‘As someone diagnosed with autism who also has children with autism, I found this book very informative, easy to read, honest, well written and unbiased. It is a great resource for newly diagnosed people, parents, adults, professionals and anyone with an interest in the facts about autism. It invites the reader to learn all they can about making decisions regarding autism and autism interventions. It is empowering and powerful in many ways.’

Shell Spectrum, a parent on the autism spectrum

‘This book is necessary and long overdue for parents. It is well structured with clear and easy to follow text, full of relevant and unambiguous information. There is a good balance of the pros and cons of an intervention supported by current research with good explanations of medical and technical terminology.’

Gen Hartup, mother of two children on the autism spectrum

‘I think this is a very useful book for people with autism and their families trying to navigate the avalanche of information available. Honest and unbiased, it is a great starting point to understanding the complexities of the different therapies and the reality of the research behind them.’

Karen Wilmshurst, Advocacy Services Manager, Autism Wessex
Contents

Foreword .................................................................................................................. 5
Preface ..................................................................................................................... 7
Introduction ............................................................................................................. 8
How to use this book .............................................................................................. 11
Key principles for autism interventions ................................................................. 14

Section 1 Key information .................................................................................... 16
Chapter 1: What is autism? .................................................................................... 17
Chapter 2: Issues facing people on the autism spectrum ..................................... 27
Chapter 3: Interventions ....................................................................................... 38
Chapter 4: Evaluating interventions ..................................................................... 43

Section 2 Interventions ......................................................................................... 56
Chapter 5: Standard healthcare ............................................................................ 57
Chapter 6: Complementary and alternative medicine ....................................... 69
Chapter 7: Alternative and augmentative communication .................................. 83
Chapter 8: Assistive and adaptive technology ..................................................... 94
Chapter 9: Behavioural and developmental interventions .................................. 105
Chapter 10: Behavioural interventions ................................................................. 107
Chapter 11: Developmental interventions ............................................................ 123
Chapter 12: Comprehensive, multi-component approaches ................................ 130
Chapter 13: Parent training and support programmes ......................................... 138
Chapter 14: Relationship-based interventions ................................................... 145
Chapter 15: Interventions for specific functions .................................................. 154
Chapter 16: Technology-based behavioural interventions .................................. 161
Chapter 17: Medications ..................................................................................... 168
Chapter 18: Special diets ...................................................................................... 194
Chapter 19: Dietary supplements ........................................................................ 205
Chapter 20: Alternative medical procedures ...................................................... 219
Chapter 21: Motor-sensory interventions ............................................................. 229
### Section 3 Making the decision ............................................... 284

Key principles for autism interventions:
- additional information ........................................................................ 287
Key questions to consider when choosing an intervention... 299
Red flags: signs that an intervention or programme
may not be what it seems ................................................................. 302
Key questions to ask about any research study ......................... 303
Summary of NICE guidance ............................................................ 308

### Section 4 Appendices ............................................................... 320

- Appendix 1: Personal perspectives ............................................. 321
- Appendix 2: Quotes on interventions ......................................... 328
- Appendix 3: Evidence levels ....................................................... 330
- Appendix 4: Glossary ................................................................. 333
- Appendix 5: Further reading ....................................................... 337
- Appendix 6: Organisations and websites .................................. 339
- Appendix 7: Main index ............................................................ 342
- Appendix 8: Index of interventions ........................................... 344

About the authors ............................................................................ 350
About Research Autism and Autism West Midlands .................. 351
About our sponsor, Dimensions .................................................. 352
Acknowledgements ........................................................................ 353
In the UK it can be hard enough – still – to access a diagnosis of autism, and even harder to access the correct educational and social support that is the statutory right of every person with a disability. Over the 30-odd years I’ve been involved with autism I have had countless people tell me that they just didn’t know which way to turn to get the most effective support for themselves or their child, and it’s easy to understand why so many look to unconventional theories, alternative therapies and unresearched interventions. As a doctor’s daughter, naturally I fear for those who make such uninformed choices and only wish that everyone had access to someone with genuine understanding and knowledge of this condition and its possible interventions. It’s vital that a fully informed choice is made and it isn’t simple: every person with autism will show the effects of their condition differently and there will never be one solution that will work for all.

There are many unsubstantiated ‘treatments’ – even ‘cures’ – that are suggested for autism (as, indeed, they are for so many other conditions), from manipulation of various parts of the body to the channelling of ‘energy fields’; from the removal of mercury from the body to changes in diet. Few of these therapies are supported by any clinical research, but you can easily see how a desperate parent might leap at the idea of some ‘miracle cure’ highlighted in one of the tabloids – something that sadly happens only too often. Some of these interventions are positively harmful, others are at best ineffective and many are extremely expensive.

That’s where this excellent book comes in. Research Autism, the charity behind it, was set up to try to redress the balance and to investigate and provide funds for research into the interventions suggested for autism. I have been involved since its launch in 2003 and have seen the wonderful work it does in negotiating the minefield of claims surrounding the complexities
of autism. I’m delighted that they have now published some of the information that has been amassed over the years in this clear and useful guide, which I am sure will be of immense help, not only to families and friends, but also to many people on the spectrum themselves.

In a user-friendly and accessible way it provides easy to understand descriptions of some of the most commonly used autism treatments and therapies together with objective and unbiased evaluations based on proper scientific research, making it easy to understand and very helpful in trying to make decisions on just which intervention might be useful. It also summarises best practice guidance from the National Institute for Health and Care Excellence (NICE).

This is currently the only book on autism treatments and therapies that meets the requirements of the NHS Information Standard, which means that the information is clear, accurate, balanced, evidence based and up to date. It won’t, of course, tell you everything you need to know about autism treatments and therapies – no single book could ever hope to do that. But it’s a really good place to start and I know that anyone with an interest in this complex condition will find it as informative as I did.

The fight continues to ensure that everyone on the autistic spectrum is able to lead a life of dignity and fulfilment. I believe that this book will play an important part in that fight.

**Jane Asher**

Patron, Research Autism
Although autism resides in an individual, it touches the lives of everyone around them – families, friends, service providers and wider society. As knowledge and awareness of autism grows, so does the need for access to the best available evidence-based information about how people with autism and their families can be supported in the most appropriate way.

We therefore warmly welcome the publication of this new book on choosing the right autism interventions, which aims to cut through the voluminous and sometimes baffling array of information that exists ‘out there’ about autism treatments, therapies and approaches.

Since they were founded, both Research Autism and Autism West Midlands have made a significant impact on the autism landscape. Research Autism’s research and information programmes, driven directly by the needs of the autism community, have set the agenda in terms of securing better outcomes for people with autism and their families, while Autism West Midlands’ specialist services, increasing range of publications and pioneering employment support are contributing to good practice nationwide.

Both of our organisations share a vision to improve the inclusion, quality of life and outlook of people with autism. This book gives practical meaning to that vision by providing guidance to enable those living with the condition to make informed choices about interventions.

It is our firm belief that good services, high quality research, and impartial information have the power to change lives for the better. We believe that this book makes a positive contribution to achieving this outcome for autistic people and their families.

Deepa Korea, Chief Executive, Research Autism and Jonathan Shephard, Chief Executive, Autism West Midlands
Introduction

Background

In recent years the number of people diagnosed with autism has risen significantly, although no one knows if this is due to a real rise in the number of people on the autism spectrum, greater awareness of autism by healthcare professionals, or a change in the measures used to diagnose autism (1).

The rise in diagnosis has been matched by a bewildering increase in the number and types of treatments and therapies. For example, the Research Autism website lists more than 1,000 different interventions, including applied behaviour analysis (ABA), chelation, dramatherapy, the gluten-free diet, Lego therapy, sensory integration training, swimming with dolphins, and vitamin supplements (2).

Unfortunately, some treatments and therapies are expensive, time consuming and potentially hazardous. Furthermore, currently very little scientific research supports the use of many interventions, despite extravagant and misleading claims about some of them.

‘There is a desperate need for parents to know where to turn for impartial advice on the various therapies. After our son was diagnosed we would literally try everything we could lay our hands on that promised to help. We followed up leads from the internet and popular press and it seemed that many of the professionals were as much in the dark as we were. We now know that many of the things on offer were a waste of time; some little more than snake oil treatments.’ Alex, parent of six-year-old Shaun (3).

Purpose of this book

We try to provide an unbiased source of information that is so desperately needed by parents like Alex.
This is what we’re trying to do:

- describe some of the interventions commonly used in the UK
- evaluate those treatments and therapies based on the published scientific research
- summarise guidance from the National Institute for Health and Care Excellence
- suggest some key questions you may like to ask about any intervention or research study
- list some useful resources including websites and publications.

We are not trying to:

- provide a comprehensive list of every treatment
- promote or criticise a particular type or group of therapies
- tell you which treatment or therapy you should or should not use
- tell you how to implement a specific treatment or therapy.

Quality

This book carries the NHS Information Standard quality mark. The quality mark is a quick and easy way for you to identify reliable and trustworthy sources of information. It means you can trust what we say because we are not trying to sell you anything or tell you what you should or should not do. It also means that we have tried to provide the information in a clear and user-friendly manner (4).

Limitations

So much information on interventions is available that it would be impractical to try and put it all in one book. So we have tried to only include information about the most commonly used interventions, the major sources of research evidence, the most robust clinical guidance, and so on. We also know that, as soon as this book is published, new research may come out which appears to contradict or modify findings from the existing research. We would urge you to keep an eye on the Autism West Midlands website, the Research Autism website, and the other resources listed in Appendix 6 of this book if you wish to be kept up to date on the best evidence.
Disclaimer

The information we present in this book is designed to support, not replace, the relationship that exists between you and your healthcare or service provider. The information has been written by non-medically qualified individuals, unless we specifically state otherwise. Any such information should therefore be treated with care.

The information in this book is not intended to act as a recommendation on whether a specific individual on the autism spectrum should or should not use an intervention. The outcome of any intervention will depend on a range of factors, including the individual’s needs and abilities, and on the way in which the intervention is implemented.

The information in this book was correct at the time of publication in April 2015. To see if there is a later version of this book please see www.researchautism.net/our-publications

References


How to use this book

This section will help you get the best out of this book.

Content

Four main sections make up this book:

1. **Key information:** Chapters 1–4 provide information on: autism, the issues faced by people on the autism spectrum, interventions designed to help people on the autism spectrum, how scientists evaluate those interventions.

2. **Interventions:** Chapters 5–26 provide details about the different types of intervention, along with an evaluation of the evidence base behind each type of intervention. Each of these chapters also provides information about the likely costs and time required to undertake this type of intervention; the supply and regulation (quality control) of this type of intervention; the risks of this type of intervention. Chapter 27 concludes this section.

3. **Making the decision:** This section provides you with some tools that may help you when you are deciding which interventions, if any, to use. The tools include: further details on the key principles that we believe any intervention should follow; key questions that you may like to ask about any intervention; red flags (signs that an intervention is not what it seems); key questions you may like to ask about research papers; a summary of the most recent guidance from the National Institute for Health and Care Excellence.

4. **Appendices:** The appendices provide a range of other information that we hope you will find useful. They include personal perspectives of living with autism, as well as lists of useful organisations, websites and publications.
Design

We have tried to design this book so that it is easy to read, it is easy to find what you are looking for, and you don’t have to read the whole thing if you don’t want to. So:

- we have included a main index (Appendix 7), a separate index of interventions (Appendix 8) and a glossary (Appendix 4)
- we have summarised some of the key information in boxes so that you don’t have to read the whole chapter
- we have used colour to differentiate between the sections
- we have repeated some of the key messages throughout the book
- we have not tried to tell you everything you could possibly want to know about each intervention (there just isn’t room in a publication like this)
- we have provided information about additional resources including other publications, websites and organisations.

Terminology

Our preferred term for the people we refer to most in this book is ‘people on the autism spectrum’. We use this term because we think that it is the most helpful, as it tells you that each person on the autism spectrum is a unique individual. We know that some people prefer other terms such as ‘autistic people’ or ‘people with autism’, and this is fine.

Our preferred term for the treatments, therapies and services people on the autism spectrum may receive is ‘interventions’. We use this term because it covers a wide range of approaches. It is also the term used by most professionals.

What works and doesn’t work?

As you read this book, you will see very quickly that many interventions have little or no research evidence to show that they are effective. This doesn’t mean that they do not work; it may simply mean that more research is required to find out if they do.
Where an intervention works for some people, this does not mean that it will work for everyone on the autism spectrum, because each person on the spectrum is unique. Also, the fact that an intervention works in a research setting does not mean that it will work in the real world.

Evidence

Our evaluation of the evidence for the interventions described in this book is based on our own systematic literature reviews of research studies published in English-language, peer-reviewed journals. Our searches covered a range of databases including the Cochrane Collaboration, ERIC, Psychinfo, PubMed, and the Research Autism publications database.

We also looked at clinical guidance from appropriate agencies such as NICE and best practice statements from other agencies where we thought this was appropriate.

Please see Appendix 3 for more information on what our levels of evidence mean.

Limitations

This book, like every book on autism or on interventions, has some limitations.

Coverage: we have not tried to describe every single intervention currently being used to help people on the autism spectrum. Nor have we described any intervention in great detail, or told you how to implement it, or told you whether it is appropriate for different people on the spectrum.

Up-to-dateness: the information in this book, including our evaluations of different interventions, was correct at the time of publication in April 2015. However research on autism is being published all the time. For details of the latest research on autism please see www.researchautism.net/latest-publications.
Key principles for autism interventions

There are hundreds of interventions designed to help people on the autism spectrum. There are thousands of research studies looking at those interventions, with more studies coming out every day.

A book of this size can only look at some of those interventions and some of that research. It can’t, of course, look at research that was published after this book was published.

So, we have written down some key principles that we hope may help you decide which interventions, if any, you wish to use.

We believe that any intervention designed to help people on the autism spectrum should follow most, if not all, of these principles.

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

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

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

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

5. The intervention is based on a theory that is logical and scientifically feasible.
6. Research evidence shows the intervention can work for people on the autism spectrum.

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

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

9. The people delivering the intervention follow established guidance.

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

11. The intervention provides significant benefits.

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

13. The benefits outweigh any costs (including risks).

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

Further information

**In this book:** Please see a detailed explanation of these principles and why we think they are important on page 287.