

Home educating our autistic spectrum children – paths are made by walking

Edited by Terri Dowty and Kitt Cowlshaw

A down-to-earth guide written by parents who have educated their children with Asperger or autism at home.

Published by Jessica Kingsley Publishers (Code NAS 441)

ISBN 1 84310 037 1

I am special; introducing children and young people to their autistic spectrum disorder

Peter Vermeulen

Designed for a child to work through with an adult present. For children over the age of 10, who can read this through themselves. It is a starting block.

Published by Jessica Kingsley Publishers. (Code NAS 394)

ISBN 1 85302 916 5

It can get better ... dealing with common behaviour problems in young autistic children

Paul Dickinson & Liz Hannah

Practical A to Z handbook of intervention methods etc

Published by the National Autistic Society. (Code NAS 284)

ISBN 1 899 280 03 0

Learning to live with high functioning autism – a parent's guide for professionals

Mike Stanton

Mike offers an honest portrayal of what living with autism was like for him. Covers from diagnosis, through adolescence to adulthood and covers challenging behaviours.

Published by Jessica Kingsley Publishers. (Code NAS 426)

ISBN 1 85302 915 7

Making visual supports work in the home and community. Strategies for individuals with autism and Asperger Syndrome

Jennifer L.Savner and Brenda Smith Myles

Richly illustrated book provides parents and carers etc with all the information they need to make effective visual supports with a variety of ordinary materials.

Published by Autism Asperger Publishing Company (Code NAS 442)

ISBN 0 967 2514 X



pursues activities repetitively



inappropriate use of toys



routine bound

\*A tendency to focus on minor or trivial aspects of things in the environment, instead of being aware of the meaning of the complete situation;

\*May display a limited range of imaginative activities, which you may well find have actually been copied off the TV etc.;

\*Pursues activities repetitively and cannot be influenced by suggestions of change;

\*Play may appear complex, but close observation, shows its rigidity and stereotyped pattern;

\*Unusual habits such as rocking, spinning, finger-flicking, continual fiddling with objects, spinning objects, feeling textures, or arranging objects in lines or patterns etc;

\*Inappropriate use of toys in play;

\*Holding onto objects, e.g. carrying a piece of wool for the whole day;

\* Noticeable physical over-activity or extreme under-activity;

\*Tantrums may occur for no apparent reason;

\*Changes in routine or environment, e.g. a change of route to the shops school or altering the position of furniture at home etc, may cause distress;



habitual rocking or flapping



tantrums

These reactions are all quite normal and the need for support from family, friends and experts must not be under-estimated. The desire to think and talk this whole new concept through will be of paramount importance to you.

Finally, you will move towards acceptance, adaptation and reorganisation. You may actually find a sense of relief; that eventually you know the situation that you and your child are faced with. You will have good days and you will have bad days. At the beginning you will have a lot more bad days than good days, but this will improve; the number of bad days will decrease and the number of good days will increase as time goes by.

Parents of a child who has been diagnosed with ASD almost have to go through the process of mourning the loss of a “normal” child and coming to terms with the “new and different” child that now stands before them.

ASD is not always obvious before the age of 18 months, or even up to the age of 3 years, so as a parent you have to adjust, usually with disbelief, to the fact that your baby or toddler is changing and the dreams which you have held precious prior to the diagnosis, are now being threatened.

You may be tempted to start desperately searching for help, cures or even another diagnosis. Turn to those of us who have been affected by this disorder. Be aware that there are a lot of “Old Wives Tales” that promise miracles. There are also many “salespersons”, who seem to take advantage of our desperation. Think carefully and investigate fully, before rushing out and selling your house, to follow rumours of cures around the world

## What will other people say and think?

Does it really matter? You love your child. There is no social disgrace in having a child with a disability.

As ASD was only officially described in 1943 by Dr Leo Kanner, it is a disorder which is often unknown to many people over the age of 60 years. As a result, you may find the older generation may be confused and unaccepting concerning the diagnosis.

## Autism in the early years

Val Cumine, Julia Leach and Gill Stevenson

Practical strategies for effective and realistic early intervention.

Published by David Fulton Publishers. (Code NAS 393)

ISBN 1 85346 599 2

## Autism: preparing for adulthood

Patricia Howlin

One of the few books on adulthood and autism. Practical resource covering many important issues that can occur for an adult with autism.

Published by Routledge (Code NAS 228) ISBN 0 415115 32 9

## Autistic thinking – this is the title

Peter Vermeulen

Humorous portrayal of how a person with autism thinks. Interesting reading.

Published by Jessica Kingsley Publishers (Code NAS 439)

ISBN 1 85302 995 5

## Autism with severe learning difficulties

Rita Jordan

Offers practical guidelines for children and adults lower on the spectrum. Shows how to build on the strengths and reduce the problems and anxieties.

Published by Souvenir Press (Code NAS 435) ISBN 0 285 63599 9

## Behavioural concerns and autistic spectrum disorders

John Clements and Ewa Zarkowska

Provides useful information for people working or living with people with autism whose behaviour is causing concern.

Published by Jessica Kingsley Publishers. (Code NAS 403)

ISBN 1 85302 742 1

## Beyond the silence. My life, the world and autism

Tito Rajarshi Mukhopadhyay

Tito is an 11 year old boy from South India with a special talent. Although almost completely non-verbal, he can communicate his thoughts and feelings through remarkable prose and poetry, written in fluent English.

Tito also has autism. Through his writing he explains how he deals with this disability and how it affects his view of the world. Tito gives us a unique insight into the mind of someone with autism, as well as a fascinating account of growing up with a disability in modern India.

Published by The National Autistic Society. (Code NAS 113)

ISBN 1 899280 31 6

## 2. LANGUAGE AND COMMUNICATION

\*The development of speech and language may be abnormal, delayed or absent;

\*Minimal reaction to verbal input and sometimes acts as though deaf;

\*Facial expressions and / or gestures may be unusual or absent;

\*Repetition of words, questions, phrases and/or sentences over and over again;

\*Endless monologues about their special interests, without adapting to the needs of the listener;

\*Words or phrases may be used incorrectly;

\*Production of speech may be unusual. A flat monotonous tone or inappropriate variations in tone, are often noted;

\*Those who are verbal, may be fascinated with words and word games, but do not adequately use their vocabulary for social interaction and reciprocal communication purposes;

\*Difficulties in starting and/or taking part in conversations.



## 3. BEHAVIOUR AND IMAGINATION

\*Imaginative play may be limited or absent, e.g. cannot play with a wooden block, as if it is a toy car;

My brother is different

Louise Gorrod

Written by a mother of a child with autism and beautifully illustrated in full colour. This book explains a child with autism's behaviour in terms that young siblings (5 – 8) will be able to understand. Published by The National Autistic Society. (Code NAS 233) ISBN 1 899280 50 2

Nobody Nowhere

Donna Williams

A moving account of Donna's struggle to come to terms with her life with autism and to survive the suffering of an unsympathetic and ignorant world.

Published by Jessica Kingsley Publishers. (Code NAS 114)

ISBN 1 853207 18 9

Of mice and aliens

Kathy Hoopmann

A sequel to *Blue Bottle Mystery*, this is a science fiction novel. Ben, who has just learnt he has Asperger Syndrome has aliens landing in his back garden and thus follows a most humorous account of his explanations of life on earth as seen by a person with Asperger Syndrome. Published by Jessica Kingsley Publishers (Code NAS 436)

ISBN 1 84310 007 x

Raising a child with autism: a guide to applied behaviour analysis for parents

Shira Richman

This book explains how parents can adapt the practical techniques used in ABA. Provides tips for play skills, communication, eating habits etc. Also includes an overview of the theory behind ABA. Published by Jessica Kingsley Publishers (Code NAS 413)

ISBN 1 85302 910 6

Siblings of children with autism: A guide for families

Sandra L Harris

An invaluable guide to understanding sibling relationships and how autism affects these relationships and what families can do to support their other children as they cope with the intensive needs of a child with autism. This book teaches parents how to improve communication in the family etc. Published by Woodbine House (Code NAS 223)

ISBN 0 933149 71 9

## References

1. "Classification and diagnosis - looking at the complexities involved"  
Dr Lorna Wing.
2. "Communication" Winter 1998.  
The National Autistic Society, England.
3. The autistic spectrum - a parent's guide  
The National Autistic Society, England.
4. Autism: Bibliography. A guide to books and videos  
The National Autistic Society, England.
5. The Autism Spectrum. A guide for Parents and Professionals.  
Dr Lorna Wing.
6. Developing a Broad and Balanced Curriculum.  
Mrs Margaret M Golding. Autism The Way Forwards RSA.  
September 1998.
7. Autism: How to help your young child  
Leicestershire County Council and Fosse Health Trust.  
ISBN 1 899280 65

## INTRODUCTION

It is very hard for parents to hear that maybe your child is not developing in a "normal" way.

Parents of children already diagnosed with an Autism Spectrum Disorder (ASD), have been down the path you are busy travelling on at present. Therefore this brochure has been written with empathy, by a few of these parents, with the aim of offering you support and useful guidelines.

## OTHER BROCHURES AVAILABLE FROM AUTISM SOUTH AFRICA

INFORMATION FOR TEACHERS

INFORMATION FOR DOCTORS

THOUGHTS OF A SIBLING

3 BOOKS WRITTEN BY AN ADULT WITH AUTISM

DIETARY INTERVENTIONS FOR THE TREATMENT OF AUTISM

ASPERGER SYNDROME

Blue Bottle mystery: an Asperger adventure

Kathy Hoopmann

Aimed at 8-13 year olds. Warm, fun-filled fantasy story for children - the hero is a person with Asperger Syndrome! Wonderful to read and a valuable teaching tool.

Publishing by Jessica Kingsley Publishers. (Code NAS 397)

ISBN 1 85302 978 5

Caring for a child with autism

Martine Ives and Nell Munro

Wide range of strategies for making life at home easier.

Published by Jessica Kingsley Publishers (Code NAS 431)

ISBN 1 85302 996 3

Challenging behaviour and autism: making sense – making progress

Philip Whitaker

Practical Strategies for preventing or managing common challenging behaviours.

Published National Autistic Society. (Code NAS 391)

ISBN 1 899 280 51 0

Children with autism: a booklet for brothers and sisters

Julie Davis

This booklet focuses on siblings of children with autism, explains what autism is and explores some of the difficulties that siblings may experience.

Published by The Early Years Diagnostic Centre. (Code NAS 121)

Children with autism and Asperger syndrome: a guide for practitioners and carers

Patricia Howlin

Looks at research into the nature, causes and treatment of autism. Different therapies are explored and evaluated and advice is offered. Good reference book.

Published by John Wiley & Sons Ltd (Code NAS) 070)

ISBN 0471983 28 4

Diet intervention and autism: implementing the gluten free and casein free diet for autistic children and adults – a practical guide for parents

Published by Jessica Kingsley Publishers. (Code NAS 402)

ISBN 1 85302 935 1

Children with ASD usually have accompanying learning difficulties.

The range of intellectual abilities amongst children with ASD is vast.

## What causes Autism Spectrum Disorders?

This question remains unanswered. Internationally, many different angles of research are being implemented, but no definite answer has been found as yet.

A very important point that must always be remembered is that ASD is definitely NOT psychological; it is NOT the result of bad parenting and children with ASD do not choose to misbehave. It would appear that ASD occurs as the result of varied and different biochemical causes and presents as a malfunctioning of the brain.

## What is the prognosis?

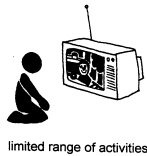
To date, ASD is not curable, but it is treatable. Intensive team intervention and an individualised, specialised education plan must be implemented as early as possible, to ensure the child reaches their full potential in life. The earlier the correct and appropriate intervention, the better the prognosis.

ASD is a disorder which changes with the age and stage of development of the child and therefore it is close to impossible for the professional to provide you with an accurate prognosis at the time of diagnosis. Your child's individual development over the years, as well as the implementation of different intervention strategies, will serve as a guideline for your child's prognosis. It is important not to have unrealistic expectations, but at the same time, not to give up hope.

**I cannot believe this is happening to my child and our family.**

Feelings of denial, sadness and anger are typically the first reactions that we as parents experience. The “messenger” - usually a professional, who has had to tell you that your child may have ASD, is usually the person who receives the backlash of our reaction.

Aggression and tears usually follow on pretty fast, followed by a fighting mechanism. You will find yourself feeling lost and confused, possibly devastated and depressed.

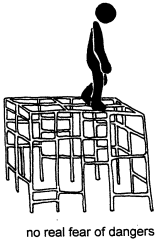


\*Interests and range of activities may be limited, e.g. only interested in puzzles;

\*A small percentage of people with ASD may have abilities that are outstanding in relation to their overall functioning, e.g. an exceptional memory in a specific field of interest;



IN ADDITION TO THIS TRIAD OF IMPAIRMENTS, YOU MAY WELL OBSERVE THE FOLLOWING ADDITIONAL FEATURES:-



\*Little or no eye contact;

\*No real fear of dangers;

\*Poor learning skills or a resistance to normal teaching methods;

\*Poor muscle tone may be noted; e.g. clumsy or struggles with picking up small objects;

\*Odd responses to sensory input, e.g. covering of ears;

\*Sense of touch, taste, sight, hearing and/or smell may be heightened or lowered;

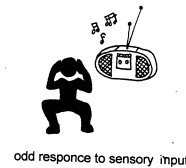
\*Bizarre eating patterns – food fads;

\*High pain threshold;

\*Crying or laughing for no apparent reason;

\*Self-injurious behaviour, e.g. head banging, scratching, biting;

\*Abnormal sleep patterns.



Everybody is different

Fiona Bleach

For siblings and schools friends etc of children with autism.

Published by The National Autistic Society (Code NAS 414)

ISBN 1 899280 332.

Exiting Nirvana

Clara Claiborne Park

Jessy is an adult with autism who has a job, helps run her home and hold exhibitions of her own paintings. She has left behind the repetitive rituals of her childhood and has become an active and contributing adult. Her Mother, Clara, tells the inspiring story of Jessy's progress from childhood to adulthood with lucidity and humour.

Published by Aurum Press (Code NAS 433) ISBN 1 85410 806 9

Growing up severely autistic. They call me Gabriel

Kate Rankin

An inspiring story of a mother's loving care for her son, Gabriel who is now a teenager. An honest account of bringing up a child with severe autism who needs constant care and has challenging behaviour.

Published by Jessica Kinglsey Publishers. (Code NAS 410)

ISBN 1 85302 891 6

Love, hope and autism

Joanne Edgar

Personal and practical account of Jo's experiences with her young son with autism, as well as experiences of other parents. Offers thoughts on some of the better known approaches.

Published by The National Autistic Society. (Code NAS 282)

ISBN 1 899280 07 3

Helping children with autism to learn

Edited by Stuart Powell

Offers specific approaches to teaching which draws together understandings of how people with autism think and learn and implications for those who aim to teach them. Offers insights into reasons behind autistic ways of behaving and guidance about ways of responding.

Published by David Fulton Publishers (Code NAS 395)

ISBN 1 85346 637 9

# My child may be affected by an Autism Spectrum Disorder.

If you have been given this brochure, you may have just been told that your child exhibits autistic traits or features and is possibly affected by an Autism Spectrum Disorder (ASD).

You will have hundreds of questions spinning around in your mind and the reason for this brochure is to try and give you some answers, guidelines and reassurance. This brochure has been written by parents of children with Autism Spectrum Disorders, therefore it has been written with empathy and understanding for the situation you find yourself in at present.

You may well have already visited several different doctors, and have been presented with a wide range of diagnoses. Sadly, this is a common pattern and is chiefly due to a lack of understanding in the medical field, concerning ASD. This matter is being addressed and as difficult as it can be, try not to despair; we have all been along that path and there is light at the end of the tunnel.

There are two points that you must get very clear in your mind. Firstly, your child's condition is NOT your fault and secondly you are most certainly not alone!

The best thing you can do for your child and your family is to find out more about ASD. You will find that once you know more about this condition and what you can do about it, you will start to feel more confident and in control. Listening to the advice that professionals offer you is important, but it is equally important that you are empowered through knowledge, to make your own informed decisions. You are the best advocate for your child.

## What is an Autism Spectrum Disorder?

ASD is a complex and variable developmental disability, which occurs as the result of disordered brain development and function, altering the child's quality of development in the areas of communication, social interaction and imagination skills. ASD is found to be 4 times more common in boys than in girls, knowing no racial, ethnic, economic or social boundaries.

Toilet training for individuals with autism and related disorders: a comprehensive guide for parents and teachers.

Maria Wheeler

Published by Jessica Kingsley Publishers (Code NAS 398)

ISBN 1 88547 745 7

Understanding and working with the spectrum of autism: an insider's view.

Wendy Lawson

Humourous account, written by someone with autism. Good insights.

Published by Jessica Kingsley Publishers (Code NAS 425)

ISBN 1 85302 971 8

What does it mean to have autism?

Louise Spilsbury

Aimed at children and young people who have just received the diagnosis.

Published by Heinemann (Code NAS 445)

ISBN 0 431 139 25 3

Why does Chris do that?

Tony Attwood

A book that offers a vast amount of practical advice as regards problems relating to high-functioning autism and Asperger Syndrome.

Published National Autistic Society. (Code NAS 066)

ISBN 1 899280 10 3

Words will really hurt me: how to protect your child from bullying  
NAS Autism Helpline

Published by The National Autistic Society. ISBN 1 899280 16 2

Autism South Africa would like to reiterate that you must please feel free to contact us any time and that we wish you all the very best.

Sleep better!: a guide to improving sleep for children with autism  
 V Mark Durand  
 Personal insights from families who have struggled with sleepless nights. The author shows dramatic improvements that are possible without medication. A variety of widely tested and easy-to-implement techniques.

Published by Paul H Brookes (Code NAS 280) ISBN 1 557663 15 7

Small steps forward

Sarah Newman

Ideas for games etc, behaviour management, toileting etc. Written by a parent of a child with autism. Good book and reference list included.

Published by Jessica Kingsley Publishers (Code NAS 428)

ISBN 185302 643 3

Talking together about growing up - a workbook for parents of children with learning disabilities

Lorna Scott and Lesley Kerr-Edwards

Practical advice to assist with the teaching of children with autism as regard sexuality and the bodily changes etc that occur in puberty. Also discusses appropriate sexual behaviours.

Published by The Family Planning Association. (Code NAS 427)

ISBN 1 899194 96 7

Teaching children with autism to mindread: a practical guide

Patricia Howlin, Simon Baron-Cohen & Julie Hadwin

Offers practical guidelines for children with ASD to improve their understanding of beliefs and emotions and pretence.

Published by John Wiley & Sons Ltd ISBN 0 471976 23 7

The Autistic Spectrum: a guide for parents and professionals

Lorna Wing

Useful, practical and easy to read.

Published by Constable. 9COE NAS 216) ISBN 0 094751 60 9.

Tobin learns to make friends

Diane Murrell

To try and teach children from the ages of approx 4 to 9 with Asperger Syndrome or High Functioning autism the social rules of friendship.

Published by Future Horizons Inc (Code NAS 443)

ISBN 1 885 477 79 1

ASD manifests as a wide range of characteristics, presenting at different levels of severity. No two children with autism are the same, so whilst you may find yourself comparing your child to another child with ASD, be aware that your child's path of development will not necessarily be the same as for that child.

You will hear the term "Triad of Impairments". This triad is typically associated with a narrow, repetitive pattern of activities and resistance to change in things that directly affect the individual concerned. It manifests as an impairment in the quality of development in these three areas:-

## 1. SOCIAL INTERACTION

\*Little awareness of others, or of their feelings;



little awareness of others

\*Poor or absent ability to make appropriate social contact;

\*The most severe form is aloofness and indifference to others, although most show an attachment on a simple level to family members or carers;



emotional indifference

\*Difficulty in forming relationships;



dislikes being touched

\*In less severe forms, the individual passively accepts social contact, even showing some pleasure in this, though he or she may not make spontaneous approaches;



difficulty with interaction

\*Indifference to or dislike of being held, cuddled or touched;



prefers to play alone

\*Prefers to play alone.



## Specialised Education

The option of specialised education for children with ASD is a very important factor to consider. Schools specifically catering for children with ASD, provide an environment that is “autism-specific”, structured, informed and empathetic.

## Additional part-time treatments

Part-time treatments, do not replace sending your child to a specialised school or implementing a home based programme, but can be introduced as additional forms of intervention.

## T.E.A.C.C.H (Treatment and Education of Autistic and related Communication Handicapped Children)

T.E.A.C.C.H is an individualised educational approach, whereby the environment is adapted and structured to promote learning at the child’s level of understanding. The T.E.A.C.C.H programme can be beneficially implemented from a young age.

## Makaton (Augmentative Communication, using signs and symbols with normal grammatical speech)

Children with ASD often have quite strong visual abilities and can therefore be receptive to the use of symbols as a form of communication.

## Speech and Communication Therapy

These areas of expertise should also cover the areas of alternative communication methods, such as symbols, sign language and computer graphics. These methods are used in conjunction with speech and they are not intended to necessarily replace or discourage speech. Alternative communication techniques often seem to result in the “pressure” being taken off the child to verbalise. These children then seem to become more open to being taught other effective forms of non-verbal communication, which in turn can assist with the possible development of verbal skills.

## Behavioural Approaches

In the past there have been some quite extreme forms of behaviour management, which are now seriously frowned upon by most people involved with ASD. The most recent methods of behaviour management encourage skill development, positive reinforcement and the reduction

## Pretoria

Association for Autism  
P.O. Box 35833. Menlo Park. 0102  
Tel: (012) 329 1423 Fax: (012) 329 1899  
E-mail: afautism@iafrica.com

UNICA School  
P.O. Box 35182. Menlo Park. 0102  
Tel (012) 460 6539 Fax: (012) 460 6324  
E-mail : autism@mweb.co.za

Lethabo Le Khutso and Abrina House  
210 18<sup>th</sup> Avenue. Rietondale. Pretoria  
P.O. Box 35833. Menlo Park. 0102  
Tel: (012) 329 3627 Fax: (012) 329 1899  
E-mail: afautism@iafrica.com

## Johannesburg

P.O. Box 84611 Greenside. 2034  
Tel: (011) 726 2445 Fax: (011) 726 7901  
E-mail: keyschool@iafrica.com

## Action in Autism (KwaZulu-Natal)

P.O. Box 30210. Mayville. 4058  
Tel: (031) 261 1154 Fax: (031) 261 9169  
lisa@fineline.co.za

## Browns School

Private Bag X 04 Ashwood. 3605  
Tel: (031) 700 3535 Fax: (031) 700 3117  
E-mail: browns@brownsschool.co.za

## Autism Eastern Cape

P.O. Box 13276  
Humewood. 6013  
Tel: 079 2677 22  
Fax:086 511 4841  
E-mail: info@autismec.org  
www.autismec.org

## Quest School

P.O. Box 13276  
Humewood. 6013  
2 Hoy Street. South End. PE  
Tel: (041) 581 0964  
Fax: (041) 581 0488  
E-mail:quest3@absamail.co.za

## East London

Antionette Bruce-Alexander  
C/O P.O. Box 1493 East  
London. 5200  
10 Fairview Place.  
Beacon Bay. 5241  
Tel and Fax: 043 748 3992

## Autism Namibia

P.O. Box 5043  
WINDHOEK. NAMIBIA  
Tel: 092 6461 22 4561/2  
Fax: 092 6461 22 8255  
E-mail: petrad@iway.na

## A FEW INTERNATIONAL CONTACTS TO GET YOU STARTED.

It is worthwhile joining various international associations and thus obtaining their regular publications. Many organisations provide additional excellent resource centres.

## National Autistic Society - United Kingdom

393 City Road. London EC1V 1NG. England  
Tel: 0944 20 7903 3563 Fax: 0944 20 7833 9666  
Website: www.nas.org.uk/  
E-mail: nas@nas.org.uk

This organisation, through Barnardos Despatch Services, also has a comprehensive publications list, listing books, videos and tapes that are available for purchase:-

## World Autism Organisation

<http://worldautism.org>

comfort in the exchange of ideas and experiences. It also makes you realise you are not alone, that there are many other parents out there who are in a very similar situation.

It is a good idea to keep in mind that a child with ASD is affected by the Triad of Impairments, and thus if we look at the areas affected, the following brief guidelines should be of some assistance:-

#### Social Interaction:-

Doing your utmost to make your child as socially acceptable as possible is one of the biggest favours you can do for your child. This will improve the quality of his life, as the better the child's social skills, the better people will respond to your child and thus the happier your child's life will be.

Try and ensure that your child's day is as predictable and structured as possible. Children with ASD often do not cope well with change, therefore try and establish a routine in your home, so that your child will be provided with a sense of predictability. If an unexpected change has to occur, try and explain this to your child either verbally or visually and then support him through the adjustment period.

Explain the manifestations of ASD to your other children, your extended family and friends. This will help them understand why your child behaves the way he does and why you are conducting your family life in a different way. Teasing and bullying from siblings and their friends must be prevented as much as possible. This can be avoided by educating and informing those concerned.

Be aware that the child with ASD will require a lot more of your time and attention and this can cause jealousy to manifest amongst siblings. Try and take time to spend special, individual time with your other children, away from your child with ASD.

It can be hard for parents to accept that their child does not seem to want to look directly at them or does not want to be held. If your child is not keen on physical contact, introduce touching and holding slowly and gently. If your child pulls away, let go and try again a little later and gradually try and increase the length of time. Also try different forms of touching and holding to find out which type your child prefers. The introduction of fun games that involve holding and touching is a way of subtly increasing physical contact.

5. Ensure that there are open channels of communication between yourselves and the teachers and that the staff are willing to receive and work on input concerning your child's educational needs;
6. Be sure that the school can and will modify your child's educational plan to accommodate the problems that can occur as a result of the Triad of Impairments;
7. Remember that the teachers may be extremely willing to accommodate your child within their school, but their good intentions can only be carried through as far as their resources and staffing allows;
8. Study the school policy as regards discipline for inappropriate behaviour;
9. Children with ASD need structure and thus a sound set of school rules is essential for a child with ASD. Check that the school rules rather list what the child may do rather than what he may not do. This approach is more easily understood by a child with ASD. A child with ASD will struggle with a school that has a casual set of rules; that the children enrolled in the school are expected to work out the rules by experience;
10. Establish whether the classrooms are open plan, as this can cause great distraction for your child. It is preferable for children with ASD to have independent work stations with all their belongings close by;
11. Establish the availability of computer assisted learning and symbolic communication methods, should the need arise;
12. A curriculum which actively introduces formal teaching of interpersonal and communication skills is beneficial for a child with ASD;
13. Be wary of a school where they have an overriding concern of treating all the children in the same way; this will not facilitate flexibility for your child's needs;
14. Establish how flexible the school approach is to accommodating differing strengths and weaknesses. Ask whether there will be the availability for your child to work with different age groups for different subjects, so that their ability in different areas is accommodated and enhanced;
15. Establish whether the school has an exclusion policy for any activities and whether your child with ASD would be excluded from any activity;

- ! Metabolic screening: Some metabolic disorders result in the manifestation of ASD. Some of these are treatable;
- ! Chromosomal testing: A small percentage of children with ASD have a chromosomal anomaly;
- ! Immunological dysfunction: You may want to test your child for certain allergies, such as gluten, casein or lactose, which may be affecting their behaviour.

## Who can I speak to and whom can I contact?

### SOUTH AFRICA

Autism South Africa is the national body for children and adults with Autism Spectrum Disorders. This organisation is here for you, so please feel free to contact us at any time:-

#### National Body

Autism South Africa  
 P.O. Box 84209 Greenside. 2034  
 Memorial Institute for Child Health  
 and Development.  
 Gate 13.  
 Cnr Joubert Street Ext and Empire Road. Braamfontein  
 Tel: (011) 484 9909 / 9923  
 Fax: (011) 484 3171  
[info@autismsouthafrica.org](mailto:info@autismsouthafrica.org)  
[www.autismsouthafrica.org](http://www.autismsouthafrica.org)

#### Cape Town

Autism Western Cape  
 P.O. Box 60375 Table View. 7439  
 47 Nottingham Close, Parklands. CT  
 Tel: (021) 557 3573 / (021) 556 2600 Fax: 086 671 9120  
[info@autismwesterncape.org.za](mailto:info@autismwesterncape.org.za)  
[www.autismwesterncape.org.za](http://www.autismwesterncape.org.za)

#### Alpha School

P.O. Box 48 Woodstock.7915  
 Cnr Roodebloem and Palmerston Roads. Woodstock  
 Tel: (021) 447 1212/3  
 Fax: (021) 448 0405  
 E-mail: [alphasch@xsinet.co.za](mailto:alphasch@xsinet.co.za)

of undesirable behaviours. This is done through attempting to analyse the reasons for these behaviours and thus aiming the education and management at this level, in an attempt to treat the cause and not the symptom as such.

### Megavitamin Therapy

Many parents have claimed that there have been significant improvements in their child's attention span and overall behaviour when the child is taking larger than normal amounts of varying vitamins. Investigators in this field, believe that certain children with ASD have a genetic or acquired metabolic disorder, which increases their requirements for varying nutrients. Comprehensive information and correct dosage must be obtained from the relevant professionals before any Vitamin Therapy is implemented.

Dr Rimland is a firm believer in megavitamin therapy and has conducted much research in this field. There is also a product called DMG (Dimethylglycine) which has received favourable responses when used by some children with ASD.

For more information, contact the Autism Research Institute at the address given above.

### AIT (Auditory Integration Training)

This method of treatment is based on the premise that some characteristics of ASD occur because of a dysfunction in the way the child processes auditory input. Many children with ASD are hypersensitive to certain sounds / frequencies. This can cause a distortion in the child's hearing and thus contribute quite significantly to the child's condition and language development.

The goal of this treatment is to reduce hypersensitivity to noise through the child listening to specific and controlled processed sounds and music. It is almost like re-training the ear and brain to hear correctly.

### Home based programmes

Home-based programmes are utilised internationally for children with ASD. Certain parents in South Africa have received international training and are implementing differing programmes with their own children.

A real person: life on the outside  
Gunilla Gerland  
Moving portrayal of a woman struggling to grow up in a world she does not understand. Due to a dysfunctional family and personal life, Gunilla turned to drugs. Gunilla fought back and in her 20's was diagnosed with high-functioning autism.  
Published by Souvenir Press (Code NAS 282)  
ISBN 285633 98 8

Autism and play  
Jannik Beyer & Lone Gammeltoft  
Easy-to-follow play strategies. It assists parents to develop their children's social and cognitive development, as well as professionals working with children on the autistic spectrum.  
Published by Jessica Kingsley Publishers (Code NAS 399)  
ISBN 1 85302 845 2

Autism: how to help your young child  
Leicestershire County Council & Fosse Health Trust  
Practical guidelines for parents and teachers.  
Published the National Autistic Society (Code NAS 247)  
ISBN 1 899280 65 0

Asperger Syndrome: A Clinical Account.  
Lorna Wing  
This book covers the topic of Asperger Syndrome from a more clinical viewpoint.  
Published by The National Autistic Society. Code NAS 010.

A user guide to the GF/CF diet for autism, Asperger Syndrome and ADHD  
Luke Jackson  
Published by Jessica Kingsley Publishers ISBN 1 84310 055 X

Autism as a metabolic disorder  
Paul Shattock, Dawn Savery and Paul Whiteley  
Guidelines for the implementation of a gluten and / or casein free diet.  
Published by the Autism Research Unit. Sunderland. (Code NAS 419)

When your child is behaving "differently", people may well not understand that your child is not just misbehaving and that he/she has ASD. This can be due to a lack of an outward visual cue that is often present with other forms of disabilities e.g. a blind person has a white stick, a deaf person has a hearing aid etc.

Some people may say to you that your child is just naughty and needs a good spanking. Keep your cool! You will soon find out who your real friends are. Stick to them, appreciating and benefiting from their friendship and support.

What medical tests / procedures should be considered for our child?

## Diagnosis

It is important to make an appointment with a doctor or multi-disciplinary team who specialise in ASD, for a correct evaluation and diagnosis. We would recommend you contact the below listed schools or Autism South Africa, for advise on the correct channels of referral.

The schools each refer to their own specialised assessment team that evaluates the children as regards a plan of action and effective intervention. This is an essential path to follow, as each child with ASD has a unique set of individual educational needs and on the basis of an individual assessment, informed decisions can be made as to the optimum way to meet your child's requirements.

## Case conference - a survival guide!

Feedback meetings or case conferences can be quite a traumatic experience for parents. So here are a couple of hints that will hopefully make these meetings a little easier:-

### 1. Be prepared

For a couple of days or so before your appointment, have a pen and paper close at hand, so that you can jot down questions you would like to ask. All too often, we try and store questions in our heads and then the nervousness of the case conference causes these questions to hide in the back of our mind, to pop back into our memory in the car on the way home!

16. Only consider placing your child with ASD in the same school as his or her's siblings, after very careful consideration and ensure that you ask these siblings what their feelings are on this matter;
17. If you struggle to find a school that can respond positively to the many questions as regards your child's education, then establish how "open" they are to constructive guidance from you as parents, or from teaching staff from the schools specifically for learners with ASD.

Questions parents should ask when exploring different non-scholastic approaches or intervention or treatment:-

1. Will the treatment or intervention strategy result in any harm to my child?
2. How will possible failure of this method affect my child and the family?
3. Has this treatment been validated scientifically, if not, are we willing to proceed?
4. Are there specified assessment procedures?
5. How will this method be integrated into my child's current programme?
6. How will the cost affect our family and are the costs justified when compared to the risk of failure?

Principles of evaluating methods of non-scholastic intervention and treatment of ASD:-

1. Approach any new method with hopeful skepticism, whilst bearing in mind that your goal is enhance your child's ability to function in society;
2. Be very wary of any programme which advocates that it can assist all children with ASD;
3. Beware of a programme that thwarts individualisation. Children with ASD must be assessed on an individual basis; general application cannot be effective;
4. Be very skeptical of a method of intervention which offers a "cure";
5. Remember that any treatment represents only one of many options for a child with ASD;

Autism Society of North Carolina  
 This organisation has an extensive list of publications.  
 505 Oberlin Road, Suite 230. Raleigh. NC 27605-1345. USA  
 Tel: 091 919 743 0204. Fax: 091 919 743 0208.  
 Web Page: [www.autismsociety-nc.org](http://www.autismsociety-nc.org)

At time of going to print, the above were the facilities available specifically for children with ASD. Autism South Africa is continually endeavouring to increase the number of services and facilities available. Please check the last page of this brochure, under "New

Contact Details" for new facilities, or else contact Autism South Africa, to establish whether there are additional services available in your area.

How can we help our child?

First and most important of all, love your child for who he or she is. Helping and loving a child with ASD can be a very demanding and thankless task at times, but there are many rewards waiting for you further down the line.

Gather information on ASD, so that you can learn what it is all about. It makes a radical difference to the relationship with your child. You will learn to understand why they can and cannot do certain things, why they react the way they do and what you can do in the home to help your child.

Children and adults with ASD generally struggle to communicate their feelings and thoughts well. There are a few adults with ASD, who have written books about how it feels to be affected by ASD and these books provide us with a wonderful insight into our child's minds.

As parents, we often feel that we are very much alone; that our child is the only child that has bizarre and inappropriate behaviours. It is not true! Reading books written by other parents of children with ASD brings great comfort and many giggles, as you read the experiences of other families whose children manifest similar behaviours to your child.

Talking to other parents can be painful at first, but as you meet other parents of children with ASD that you can relate to, you will find great

#### Autism Research Institute (USA)

This institute is headed by Dr. Bernard Rimland, Ph.D. and is a most interesting resource centre. Dr Rimland focuses on a wide variety of treatment methods and is a great believer in dietary and vitamin therapy. The Institute's monthly journal "Autism Research International" makes for most thought provoking reading.

4182 Adams Avenue. SAN DIEGO CA 92116. USA

Tel: 091 619 281 7165 Fax: 091 619 563 6840

Web site: <http://www.autism.com/ari>

#### Autism Research Unit (Sunderland, UK) (Casein and Gluten research)

School of Health Sciences, University of Sunderland, Sunderland, SR2 7EE. England

Tel: 0944 191 510 8922 / 0944 191 515 2581.

Fax: 0944 191 567 0420

E-mail: [aru@sunderland.ac.uk](mailto:aru@sunderland.ac.uk) or

[p.shattock@sunderland.ac.uk](mailto:p.shattock@sunderland.ac.uk)

Web Address: <http://osiris.sunderland.ac.uk/autism/>

#### The Autism File

P.O. Box 144. Hampton. Middlesex. TW12 2FF. England

Tel: 0944 20 8979 2525. Fax: 0944 20 8979 9665

[www.autismfile.com](http://www.autismfile.com)

#### Autism Europe

Avenue E. Van Becelaere 26b. Bte 21. B-1170. Bruxelles Belgique.

Tel: 0932 2 675 75 05 Fax: 0932 2 675 72 70

E-mail: [autisme.europe@arcadis.be](mailto:autisme.europe@arcadis.be).

Website: <http://www.autismeurope.org>

#### Autism Society of America

7910 Woodmont Avenue. Suite 650. BETHESDA. MD 20814 USA

Tel: 091 800 328 8476. Fax: 091 301 657 0869

Website: <http://www.autism-society.org/>

6. Proceed with extreme caution if the programme under investigation, has never been applied to children with ASD. Be aware that your child may well be used as a "guinea pig";
7. Be aware that new treatments often have not yet been validated scientifically.

Below, we have listed some of the methods of intervention which have been beneficial for some people with ASD. Although there may well be overlapping, there are basically two types of approaches; one that attempts to "change the child", whilst others attempt to change the environment for the benefit of the child with ASD. The evidence, as it is at present, favours the provision of a suitable environment, as the best method of helping the individual concerned, rather than attempting to change the individual.

Forms of intervention which have been found to be beneficial to people with ASD, are as follows:-

Specialised Education

Behaviour Modification

T.E.A.C.C.H

Occupational Therapy

Speech and Communication Therapy

Vitamin Therapies

Medication

Dietary Intervention

Sensory Integration

Social Skills Training

Makaton

Play Therapy

Applied Behaviour Analysis

Physiotherapy

Music Therapy

Higashi Teaching

Option Institute

Auditory Integration Training

Developmental Therapy

Animal Therapy

Reflexology

Keep all your child's reports, test results and ages at which milestones were obtained etc in a file, in date order and take this with you.

If possible make sure that both parents can attend these case conferences, or if this is not possible, consider taking along a relative or a close friend for support.

## 2. On the day

Take writing paper with you, to write notes as the interview takes place. Wear clothing that is comfortable and makes you feel emotionally strong and confident.

If both parents attend the meeting, try not to sit next to each other, so that you feel like frightened little rabbits in a corner! Try and sit opposite one another, so that you can visually communicate and exchange glances of reassurance and comfort.

As far as it is possible as a parent, listen objectively and carefully to what the professionals are telling you. Don't be afraid to ask questions or for explanations of medical jargon. If you have a list of questions, make sure you immediately write down the answer next to your question.

If two of you are present at the meeting, both of you should take notes, this way should have a pretty accurate record of the meeting.

If time is running out and you have not asked all your questions, either book another appointment for as soon as possible, or else leave behind your list and ask them to please contact you with the outstanding answers.

When you leave a Doctor's room, X-ray department or wherever, do your utmost to take home the reports and films etc. If this is not possible, then at least remember to ask for a copy and follow up on this. These reports could be required at a later stage and this may well prevent your child from possibly having to go through repeat procedures.

Remember that the professional in front of you, or the assessment team are there to help you and your child; they are on your side!

The above-mentioned therapies represent only some of the options and/or methods by which you may be able to assist a child with ASD. The results of any therapy will depend on the individual. For all forms of treatment, one must remember that some people have wonderful results, whereas others have not noted a significant effect.

As parents you are ultimately responsible for your choice of treatment or therapy. Please understand that Autism South Africa has listed different approaches, but this is not an endorsement and is not a comprehensive statement of each form of intervention. Thus, we provide you with the information, but we do not take any responsibility for the people or organisations who implement the programmes.

The below list is just a few of the many books which are available on matters relating to ASD and new books are being published on a regular basis.

### Approach to autism

The National Autistic Society

A good starting point for anyone who wishes to gain insight into the host of strategies, forms of interventions and therapies etc.

Published by National Autistic Society. (Code NAS 401)

ISBN 1 899280 56 1

### A positive approach to autism

Stella Waterhouse

General thoughts on the causes and manifestations of autism as well as some of the approaches that have been implemented over the past couple of years.

Published by Jessica Kingsley Publishers (Code NAS 390)

ISBN 1 85302 808 8

Please contact Autism South Africa, concerning information we may have as regards parents in South Africa, who have investigated or are implementing the differing home-based programmes.

#### The Lovaas Method / Applied Behaviour Analysis

This is a home based programme which is gaining popularity. It is an early intervention programme designed by Dr. O. Ivar Lovaas, Ph.D. at the University of California, Los Angeles (UCLA).

The programme uses Applied Behaviour Analysis methods (ABA) as part of an intensive pre-school programme for children with ASD, where the child receives one-on-one therapy by people trained in the technique. In other words, the child is not placed in a nursery school setting. The programme focuses on imitation skills, communication and language, appropriate social behaviour, co-operative peer play and on decreasing ritualistic behaviour and tantrums.

This programme is conducted in the home environment, using volunteers or paid assistants, who are trained by qualified professionals to administer the programme.

#### Options Institute - Son Rise Programme Method

The Son Rise Programme was developed by the Kaufmann family in Massachusetts, USA. It is a child-centred approach where you are encouraged to enter the child's world first in an attempt, through play, to encourage the child to communicate and inter-relate with those around him.

The programme is based on a fundamental attitude of loving and acceptance (ie. lack of judgement). The child is never confronted or treated in a judgmental way. The child receives intensive 1:1 attention at all times from a rota of parents, family and friends, who will be required to be trained in this method before they join you to help your child.

#### Summary

ASD is a multi-faceted disability and as such requires a multi-disciplinary approach to determine an individualised programme for each child. The type of therapy or intervention will depend on the developmental stage and abilities of the child.

#### 3. After the meeting

Read your notes soon after the meeting, as you may have missed something that you should have written down. At this stage the varying points should still be fresh in your mind. What you can do is write a summary of what you understood from the meeting and send this to the Doctor or assessment team, asking them for confirmation of your perception.

#### Medical tests

There are no specific medical tests for ASD. The diagnosis of this condition is made by experienced medical practitioners and multi-disciplinary teams using internationally recognised criteria. Therefore no scientific test can be done to "prove" a diagnosis.

There are certain tests that are recommended to rule out the possibility of other conditions, or that may point to problem areas that could be exacerbating the problem. Not every child needs to go through all these tests, but it is important to discuss the suitability of these tests with the informed doctor or assessment team.

#### EEG (Electroencephalograph)

This test records brain wave activity. Some children with ASD suffer from seizures that may not necessarily be evident on general observation. Seizures are treatable using medication and it is important to identify whether there is any abnormal electrical activity in the brain and then treat this accordingly.

Brain activity abnormalities can also be the cause of "temper tantrums" and abnormal sleep patterns.

#### CAT Scan and MRI (Magnetic Resonance Imaging)

These tests can detect any structural problems in the brain.

#### Blood tests

Your doctor may recommend one or more of the following blood tests:-

! Fragile X syndrome: 5-10% of children with ASD have also be found to present with Fragile X syndrome;



Try not to get too wrapped up in making every playtime a pressured learning time. Learning can be achieved through play, but your child also needs to have fun and relaxed, unchallenged playtime.

Imitation is an excellent way of teaching new skills to a child with ASD. Encourage siblings to play their games near your child with ASD and when you are sweeping the house etc., give your child a broom and encourage him to copy you.

*The UK National Autistic Society (NAS) has recently published a very helpful and fun book called "It can get better" This is a guide for parents and carers when dealing with common behaviour problems in young autistic children. Written by Paul Dickinson and Liz Hannah. Available from the NAS.*

What toys and leisure activities will be beneficial to my child?

Children with ASD seem to prefer toys that involve visual/spatial aspects, such as jigsaw puzzles, construction toys, shape and colour matching etc.

Toys that are visually interesting for children with autism are:-

- \* Bubble Blowers
- \* Coloured patterned torches
- \* Cause and effect toys, such as Jack-in-the-Box
- \* Activities which include colouring and painting
- \* Books, especially those with pop out/stand up figures or have different textures
- \* Children's videos which have a definite visual story rather than verbal.
- \* Jigsaws
- \* Train or car sets
- \* Push & Go toys
- \* Picture word lotto

Physical activity is important for the child with ASD, but these activities must not rely on verbal input or the use of imagination and must be under adult supervision, mainly due to the fact that the child with ASD has no real fear of danger. Try making use of the following:-

Swings and slides	Trampolining	Rocking Horse
Climbing Frame	Ride-on toys	Paddling pool
Sandpit	Walking	Basic ball games

Physical activity has been found to diminish inappropriate behaviours and has the added benefit of improving co-ordination and muscle tone.

The involvement of children with ASD in games can be quite a challenge, so start off with simple games and progress according your child's abilities. It is important to introduce challenges into your child's life, but the challenge must not be too great to cause frustration.

Below is a list of possible games, which starts at the top with the easiest type of games for a child with ASD and then progresses through to harder and more challenging games:-

Tapes of singing and dancing games	Picture lotto games
Snap	Skittles
Guess Who?	Snakes and Ladders
Ludo	Chess

Computer games can also be very beneficial to a child with ASD. Again start off with the simplest and then progress upwards slowly, to prevent frustration or boredom.

Leisure activities have been researched in the United Kingdom and the top 20, in order of popularity, are listed below:-

1. Swings, slides, climbing frames etc
2. Swimming
3. Seaside, paddling pools, water play
4. Videos, television
5. Eating out
6. Walking in the woods
7. Music, singing
8. Computer
9. Riding Bikes, go-carting
10. Trampoline, bouncing
11. Fun fairs, rides
12. Books, comics
13. Animals
14. Sports
15. Car Rides
16. Trains and Thomas the Tank Engine
17. Sand
18. Drawing and colouring
19. Games
20. Running and chasing

*(The above suggested lists are taken from "The Autism Spectrum: a guide for parents and professionals" by Lorna Wing).*

What treatments / educational options are available for my child?

There are many potentially beneficial treatments available for children with ASD, but to date, there is no "cure". Be extremely wary of therapies that promise a cure and treatments you do not feel comfortable with.

Remember, no two children with ASD are the same, so there are approaches that are beneficial to certain children, but not to others. Fully investigate all the different methods before spending your precious money. It is strongly advised that you seek guidance from the professionals, as well as contact the organisation which deals with the approach which interests you and ask them for contact details of other parents who have participated in their programme and then chat to these parents.

Parents need to try many things, not only for the child's sake, but also for their own. A lot of parents have tried many different approaches, some with success and some without. You need to decide what options suit your circumstances, enabling you to balance doing the best for your child, whilst meeting the needs of your family as a whole. At the end of the day if you have maintained this balance, and you have not jeopardised the rest of your family, you can at least have the satisfaction of knowing you did your very best for your child with ASD.

When it comes to the day-to-day education and treatment of your child, there are basically two options that can be considered; the placement of your child into a carefully monitored specialised education programme, utilising the schools and facilities that are available, or else implementing a supported home programme.

In regard to placing your child into the schooling system, the assessment team should be able to advise which route you should investigate.

If the assessment team feel that your child could benefit from mainstream or remedial schooling, there are varying issues that must be considered when you are screening potential schools for your child with ASD:-

1. Bear in mind that it is not only your child's education that is important, but how that school's environment will affect your child emotionally on a day to day basis;
2. The teaching staff at the school must have a broad and sound knowledge of ASD;
3. The ethos and curriculum of the school must be able to accommodate and be sympathetic to a child with ASD;
4. Be wary of schools that do not have a relatively high staffing ratio, or have an extremely strict adherence to their syllabi. This environment will not offer a satisfactory opportunity to enable them to fully cater for your child's diverse needs;

## Communication

Children with ASD often seem to have no real desire to want to be involved in communication. They also have difficulty in understanding the verbal word, gesture and body language. Babbling is an important part of your child's development and thus this must be encouraged and made to be seen as fun. Use the daily routine as a way of helping your child to make sense of the language they are hearing around them. Use a lot of visual cues with the words as you use them.

Encourage your child to "take turns in conversation", whether it be babbling or just noises. This will help your child understand the two-way process of communication.

You want to encourage your child to try and say words, so promote this process by offering a lot of praise at any effort at speech and don't correct the child each time the word does not come out quite right.

For a child with ASD, who seems so wrapped up in his own existence, promoting communication concerning their own needs is a good source of motivation. Make use of straws and blow-bubbles etc, to encourage your child to exercise and get to know his lips and mouth.

Development of language, whether it be the spoken word or gesture takes a long time for a child with ASD. It requires a lot of patience and there will be times when you feel you are making no progress. Do not give up and try not to get despondent; your endeavours will bring reward one way or the other. It may not be what you hoped for, but the most anyone can ask of you and your child, is that you have tried your best.

## Limited imagination

Children with ASD do not usually play with toys in an appropriate way. They do not have good imagination skills and they usually play with toys for what they are made of and what they look like, rather than what they are supposed to represent. For instance a child with ASD will probably not be able to understand how to have a tea party with a little tea set, but will rather stack them or put them all in a straight line.

A child with ASD should regularly be encouraged to expand their choice of toys. Introduce toys that require limited imaginative skills and then try to teach your child to use that toy as appropriately as possible, ie. puzzles.