

# Key questions to consider when choosing an intervention

<b>Background</b>
What is the full name of the intervention or programme? Does it have any other names?
How was the intervention developed? (For example is it based on clinical or personal experience, religious or philosophical belief, does it come from another field of medicine or disability?)
Were people on the autism spectrum actively involved in, or consulted on, its development?
<b>Philosophy and aims</b>
What is the aim of the intervention or programme?
What is the underlying idea or philosophy behind the intervention or programme?
What is the underlying mechanism, that is, how is it supposed to work?
Does it focus on one specific skill or problem or is it a general approach?
Are you happy with the philosophy and aims of the intervention or programme?
<b>Key features</b>
What type of intervention is it? (Is it a training programme, a special diet, a medication or a service?)
What are the major features of the intervention or programme? For example: <ul style="list-style-type: none"><li>● Who delivers the intervention?</li><li>● Where is it delivered?</li><li>● How is the intervention delivered?</li></ul>
Is the intervention or programme adapted to the needs of people on the autism spectrum? If so, how?
Is the intervention or programme personalised to the needs of the individual? If so, how?
How is it different to any similar interventions or programmes?
Will I have to undertake or stop other treatments or activities if I start this?

**Evidence**

What evidence is there for this intervention? (Research studies, personal accounts from other people?)

Are you happy with the level of evidence?

**Participants**

Which group of people is this intervention or programme supposed to help? (Anyone, people on the autism spectrum, children?)

Are there any people who should not undertake this intervention or programme – such as people with epilepsy or other medical conditions?

**Supply and availability**

Is this intervention available throughout the UK, only in certain places in the UK, or only overseas?

Which organisations and individuals provide this intervention or programme? If there is more than one supplier, what is the difference between the suppliers?

Is there a waiting list? If so, how long is it and do I have to make a payment to be put on it?

**Training**

Do I need any training in order to undertake this intervention or programme?

Who provides this training, what does it involve, how long does it take, and how much does it cost?

**Equipment and materials**

Do I need to buy or rent any special equipment or materials?

Do I need to make any special adaptations or modification to my home?

**Time**

How long does the intervention or programme last – days, weeks, months, years? (Maximum? Minimum?) How often does it take place (hourly, daily, weekly, monthly)?

How much time is involved over the course of a month (or year, including travel, training and any follow up activities) – for the participant, parents, carers, and professionals?

**Costs**

Do I have to pay for this intervention or programme? Can I get help to pay for this intervention from anywhere? If so, where?

How much in total does the intervention cost (including enrolment fee, training, materials or equipment (including renewals), fees, administration charges, travel costs, follow up or recurring costs such as re-registration, other additional costs)?

Can I get my money back if the intervention or programme is not effective?

### **Risks and safety**

Does the intervention or programme use techniques that are:

- painful or hazardous
- distressing for the participants
- socially unacceptable (such as sanction-based or restricting liberty)
- illegal (such as physical assault, confinement or use of illegal substances)?

Does this intervention or programme have any side effects for the participants or effects for other members of the family (such as increased anxiety or stress)?

### **Staffing**

What is the background of the programme director and staff?

Which staff will be working with me or my child and can I meet them before making my decision?

What experience do these staff have of working with people like me or my child?

Do programme staff co-ordinate their work for me or my child with other professionals?

### **Regulation and complaints**

Is this intervention or programme regulated by an external organisation, such as a professional association or university? If so, when was the date of the last audit and what did it say?

Is there a complaints process? Have there been any complaints or legal disputes about the intervention or programme? What were the outcomes of those complaints or disputes?

### **Evaluation**

What do people say about the intervention (including the providers, people on the spectrum, parents, independent professionals, research evidence)?

Are programme staff open to suggestions about improvements from people on the autism spectrum, families and other professionals?

Can I talk to other people (such as individuals on the autism spectrum, parents) who have been involved with the intervention?

# Red flags: signs that an intervention or programme may not be what it seems

	Celebrity endorsement (why should celebrities know more than you?)
	Glitzy presentations (for example videos and PowerPoint presentation) which include bogus scientific data.
	Commercialisation of the intervention or programme (expensive fees or opportunities for you to make money by becoming a reseller of the intervention).
	'Research' findings that have not been published in reputable peer-reviewed journals.
	Use of outdated or incomplete research studies and reviews which don't show the full picture.
	Hard-sell techniques (including emotional blackmail or special offers).
	Use of words like 'miracle', 'faith', 'trust', 'cure', 'recovery'.
	Claims of high success rates and rapid results.
	Claims that the intervention is effective for many conditions, disorders and diseases.
	Claims that the intervention is easy to use, requiring little training or expertise.
	Claims that other proven interventions are unnecessary, inferior or harmful.
	Warnings and reprimands from appropriate organisations, such as the National Institute for Health and Care Excellence or the Advertising Standards Authority.

Remember: if an intervention looks too good to be true then it probably is.

(These questions and flags are adapted from materials originally developed by Richard Mills, who was indebted to Dr Judith Gould, Professor Gary Mesibov, Professor Patricia Howlin, Damian Milton, Bernard Fleming and the late Dr Lorna Wing and the late Professor Eric Schopler.)