervention – why should it create an improvement?
2. What is the intervention aiming to change?
  - a. An undesired behaviour or a desired behaviour?
  - b. A single behaviour or many behaviours at the same time?
  - c. Is it aiming to create change for my child, or me or both of us?
3. What method is being used? How will the therapist explicitly measure each of behaviours that will change? Are the measures reputable?

## Q2. Where is the research evidence?

The people who designed the intervention should be able to show you where the research evidence is that supports their claims. Scrutinise this evidence carefully. A good question to ask is where the research was published. Research that has been published in scientific journals (e.g. The Journal of Autism and Developmental Disorders, The British Medical Journal) will generally be more **reliable** than research that is unpublished or published elsewhere. This is because it will have been subject to **peer review**. This will help to check for **rigour** and **objective testing**.

Published research should test the methods of the intervention to show that they are reliable when used across different therapists or across different children. A good test of an intervention is if the research evidence has been replicated across a number of scientific publications. Published research should also show that the intervention is **valid**, meaning that it delivers what it aims to deliver. For example, if you design an intervention to improve children's self injurious behaviour and self injurious behaviour does not change, then the intervention itself is not valid, even if the child seemed happier when the therapist was with the child or even if the parent felt more confident after the therapy.

Even if there is research evidence for the intervention, is there good reason to believe that intervention should work with your child? As you know, every child is a complex individual with a unique set of strengths and weaknesses. Therefore, an intervention may need to be adapted to your child so that your child's strengths can be further developed and weaknesses improved. Can the intervention you are looking at be adjusted to suit your child? Adapting an intervention to every individual child is a complex process, but established comprehensive interventions have clear strategies for doing this. You should expect the same from any intervention that is offered to you and your child.



Questions you might ask are:

1. What research has been carried out on this intervention?
2. Have the findings been reported in a scientific journal?
3. Is the research evidence reliable and valid?
4. Is there evidence to suggest that the intervention will be appropriate for my child's needs in particular?

### Q3. Who is carrying out the intervention?

It is very important to know the training and experience of the people who deliver the intervention. For the therapists to be efficient they should have extensive knowledge of ASD, experience in working with children with ASD, as well as training in any intervention that they deliver to your child. You could ask to see the therapist's training certificate.



The therapist should also follow standard practices or procedures as part of the intervention method. These procedures will include variations for different children's needs. Therapists may follow a published **manual** which provides this guidance. When an intervention has a published manual, this helps to ensure that there is consistency across practitioners.

Questions you might ask are:

1. What training has the therapist had?
2. How is that training accredited?
3. How much experience has the therapist had with this intervention and does that experience include working with children who are at the same age or developmental level as my child?
4. Does the therapist follow an established set of instructions or guidelines set down by the intervention designers?

### Q4. What kind of involvement is expected from me and my child?

Some interventions can be quite time-consuming and demanding for the whole family. Life can be pretty busy or hectic and it is good to find out as much as possible about the demands of the intervention before you start. If it sounds like the intervention will be very intense or demanding, you can ask the therapist why. For example, has there been research done on that



intervention to show that such intensity is actually needed?

It is also important to know where the intervention sessions will usually take place e.g. school, home, intervention centre. This is important, as it is known that if children with autism learn a new skill in one setting, they often have problems applying that skill in a different setting. You can also ask about steps that will be taken to help your child apply the skills learned during the intervention to new settings.

Questions you might ask are:

1. How frequent are the intervention sessions?
2. How long does each intervention session last?
3. Where do intervention sessions usually take place e.g. school, home, intervention centre.
4. Are parents actively involved in the intervention and if so, in what way?
5. What are the financial costs of the intervention?

### Q5 When can I expect to see changes?



The time needed for an intervention to start to have beneficial effects may vary. For some interventions the benefits can be observed within only a few hours or days, but for others it may be several months before you start to see the benefits.

Importantly, estimation of the time-frame in which improvements may occur is based on very sound scientific facts. These are:

- 1) Knowledge of the mechanisms that are behind intervention techniques (see the 'Why should it work?' Section earlier)
- 2) Time frames based on research evidence
- 3) Extensive clinical observations.

You therefore have the right to ask for a reasonable time frame within which you may expect to see improvements. Usually, 2 or 3 months is sufficient with most interventions to start to see effects.

Questions you might ask are:

1. How many days/weeks before I see the first positive effects and what will they be?
2. Can I expect improvements to continue over time or will they level out? If the change levels out when is that likely to happen?
3. When should I be concerned that the intervention is not having an effect?
4. When will be the time to stop the intervention?

In summary, an intervention should be carefully designed with:

- ◆ a clear theory behind it
- ◆ evidence to back up that theory
- ◆ a reliable method designed for use by a qualified therapist
- ◆ The person who designed it should be able to answer any questions or concerns you may have with reasonable certainty.

Interventions that have been shown by scientific research to be effective are known as **evidence based**. For some interventions the evidence base is still not in place. Where intervention evidence is slow in being developed then the researcher or clinician should be able to tell you that.

### So I choose one intervention, what next?

There are some simple things that you can do that will help to evaluate whether a certain intervention works for your child. Before starting the intervention, try keeping a daily diary of your child's behaviours. Keep a note of:

- ◆ How often the behaviours that the intervention will target occur
- ◆ Whether there are any apparent triggers for those behaviours. For example, does your child become more anxious just before you go to the supermarket, or to visit friends or family?

This diary will give you something to compare your child's behaviour to after the intervention, so you can see if there is a difference.

### Points to bear in mind

When evaluating whether an intervention had any impact on your child you should be aware of the following:

- ◆ It is best to start new interventions one at a time in order to see how effective they are. If you start two interventions at the same



time, it is difficult to tell whether the improvements that you see are due to one particular intervention.

- ◆ Intervention providers should indicate to you how much time is usually needed for the intervention to have first positive effects on your child. If your child doesn't make improvements after this time, you will know that that particular intervention was not effective for your child and you may opt for some other intervention.
- ◆ ASD is a developmental disorder, which means that children with ASD develop differently compared with typical children. However, children continue to develop their skills over time whether or not they are involved in an intervention. Therefore improvements may simply be due to your child's natural development rather than the intervention.
- ◆ Finally, we all have bad days or weeks. These effects are even more pronounced in children with ASD. This is something to consider when assessing the effects of an intervention. Imagine a child who has more difficulties during the unstructured summer holidays than during the structured school terms. If the intervention started in the summer but ended during the autumn, improvements in their behaviour at the end of the intervention might simply be because of your child responding to the routine and structure rather than the intervention. In this case, to see if the intervention had really had an effect, you would need to wait until the holiday season again, to see if the improvements that you had seen in behaviour were still there.



### **How can I recognise pseudoscientific therapies:**

#### **Some Warning Signs**

#### **How promoters sell the intervention**

- 1) High "success" rates are claimed.
- 2) Rapid effects are promised.
- 3) The therapy is said to be effective for many symptoms or disorders.
- 4) The therapy is said to be easy to administer, requiring little training or expertise.
- 5) Other, proven, treatments are said to be unnecessary, inferior, or harmful.
- 6) Catchy, emotionally appealing slogans are used in marketing the therapy.

## How promoters avoid uncomfortable scrutiny in order to promote the intervention

- 1) Promoters resist assessment and scrutiny of the therapy by people who are not connected with the intervention.
- 2) Negative findings from scientific studies are ignored or dismissed.
- 3) Critics and scientific investigators are often met with hostility, and are accused of persecuting the promoters, being “close-minded,” or having some ulterior motive for “debunking” the therapy.

## Signs that all is not what it seems:

- 1) Promoters of the therapy are working outside their area of expertise.
- 2) Promoters benefit financially or otherwise from adoption of the therapy.
- 3) Testimonials, anecdotes, or personal accounts are offered in support of claims about the therapy’s effectiveness, but little or no **objective evidence** is provided.
- 4) The “theory” behind the therapy contradicts information that is considered factual.
- 5) Belief and faith are said to be necessary for the therapy to “work.”

(Adapted from the American Arthritis Foundation) \*originally printed in Science in Autism Treatment, Spring 1999.

## Conclusion

Choosing the right intervention is no easy task. This information should help you to think about asking the right questions in order to make the best decision for your child. If you have any questions about anything written in this booklet, please contact [warc@cardiff.ac.uk](mailto:warc@cardiff.ac.uk)

A good place to find out more information is the website for the charity Research Autism. This charity was set up to undertake research into interventions for ASD. It was set up to provide an objective assessment of the scientific evidence behind the most commonly used interventions. Please look on this website for more information

<http://www.researchautism.net/evaluations>

## Glossary

In scientific research we use a lot of technical terms. We have tried to explain things in the text but here is a glossary that might help.

- ◆ **Behaviour** - the way in which a person behaves in response to a particular situation or stimulus.
- ◆ **Behavioural intervention**: Interventions designed to encourage desirable behaviours and/or discourage undesirable behaviours, using particular

techniques.

- ◆ *Data* - information, often in numerical form.
- ◆ *Evidence based* - Professional practice or policy using techniques/ interventions that have been shown to be effective by scientific research,
- ◆ *Impact* - the benefits of a piece of research.
- ◆ *Intervention* - a treatment or therapy that can lessen or improve some of the symptoms of ASD.
- ◆ *Manual* – a manual is a set of published guidelines that all therapists must follow.
- ◆ *Objective evidence* - information which can be demonstrated, based on facts that support the change being made. The evidence must not be circumstantial but must be obtained through observation, measurement, test or other means.
- ◆ *Objective testing* - is intended to scientifically measure an individual's abilities and to be scored without bias or judgment.
- ◆ *Peer review* - anonymous evaluation of a research proposal or piece of research by scientists who do the same type of research.
- ◆ *Psychology* - the study of the behaviour of living things.
- ◆ *Reliable*- consistency. So a very reliable measure (e.g. questionnaire) will give the same results when it is used with different populations, at a different time, with different observers etc.
- ◆ *Rigour* – An intervention or a study of an intervention should be rigorous. The methods should be carried out properly. No suspicion of double standard should be allowed and uniform principles should be applied.
- ◆ *Scientific research* - Using scientific principles to test hypothesis and systematically collect and test data.
- ◆ *Valid* - validity is the extent to which a measure actually measures what it is supposed to.



Wales Autism Research Centre (WARC)