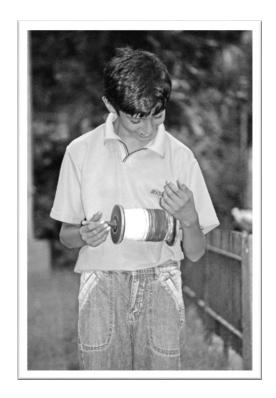
AUTISM BASECAMP

A Toolkit for Positive Parents



Stella Waterhouse

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Illustrations by Kate Vargues

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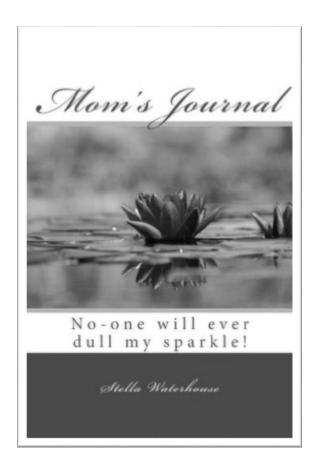
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INTRODUCTION

Some people still think that educational or behavioral techniques offer the key to unlocking autistic behaviors, but actually the most effective approach is to begin by alleviating the underlying problems.

If any of the problems discussed in Why Does He Do That? described your child, you may find some of the relatively simple ideas in this book helpful. While they do not offer a quick fix or miracle cure, they are fairly easy to implement and can be very effective, which should, over time, make both the child's life and yours much easier.

It is important to note that:

- As parents you know your child better than anyone, so share your knowledge with all those professionals who are willing to listen.
- Remember his difficulties make many apparently ordinary things extremely hard to do and he will have to make far more effort than his peers to complete tasks.
- Despite that it is vital that you do no underestimate his intelligence or make your expectations too low.
- If you treat him in the same way as his peers, he will probably fail and this will diminish his self-esteem.
- It is highly likely that he knows he is not the same as his peers, even if he does not understand the reasons why.

- The child with ASD can be extremely sensitive to other peoples' feelings so if you feel stressed or worried he may get anxious.
- ASD is extremely complex and even the experts cannot always keep up with all the ongoing research.

Unfortunately, finding a suitable practitioner to treat your child may be difficult. It is important to beware of any professional who claims their approach alone will 'cure' your child. Perhaps the best approach is personal recommendation, so talk to two or three families who have already used a particular practitioner or treatment before going ahead yourself.

Please note that the information in this book is not intended to be a substitute for professional advice. Wherever possible, do seek professional advice, especially if your child has a medical condition such as epilepsy.

It will be worthwhile reading the book first so that you can decide which of the ideas might prove effective for your child before you try implementing any of the ideas.

Generally, it is best to use one treatment at a time, as that will help you assess how effective each one is. Even so the dietary program can be used in conjunction with any of the treatments for sensory problems.

While the text refers mainly to children, everything in this book can be adapted to apply to adolescents and adults.

THROW HIM A LIFELINE

The majority of children with ASD can neither believe their eyes, their ears or any other of their senses. That contributes to a number of other difficulties including frustration, poor concentration and short-term memory problems. These can blight their daily lives and create great anxiety and confusion.

Until any sensory problems have been treated, allowances have to be made just as they would be for children with other disabilities.

Some people feel that the child with ASD should not receive special treatment but this merely reflects their very limited understanding of the problems and should be ignored.

Your child's reactions will help you determine which of the sensory problems affect him and whether he is hypersensitive, hyposensitive or a mixture of both. If your child suffers from any of these problems, use whichever of ideas that follow are most appropriate to make his life more secure.

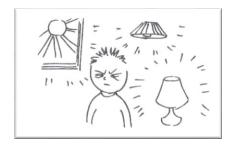
GIVE HIM A SHIELD

- Encourage the use of earplugs or a Walkman in certain situations, such as at mealtimes or during shopping trips, as this will relieve stress.
- Encourage the wearing of tinted lenses, sunglasses or a peaked cap to minimize the effect of bright sunlight, glare and

- fluorescent lights. Explain the reasons behind this to his teachers so that she/he will realize the benefits.
- Work out the clothes he finds most comfortable and buy more than one of each item.
- Wash new clothes, sheets, etc. before use to help soften them
 or use specially manufactured soft clothes (see index).
- Ensure that all chemical or non-edible items are stored safely out of reach.

MAKE YOUR HOME A COMFORT ZONE

- Make everyone in the family aware of his sensory differences and the anxiety these cause.
- Ensure he has a quiet place to go and suggest he uses it when noisy things (like the 'hoovering', washing up, lawn mowing etc.) are going on.
- Change the lighting in the house if necessary, as fluorescent
 - lighting and bright lights can aggravate visual problems.
- Minimize obstacles for him and don't rearrange furniture, etc., as this could confuse him.



- Be aware that he may have difficulty recognizing people even you.
- Help him to find things easily by using dark or brightly colored items in the house.

- Use colored towels and a different colored toilet paper for easy identification.
- Color bath water, as some children have difficulty seeing things that are clear, especially under bright lights, but be careful if adding "smellies" as they can cause problems if he is hyper.

THROW HIM A LIFELINE

- Minimize obstacles for him and don't rearrange furniture, etc., as this could confuse him.
- Help him to find things easily by using dark or brightly colored items in the house.
- Change the lighting in the house if necessary, as fluorescent lighting and bright lights can aggravate visual problems.
- Use toys designed for children with visual impairment.
- Check that clothes do not have "prickly" labels or scratchy stitching

 using soft or comfort clothes
 instead.
- Wash clothes prior to use.



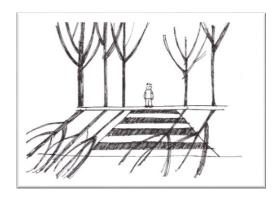
PROVIDING SUPPORTS

 Set limits for your child that are consistent and clear and stick to them.

- Provide routine, but do not make it too inflexible or the child will simply let it take over his life as in the film Rainman, where Raymond insists on eating the same food on the same day every week.
- Teach your child self-calming techniques such as using his hand to tap out a familiar tune or playing relaxation tapes, CDs, videos or DVDs.
- Correct any digestive problems.*
- Give information such as instructions in simple, short sentences, one at a time until the child can cope with more.
- Help build his self-esteem by breaking things down into small achievable steps.
- Provide memory joggers, such as timers, post-it notes, an alarm clock, etc. or for older children, an electronic diary.

BE AWARE THAT:

- His hearing may be very acute, so don't talk about him unless you are absolutely sure he cannot hear you (or you want him to hear).
- He may find physical touch painful, especially when it is unexpected.
- If he has visual problems, he may have difficulty recognizing people especially if they are 'out of context'.
- Remember some everyday things can cause visual distress, such as striped shirts, road surfaces, or even an avenue of trees.
- Your idea of fun may involve things he finds very difficult like a spontaneous trip out, physical touch, etc.



 His short term memory may be poor so you may have to repeat things several times.

POTENTIAL BATTLEFIELDS

Mealtimes

Try to make mealtimes pleasurable, as being stressed prior to eating can exacerbate digestive problems. If he finds mealtimes difficult, try playing background music or suggest he uses ear defenders or earplugs during the meal.

Bedtimes

Lack of sleep can cause a whole range of additional problems, so try to establish a good bedtime routine using some of the ideas below:

 A warm bath, a drink and a snack before bedtime (avoid sugary things).

- Avoid late television or computer games.
- Introduce a quiet period before bed to include a story or some soothing music.
- Check that pajamas and bedclothes are comfortable as some children have been found to benefit from weighted blankets or quilts.
- Ensure that his room is quiet and if he is very sensitive to noise, mask external noise with music or a sleeping machine.
- Shut the door after you have said goodnight and use a night light if he is afraid of the dark.

AVOID

- Arranging or canceling outings at short notice, unless he copes better with little time to worry.
- Black mats in front of doorways as these may be seen as a gaping hole.
- Confusing language such as abstract terms; phrases like 'pay attention', you're not listening', 'take it easy'; sarcasm and double entendres (as in many jokes); idioms like 'right up my street', 'on second thoughts', 'save your breath' and the increasing tendency to use verbs as nouns, for example, 'that was a big ask'.

PARENT TRAPS

To avoid making a rod for your own back, it is important to be firm when dealing with anxiety related behaviors:

- Try to ignore stereotyped behaviors unless they are anti-social.
 If the stereotyped behavior is very
- difficult to cope with (e.g. spitting), establish clear guidelines and try to limit the behavior as much as possible.
- Try to keep the number of special objects acquired within reasonable limits.
- Do not take away 'special objects', which mean a lot to the child, as punishment, as this will only
- increase stress and could lead to tantrums.
- Repetitive questions can arise from a lack of concentration and/or be linked to anxiety.

Try writing the answer down or draw pictures to illustrate your answer. Alternatively, it may help to tell him you will only answer a set number of times – and then stick to it. Try to vary the number of responses so that he does not become inflexible.

Don't get into a repetitive argument with him — he will probably win.

All these unusual behaviors are stress related and they will lessen if you can anticipate and alleviate the causes of anxiety. The following chapters will give you some idea how to do this.

MAKING SENSE OF NONSENSE

The child needs at least one reliable sense with which to experience and make sense of the world.

Correcting his sight or hearing, for example, will involve a therapist. Alternatively, the home based Gold Program will begin to correct all the senses, while a good diet will also help alleviate some of the problems.

VISION

It has been suggested that approximately 80% of those with ASD have some degree of visual perceptual dysfunction. Currently, the use of tinted lenses is one of the simplest and quickest ways to correct these problems.

The Irlen Institute in the U.S.A. have been using tinted lenses to assist people with dyslexia since the 1980s as have some other organizations.

Unfortunately, some opticians still remain skeptical although others, like Ian Jordan, have done a great deal of research in this area confirming that many such children have visual differences that affect their lives.

Hopefully, in the near future every child with problems will be tested for visual stress as early as possible.

Potential benefits of using tinted lenses.

These include: better eye tracking and depth perception; improvements in the ability to listen, concentrate, learn and remember things; less confusion; improved behavior; a reduction in hyperactivity and increased confidence, sociability and communication.

Even so don't expect miracles. You need to remember that while it will be relatively easy for a young child to adapt to the 'new world' provided by tinted lenses the older child or adult will have already learnt to live in his own world with all its limitations and wearing tinted lenses may initially make everything seem even more confusing.

In time, the correct lenses should reduce the possibility of eyestrain and headaches and wearing them throughout the day should be beneficial. Remember though, the hypersensitive child may refuse to wear glasses simply because the frames feel uncomfortable. Also, be aware that having the wrong lenses may have no effect or even worse may cause headaches or behavioral problems.

HEARING

Hearing tests are generally geared to assessing hearing loss and may not pick up the type of problems found in people with ASD. It may be necessary to ask for specific tests for hyperacusis and loudness tolerance.

Unfortunately, older children and adults may be so adept at blocking out sounds that test results could be misleading. In these circumstances the child's history may be important so do share your knowledge with the audiologist.

One of the most effective treatments available is Auditory Integration Training (AIT). This treatment was developed by Dr. Berard to correct his own failing hearing and he used it for over 25 years helping people with a variety of hearing distortions associated with dyslexia, ASD and others.

While it is not a miracle cure, it is widely used in the U.S.A. where it has improved the quality of life of many children and adults whose difficulties related to auditory processing, communication or behavior.

AIT treatment effectively retrains the hearing, thus correcting some hearing distortions, under-sensitivity and hyperacusis. It can also increase the tolerance of previously uncomfortable noise levels, thereby reducing stress.

A FREE checklist and FREE video course about the auditory is now available – please see the front of this book for download details.

These changes can lead to improvements in speech, communication skills, social interaction, behavior and self-motivation, as well increasing the ability to listen, understand, concentrate and learn.

Several approaches are useful for helping with sensitivity to touch:

- Massage may be appropriate for children who are hypersensitive or hyposensitive to touch. Begin by massaging the hands and then the feet before gradually moving onto the arms than the rest of the body. Use a firm touch initially (i.e. deep massage) and then gradually move to a light touch.
- Weighted t-shirts can help some children. It is thought that this
 is because the pressure supplied by the weights releases a
 chemical in the brain which has a calming effect. Beware
 though as some unscrupulous firms use lead weights which are
 a health hazard.
- Gentle desensitization can be beneficial for the hypersensitive child. This should only be done if the child or adult knows you well, and is aware that you are going to touch him so that it will not be unexpected.

This desensitization is simply done by touching him several times a day, briefly but firmly. The touch should always be on a part of the body which is not too sensitive so that it does not feel threatening (perhaps on the shoulder or forearm). It is vitally important to stop before the child becomes too uncomfortable, although the duration can be gradually increased as he becomes more able to tolerate it.

As well as helping the child to tolerate touch, this treatment ,if successful, can lead to increased affection, improved eye contact and a decrease in self-injurious behavior.

THE GOLD PROGRAM

This home-based program aims to treat all the sensory problems. Based on a neurodevelopmental approach, it works on the theory that some of the early stages of development are missing or incomplete and need to be recreated.

The program was developed by the late Svea Gold, an inspirational writer and therapist, who worked with children with a variety of difficulties.

Initially designed for children with attention problems, these exercises should also help some children with ASD, although you may have to adapt the language to suit your child.

The exercises begin by mimicking pre-natal stimulation, which simply means repeating the movements that the foetus should make in the womb. Ideally, these will be done with eyes closed in a warm pool, but the floor or a bed will do fine.

Since it will not be possible to do all of the exercises in the program, choose those which are easily manageable in your own circumstances. If nothing else, try the suggestions marked with an asterisk.

If possible, the exercises should be done every day for at least three weeks. Some improvement should be visible within three or four weeks and if this is the case, continue with the treatment.

Note: If any of the following exercises cause nausea, slow them down to the point where the child can tolerate them.

Rotating Chair (1 min. each way)

Slowly turn the child in a rotating chair with his eyes closed. Take one minute to complete one turn in one direction, and then after a few seconds rest, an equally slow return in the opposite direction. Try to be precise using a stop watch as a guide to turn one quarter every 15 seconds.

Follow this by turning the chair rapidly for 2 minutes, with the parent controlling the speed, interrupt the movement, and change direction and speed often. The child should have his eyes open during this. This forces quick adjustment of the eyes.

Log Rolls (3 mins.)

Do log rolls on the floor, both slowly and fast, at first with the eyes closed, and then open. Doing them as slowly as possible allows for the greatest input into the brain.

This movement provides input from the senses of touch, smell and enables the child to adjust to the distance of the walls of the room. Talking to the child during these exercises also helps to develop auditory space perception.

Helicopter (5 mins.)

As an alternative to log rolls, get the child to 'twirl' like a helicopter with arms out to the sides until dizzy - repeating 10 times. About 15 seconds is usually long

enough. Then get him to wait with eyes closed with someone supporting him, until the dizziness passes and the child feels ready to twirl again.

Trampolining (5–10 mins.)

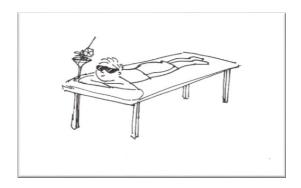
This achieves a measure of visual stimulation, combined with input from the entire body. As the child reaches the highest part of the jump, there is a moment of weightlessness before gravity takes hold. When the child hits the trampoline, the body feels its weight and compression between the joints and this will add to the child's body image.

Jogging (5–10 mins.)

If a trampoline is not available, jogging is an excellent alternative because the pressure of hitting the ground jars the spaces between the joints, which helps tell the brain to know where the body is. The eyes constantly have to adjust to changes in space and the vestibular canals in the ear are stimulated by the constant up and down movement.

Massage (5–10 mins.)

This needs to be done by the child's parents or a professional therapist. Ideally, the child should experience a deep and a light massage every day. This should include the face and the scalp. If the child is ticklish, start with a deep massage and slowly move to light touch. This can be done before the child gets out of bed in the morning as this will also have the child wide awake before eating breakfast and going off to school.



Marine Crawls (5-10 mins.)

Crawling on the stomach and creeping on hands and knees can be added later to integrate what has been achieved. It may help if you call the creeping 'tiger stalking' or 'indian stalking'. Stress the expected improvement in athletics, since this may be more important to the child than academic achievement.

Once the child's body is better coordinated, it is time to establish a preferred or dominant side. Encourage him to become totally right-sided or totally left-sided. The side chosen should be based on the side of the stronger eye use.

Ask him to write something with a pencil between the toes as the side chosen is usually a good indication of the preferred side.

A well-established, dominant side will help the child to know right from left. This is vitally important, not only for reading and writing, but also for simple things like knowing which side to pick tools up with.

Teenagers might be persuaded to give this program a four-week trial by stressing the possible improvement in athletic skills. This should be enough time to bring about some improvements which may encourage them to continue with it.

(Program quoted by kind permission of Svea Gold)

The complete version of this program can be found at www.fernridgepress.com.

OTHER USEFUL RESOURCES RE SENSORY PROBLEMS

Pediatric Osteopathy

This aims to correct any structural problems such as those resulting from trauma during or after birth. It is thought that such problems often underlie digestive problems in the newborn child and recurrent infections or allergies in infancy and childhood. These problems are also implicated in attentional difficulties, dyslexia and ASD. Osteopathy may also be helpful for children who have developed stress-related physical problems, such as muscle tension in the shoulders or neck.

Occupational Therapy

This is helpful in coping with a range of sensory problems. The therapist will be able to assess the child's ability to cope with all aspects of life including home, school and at play. This will enable her to devise a program to help the child develop more fully. This involves specific exercises which can be incorporated into the school day or completed at home. Unfortunately, this service is not always readily available.

A QUESTION OF DIGESTION

It is often said, "we are what we eat", but such a simplistic approach takes no account of individual differences. Indeed, the foods eaten are irrelevant unless the body is able to digest and process the food correctly.

The following abbreviated version of The Stay Well Program is not intended to be a substitute for medical or nutritional advice.

It is important to seek professional advice prior to implementing any dietary program, especially if your child has epilepsy, constant stomach aches, etc.

Various studies indicate that the majority of children with ASD have one or more digestive problems, which may include food intolerances, hypoglycemia and candida. All have an effect on the brain and behavior. One example is a little known link between milk allergy and head banging.

While vitamin and mineral supplements have long been found to be helpful, many people nowadays advocate a gluten and/or casein free diet.

Stay-Well initially attempts to tackle any digestive problems without eliminating any foods, unless there is a very clear need to do so (as with the head banging).

However if you have already taken some foods out of the child's diet, please do not re-introduce them as a reaction might occur. Stay-Well involves some changes and additions to the diet but it is vital that all changes are made slowly.

The recommended supplements should be introduced gradually so that any possible adverse reactions are minimized. Similarly, if you need to eliminate a particular food and change to another, do it gradually by adding a little bit of the new food to the old. For example, add a drop of rice milk to a glass of cow's milk, gradually increasing one and decreasing the other a drop or two at a time.

If making changes to the diet bear the following points in mind:

- Use organic or locally-sourced food where possible. This will reduce the number of additives consumed.
- Instead of eliminating cakes, biscuits and sweets, which may be unpopular, try organic or homemade products.
- Use the GI approach, which means opting for foods low on the glycaemic index.
- Be aware of food combinations, for example, avoid eating proteins and carbohydrates together.
- Alternate the most frequently eaten foods (and those to which you think he is intolerant) with other foods, so eventually he only eats them every third day.

THE STAY-WELL PROGRAM

Phase 1: Reduce the stress on the Digestive System

- Add a good probiotic to his diet.
- Provide a snack for mid-morning and mid-afternoon.
 Depending on age this could consist of a piece of fruit, a fruit & nut bar etc.

Phase 2: Supporting the Digestive System

Over the next few weeks gradually add:

- A good digestive enzyme (unless contained in the probiotic) before meals. Avoid those which contain Hydrochloric acid (HCI) as it can cause heartburn.
- A good quality multivitamin and multi-mineral supplement.
- Then, unless these are contained in the supplements above add:
 - A Vitamin B complex
 - Essential fatty acids
 - Vitamin C
 - A calcium supplement (especially if the child is on a milk free diet)

GENERAL PROBLEMS

NOTE: Do seek medical advice if your child has frequent bouts of diarrhea or is chronically constipated. These are serious issues and the causes need to be identified and remedied as soon as possible.

Constipation

If your child suffers from severe constipation, begin correcting this before giving any other supplements.

This can be done by adding a daily dose of magnesium to his diet at bedtime. Magnesium can have a dramatic effect so do begin with a relatively low dose (100–250 mg) and gradually increase until his bowel movements become regular.

Diarrhea

This should gradually rectify itself during this program but do ensure that he drinks a good supply of water but if the problem is severe or persistent please consult your doctor.

It is important to note that runny diarrhea can sometimes be indicative of severe constipation and impaction (a blockage of feces).

Sleeplessness

If this is still a problem you may need to use medication or a natural supplement. It is best to consult a nutritionist but if this is not possible, choose a reputable supplier and remember some children with ASD will become hyperactive when given sedatives.



DO:

Monitor each product used carefully for possible side effects. Some natural remedies (e.g. serotonin based products), are not compatible with some medications so check with your doctor before use.

Supplements

If these are to be swallowed rather than crushed, do check their size and if the child is hypersensitive, be aware of the smell and taste.

Getting children to take supplements can be challenging but some of the following ideas may help:

- Mix supplements with some fruit juice/fruit smoothie or add to a pudding, fruit
- sorbet, jelly, trifle, etc.
- Disguise supplements in rice-crispie cakes, scramble eggs, spaghetti sauce, peanut butter, etc.
- Make ice pops with liquid vitamins.
- Use calcium and magnesium in cooking and baking.

NOTE: If you are concerned as to whether your child has unresolved problems linked to vaccines do seek professional advice.

To find out more check out this site - https://www.tacanow.org/

FACILITATING LEARNING

The concept of exposure anxiety which affects many children with ASD challenges many common assumptions such as:

- The child is rejecting. Although the child's actions may indicate this, they do not necessarily relate to his real feelings.
- Stereotyped behaviors should be discouraged. Stereotyped behaviors can often be positive acting as a gateway to learning, a reward, or a pressure valve helping the child to unwind when he is particularly stressed.
- Bad behavior should be ignored and good behavior should be praised BUT although this strategy may work for some children, it may be counter-productive for the child who cannot cope with direct attention.

Many of the following ideas are based on the work of Donna Williams (who has autism herself) as detailed in her book Exposure Anxiety—The Invisible Cage.

INDIRECT APPROACHES

There are many different aspects to this approach all of which aim to avoid triggering anxiety. While the following ideas may seem a little strange to start with, they can prove extremely effective with some children:

Indirect communication

There are times when he may want to do something, but is unable to pose the question to ask. Help him out by making statements but do not address them directly at him. Some simple examples are shown as follows:

- Ask him to do things for another person.
- If you think he wants to go to the toilet, suggest he takes a sibling to the toilet or get him to go to see if something has been left in the bathroom. He may then use the toilet while he is there.
- If you wish to discuss a particular situation with the child, talk
 quietly to yourself about the subject so he can hear.
 Alternatively, take advantage of his supersensitive hearing by
 talking to someone else about it or by talking to a nonexistent
 person on the phone. NB. Use a similar approach for mealtimes
 if these are difficult.
- Suggest (to someone else) that he should eat separately until
 he can cope with mealtimes. If he then decides to join you at
 the table, accept this without comment and do not expects it
 to happen every time.
- Play hard to get so if he is actually enjoying you playing with him, take a break, so that you leave him wanting to return to the activity.
- Also, try to avoid making eye contact with him by looking away each time he looks at you. This may intrigue him and will also let him know that you realize he finds eye contact difficult.
- Modeling. Show the child how to use things by using them yourself first while he is in the room. For example, switch on the tape recorder and play a relaxation tape. Make sure it looks

- as though you are doing this for yourself. Do not show him how to use things directly as he may then reject them altogether.
- Discovery learning. This simply means introducing new toys or equipment by abandoning them in his room or leaving them around the house for him to find. The type of items could include: a tape recorder, a talking parrot, a video, a computer, a relaxation tape, games, crayons, paper, a dictionary or some books.

If/when the child becomes interested in or begins to use these items continue to ignore him.

Full length mirrors are also useful to enable the child to explore his own sense of identity, although some children dislike them intensely.

A similar technique can also be used when the child has to make a transition, for example, from home to school or to a new house. Familiarity lessens fear, so decrease his stress in the new situation by introducing him to a few of the things that he will find when he gets to the new place.

The type of item will depend on the transition being made but a few suggestions follow:

Situation
Object
Starting nursery school
Primary school/moving class
Chair, chalks, books, etc.
Respite care/hospital
A favorite toy, cushion, pillowcase, etc.
Moving house
A piece of curtain, wallpaper, a rug, etc.

These items should be left around the house so that he can look at them in his own time. The objects can then disappear again, only to turn up in the new and unfamiliar surroundings where the instant familiarity will offer some security. Similarly, you can use a particular aroma which he likes and is used to before he first visits the new house.

Conversely, it may also help if he takes something from the old situation into the new one. If he is going into a new school situation, this will need to be done in an age-appropriate way. It could involve taking a familiar toy with him or, for example, a pocket sized object like a key ring, if he is older.

Computers

The indirect learning offered by various computer programs can be extremely helpful to the child with ASD. A large range of educational games are available commercially. There are also some games available free on the internet which are designed to develop a range of skills including memory, attention and auditory skills.

Praise

Do not praise or comment on his achievements directly as he may destroy or abandon them.

If you feel you have to reward him, comment indirectly, praising the items he used rather than him, for example, "those crayons drew that picture well", or alternatively use a star system which focuses on the achievement rather than on him.

Sloppy teaching

This is good for the child who uses you to carry out his actions for him, such as using your hand to open a door. Initially, you may perform many tasks for him, but try to gradually remove your support so that he has to take some action himself if the task is to be completed.

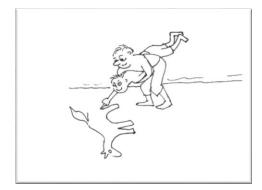
Examples:

- Turning the door handle and leaving it slightly ajar so that he has to finish opening it.
- Fetch the biscuit tin for him but only partially open the lid.
- Put food on his plate but then ignore him totally.

Remember:

If you are using any of these techniques, do not praise him when he completes an action as this could trigger his exposure anxiety and inhibit him from repeating the action.

It can also be helpful to swap roles, for example, when painting or playing an instrument so that you use his hand to make a picture in the sand, bang a drum, etc.



Topsy Turvy!

There may also be occasions when you need to turn this indirect way of working totally upside-down.

Rewards

Direct praise can act as a deterrent so you will need to work out what he actually finds rewarding—whether it be a special CD, using a trampoline or swing, playing with a kaleidoscope, etc.

Provide this when appropriate, but do not praise him first or make any comment about it being a reward.

Note: The word 'No!' can often trigger the action you are trying to avoid, but this does not mean that you should let him do anything he wishes. Allowing him free rein can lead to a whole range of difficult and unacceptable behaviors, and these will be harder to prevent as he gets older.

• Changing behavior

There are several strategies that you can try to alter certain behaviors:

- Use direct communication to inhibit a behavior by drawing attention to it. This should not be done in a derogatory way but rather as if you were watching a performance. For example, you
- could say, "Look in a minute he is going to....." ('throw a chair', 'hit his head', 'spit', etc.)

- Stating in a very matter of fact manner that, of course, "he will not be able to do...." Do not say this directly to him but rather to another member of the family or to an imaginary person over the phone, etc.
- Encourage him to be gentle, especially if he is biting, slapping, hitting, hair pulling rather than saying 'don't . . .'.
- Withdraw something he considers to be rewarding until he ceases misbehaving. You should also warn him (indirectly via a story or conversation with someone else) that missing the reward will be the consequence of the behavior you want to stop.

Communication strategies

Being unable to communicate your feelings or to make your needs known can be extremely frustrating and lead the child to temper tantrums and withdrawal. In order to avoid this, it is important that the child is able to communicate in some way. There are several strategies that are consistent with using an indirect approach:

Speaking to and through objects

- Take the focus off the child by using everyday objects as if they were puppets, for example, 'taking his shoes for a walk.'
- Using sign language. There are several different methods of sign language including baby language which may be appropriate for some children as it links real objects to signs instead of pictures.
- Makaton is the most popular form of sign language used for children with ASD. It encourages the child to communicate via

signs which illustrate the meaning of individual words and sentences.

It is hoped that, as the child makes the link between the word and the sign, speech will gradually take over from the signs. Even so it is important to monitor the child's progress carefully to ensure that he fully understands the signs he is making.

Augmented communication.

This encourages the use of objects, symbols, pictures or a picture board to indicate the child's likes, dislikes, wants and needs.

This includes two well known 'exchange systems'.

- The Picture Exchange Communication System (PECS) which teaches the child to give a picture of an item to the teacher, who responds by giving him the item immediately. It is reported that many preschool children using PECS also begin developing speech.
- o The second is The Early Learning Images (elliecards™). These are very similar to PECS, but make use of photographs instead of drawings. There are 192 photographs of common household items, foods, colors, toys, etc. each labeled with the name of the item. Some children may find these easier to use than small drawings.

Facilitated communication (FC)

This refers to writing or typing with the assistance of a facilitator who gives whatever degree of support the individual requires. It

is now used in many countries across the world. It is thought to be effective for people with ASD because it helps to counteract: anxiety; visual problems; lack of coordination and motor deficits.

FC is controversial as it is reported that some people who have never communicated before have, via FC, conversed in quite a sophisticated way, or to accuse others of hurting them. This had led some people to argue that it is the facilitator who is actually providing the words.

Generally, children and adults with ASD are far too literal to lie, but it is certainly possible to influence some of them into giving a particular answer. Even so, there are many examples of people who have written about feelings or concepts which were unknown to the facilitator.

Despite the arguments, please do not be deterred from trying FC with your own child as you may well find it useful. Many people with ASD are extremely positive about FC and, while it is certainly not a cure, it does enable some children to take a more active part in life. It helps children to make decisions and communicate their ideas, hopes and problems while at the same time relieves their frustration.

Give the child a voice

Today there are a number of different Communication Apps on the market which are particularly useful as people generally take more notice if they can "hear" the child. See Appendices.

TEARS AND TANTRUMS

Tears

The child with ASD may feel pain in an unusual way so while one child may either indicate that he is in pain some time before the actual physical symptoms become apparent, another may totally ignore the gash on his knee as he drips blood all over the carpet.

While cuts and bruises are obvious, you cannot rely on the child with poor communication skills to let you know if he is in pain. Often, the onset of new and strange behaviors will be the only indications of a problem. Some examples would be head banging, caused by a headache or milk allergy, or hugging his knees to his chest when he has stomach ache.

Sometimes the behaviors are even stranger, as with the boy who hid in a cupboard, because he had a toothache.

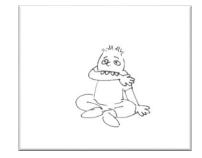
Thus, you will need to rely on your intuition and keen observation to determine whether he has a physical problem which needs attention.

How you respond will very much depend on your child, his sensitivities, level of exposure anxiety, etc. You will have to do whatever seems right at the time, altering course if your reaction makes the situation worse.

Tantrums

Your knowledge of the child should help you to determine the causes of any bizarre or difficult behaviors.

Potential causes could include:



- Fear or exposure anxiety which can result in a delayed reaction.
- Confusion and shutdown.
- Frustration because he cannot communicate his needs or because he cannot achieve a particular thing.
- Being in pain or feeling unwell.

FIRST AIDS

Always remember to use *First AIDS (Anticipation and Intervention Defuse Situations)* wherever possible.

Anticipation

Learn to identify which situations are difficult for him and be aware of the warning signs leading to difficult behaviors.

If you know a particular situation will be potentially difficult, for example, a party or a shopping trip, use whichever shields are appropriate to the situation. Help him to anticipate the situation by using a social story to explore possible reactions and ways he might cope.

Try to give him some control over the situation by setting a time limit for it and by organizing breaks during it.

Intervention

As soon as you notice the early warning signs try to alter things by changing the environment. Do this even if you cannot actually identify the cause of the problem.

It may be helpful to suggest he spends some time in his room or in a quiet place, listening to music or doing an activity you know he likes. If you do this while he is still behaving well, it will reinforce his good behavior. In most cases this alone will defuse the situation.

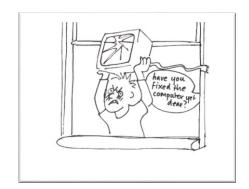
If you are too late to intervene in this way or if the situation deteriorates so that he is wrecking things or is in danger of hurting himself or others you may need to try using other methods.

THE THREE CS—CARE, CONTAINMENT AND CONSISTENCY

Self-control is a skill that is gradually developed in the first few years of life. All too often, when an infant has a tantrum, he loses control completely. At this point, he needs to know that you will not let him destroy things or hurt other people. The child with ASD, regardless of age, who is out of control is similar to a small child.

Care

Some people think that the child should be free to wreck his own room if he chooses to. This is a danger zone as he will simply learn that it is acceptable to destroy things when he is having a tantrum, and that type of behavior may continue even as an adult.



Similarly, the child who hits out and hurts other people when upset may be tolerated or even laughed at when young. Obviously though such behaviors will not be tolerated when as he gets older and may mean that he ends up in court – or worse!

You can minimize the risk of this by help him develop his own inner (self) control by using containment.

Containment

While it is far easier to deal with such difficult behaviors when the child is young, containment also works well with adolescents and adults.

The simplest way to calm him is to hold him firmly until he has calmed down.

This is most effective if he is facing away from you and you answer all comments, shouts or cajoling by repeating a simple sentence such as "Get up (or go) when you feel better."

As soon as he has calmed, let him go (immediately).

Only repeat the process if he starts hitting out or hurting himself again.

How you hold him is a matter of choice but also depends on his size. The child can sit on a chair or on your lap, lie on a settee or bed or alternatively, you could sit on the chair yourself with him sitting on the floor in front of you.

Whichever method you choose, make sure he is not in a position to hurt himself or you. Be especially careful if he is on your lap, as even a small head jerking backwards can be extremely painful if it connects with your face.

Consistency

If you use the above method consistently in such situations, you should see a gradual decrease in the length of time it takes to calm him down. In time you may even be able to dispense with the holding by prompting him to sit or lie down until he feels better.

The aim is to eventually reach the stage where he is able to take this action for himself—sitting or lying down until he feels calm again.

A SPOONFUL OF SUGAR

Despite an often negative press, the right medication can be extremely therapeutic for some people.

The type of medication used is individual and can vary widely as it may be used to combat any aspect of ASD including obsessive or compulsive behaviors, hyperactivity, behavioral problems, depression or anxiety.

If it is suggested that medication could be beneficial to your child do not simply dismiss the idea. While you will need all the relevant facts prior to making a decision, the correct medication given in the right amount may improve the child's quality of life.

Be aware that if your child has limited communication skills, you will need to monitor his reaction to the medication carefully so that the correct dosage can be determined and any side effects can be minimized.

Keeping a daily diary can be of help in this situation as it is all too easy to forget exactly what happened when.

GROWING UP

Adolescence can lead to more behavioral problems. These are often compounded by a lack of awareness and the continuing problems of literalness, giving rise to some strange confusions, as with the 14-year-old who, totally unaware that he was growing taller, became very distressed because he thought the adults around him were shrinking.

Help him make sense of these changes and any confusions by using age appropriate books, social stories, etc.

The more socially aware adolescent or adult may be prone to depression, which may be overlooked if he has a diagnosis of ASD.

The signs usually include a loss of appetite, poor sleeping patterns, loss of concentration and a reduction in social activity. He may also find it harder to control his behavior or cope with uncertainty.

If you feel your child may be suffering from depression seek medical advice so that things do not deteriorate.

Treatment may involve some form of medication but could also involve counseling Cognitive and behavioral techniques have often proved useful in this respect by helping the person to change things.

Further information is available from the National Autistic Society.

WHAT COMES NEXT?

The following ideas should, as far as possible, be made age appropriate, as this will minimize the chances of the child being teased by his peers. Most can be adapted to an indirect approach if required.

By implementing some of the ideas in this book, hopefully you should have a child who no longer has to use all his energy for everyday tasks.

Although he will continue to have some of the problems of ASD, he should be less anxious and have less need to use stereotyped behaviors and be more able to concentrate, understand and learn.

It is important to try to build on this by consolidating his auditory, visual and tactile skills, as well as his ability to remember things more easily. Some ideas for this include:

- Games designed to develop greater sound discrimination (see appendices). If these are computer
- based, remember the child may need adult support with using the computer to start with.
- Activities which help the child to 'read' emotions and body language. 'Mind reading' CDs may be helpful with this (see appendices). Younger children may also find potato men with their overdeveloped features interesting.
- Activities which help the child to learn to interpret and understand what he is seeing. This will be more difficult for the

older child so you may need to build on concepts he already understands, for example, a bustling market may be similar to a fairground.

- Games which use fun exercises for improving memory skills (see appendices).
- Speech Therapy as the speech therapist will be able to diagnose and treat a variety of speech, voice and language disorders.

Once the assessment is complete the therapist will be able to develop an individual treatment program which you can use at home. Even so don't forget to check whether he has any auditory differences first as those can greatly affect his speech.

 In addition to consolidating his sensory perceptual skills he will also need help to acquire the normal developmental skills he has missed.

The ideas used depend entirely on the child's stage of development and the skills he has already acquired so a book such as Small Steps Forward will be helpful as it gives specific advice for each stage of development.

Other useful ideas include:

- Using his preoccupations (obsessive interests) to introduce a whole range of activities, educational games, toys and books linked to his interests.
- Developing his ability to play either by playing directly with him or using an indirect modeling approach.
- Using music therapy, simple rhymes, modeling, etc., to help him understand concepts such as taking turns.
- Helping him understand abstract terms (see appendices).

- Putting naming labels on the furniture, doors and other equipment. Extend this to include size, color and any other relevant details such as the big cupboard, the small white table.
- Using the Davis Dyslexia Program which is good for the child who is a visual thinker. This will help him learn to read as well as improve his understanding of directions, sequences and sense of time.
- Involving him in activities such as drama, music therapy, horse riding or visiting a sensory room.
- Adding an age appropriate story to his bedtime routine. This
 could initially be based around an obsessive interest. The story
 can be read to one of his toys rather than directly to him.
- Social stories can be used to help him understand how to cope with a variety of different situations.

Some areas in which he may need help could include:

- Friendship, as he may assume that anyone who is friendly towards him is actually a friend, even if he only met them halfan-hour ago.
- Dealing with people in a range of social situations as he may need to learn social graces that most people take for granted, such as taking turns when speaking in a conversation, or what different types of eye contact mean.
- Learning that actions have consequences.
- What to do if he gets lost such as where to go and who to approach safely.
- How to use the internet safely.

With younger children you may also find it useful to try:

- The Early Bird System designed for parents of young children with ASD.
- Portage which is a home based educational system for preschool children.
- More Than Words The Hanen Program® is an early intervention program for children under 6-years-old who have difficulties with social interaction and communication. It shows parents how to improve communication and interaction through predictable daily routines, pictures, print, play skills and helping the child make friends.

FUNDING

Some of the treatments mentioned are only available privately at present and charges (and the quality of advice/treatment) can vary so it is important to "shop" around, look at the alternatives and ask other parents for their views before committing yourself to any expensive treatments.

It is also worth exploring funding possibilities, as some private

health care schemes will pay towards treatments such as Auditory Integration Training.

Join forces and share resources.

Other families may like your help and be able to offer help to you in return.



Join your local autism support group and join a library/toy library so that you can have access to books, toys etc.

AND FINALLY...

JOIN THE SELF PRESERVATION SOCIETY

Getting overstressed and overtired can lead to illness. Do ensure that you make time for yourself and the rest of your family.

Use all the resources available to you and do not be afraid to ask for help. Support could include:

- Family and friends may be able to provide you with some "space" on a regular basis, even if only for a couple of hours a week.
- Your local autism support group will enable you to share ideas and support.
- Your doctor should be able to offer advice and help you get further information and support.

If necessary, ask for an extended appointment and go armed with a list of questions.

It is also important not to minimize the problems or their effect on you, especially if you are experiencing stress or anxiety.

In the UK another area of support is the local Social Services
Department which is responsible for providing you with a break
from your caring role. Contact them directly or via your doctor.

The type of services available vary from area to area but they may be able to provide any of the following:

o A regular visit from a home help.

- A day-sitting service so that you can go out or a night sitting service to allow you to get a good night's sleep.
- A nursery/play group/play center if your child is not at school.
- o Regular respite care, residential breaks, holidays, etc.

Unfortunately, in reality, some areas have very limited resources, while in others there may be a lengthy wait.

Sadly, some professionals also tend to underestimate the impact of ASD on the family so if the help you need is not forthcoming continue to ask and ask and ask...

BE PREPARED

Be prepared for emergency situations by having information at hand such as:

- Cards that explain that your child has ASD which can be given out to passersby if you ever have to cope with difficult behavior in a public place. Readymade cards such as The Autism Alert Card (see appendices).
- Printed information sheets on your child including a current photograph of your child, a physical description, basic contact details, details of medical or dietary requirements, details of his level of understanding, communication abilities, the best way to approach him, etc.

These can be used if you become separated from your child.
 Alternatively, they can be given to professional staff (dentist, teacher, speech therapist, etc.) to provide basic information on your child.

Liaisons

Make regular contact with the playgroup, school, center, that your child attends so that staff are aware of his abilities, interests or needs. This also ensures that any concerns can be dealt with promptly.

WORRIED ABOUT BULLYING?

As mentioned in *Why Does He Do That?* being different can make a child more vulnerable to bullying. Sometimes, another child may encourage him to break rules or act in a strange manner, or 'wind him up' so that he becomes agitated.

Unfortunately, this bullying may not always be confined to children, for occasionally a member of staff will misinterpret ASD behaviors as 'bad' behavior, and respond unhelpfully.

Signs of Bullying

While physical signs such as torn clothes, cuts and bruises are easy to see the more subtle signs may be less easy to identify. Look out for changes in your child's behavior such as a reluctance to go to school, increased anxiety, wetting the bed, more frequent tantrums, problems in the classroom, etc.

These changes may be the result of bullying, but remember they may result from other causes, such as a change of teacher, for example.

Communication

Find a way of helping your child to tell you of any problems. If he cannot communicate verbally, try using augmented or facilitated communication etc.

Alternatively, use puppets or toys displaying different expressions (including aggression) to get him to describe what his day at school has been like.

REMEDIES

At school

Some schools are still far better at dealing with bullying than others.

Discuss any problems that arise with your child's teacher.

It may help to suggest the setting up of a 'buddy scheme' so that another child plays with, and keeps an eye on, your child in the playground and also that ancillary staff are aware of his problems so that they can keep an eye on him.

If there is conflict with a member of the teaching staff, discuss the problems with the head teacher and ask what action will be taken.

Do write to the school as well and express your concerns – and ask for a written response. This will be useful documentation if you ever need to take further action.

Cyber Bullying

While historically, bullying has been a largely school-oriented phenomenon, cyber-bullying and text bullying is now on the increase. This allows bullies to torment, threaten, humiliate or embarrass their classmates via e-mail, instant messaging and through online communities such as Myspace and Facebook.

The teenager who is able to use the internet without support is obviously a possible prey to this awful form of bullying.

Protect your child from cyberbullying:

- Where possible get involved with your child's online activities.
- Know all the passwords and make it a policy to check them regularly.
- If your child has an online web page, such as with MySpace, visit it often to see what he or she is posting.
- Suggest 'reputable websites' that he can join. (see Index)
- Things are gradually changing and although many countries feel unable to bring criminal charges under current law some states in the USA are beginning to explore the possibilities of various kinds of criminal charge and, in some cases, parents can now be held accountable for their child's cyber bullying if they have failed to supervise their child's online activity properly.

Meanwhile if your child does suffer from this type of bullying civil litigation may be the only possible route to take.

APPENDICES

Books

Davis (1994) The Gift of Dyslexia Souvenir Press

Newman (1999) Small Steps Forward Jessica Kingsley

Emmons & McKendry Anderson (2005) Understanding Sensory Dysfunction Jessica Kingsley

Caldwell (2005) Finding You, Finding Me Jessica Kingsley

Baron-Cohen (2004) Mind Reading Jessica Kingsley

Gray & White (2002) My Social Stories Book Jessica Kingsley

Stuart-Hamilton (2004) An Asperger Dictionary of Everyday Expressions Jessica Kingsley

Waterhouse (2003) The Problem is Understanding—A Teacher's Guide to Autism and Asperger's

Welton (2003) Why did you say that? What do you mean? Jessica Kingsley

Williams (2003) Exposure Anxiety Jessica Kingsley

Jordan (1998) Visual Dyslexia—A Guide for Teachers and Parents Jordan (2003) Visual Dyslexia—Signs, Symptoms and Assessment

Useful websites

www.talkingpoint.org.uk Speech, language and communication difficulties.

www.brainconnection.com Free games. Use 'brain teasers' button. www.portage.org.uk Portage services.

www.rnib.org.uk Games, etc. for children with visual impairment. www.info.autism.org.uk

www.direct.gov.uk Information for carers.www.eparenting.co.uk Information on Education, Health,

Autism Resources

Autism Research Institute (ARI) - www.autism.com
Autism Society of America - ASA - www.autism-society.org
National Autistic Society (NAS) www.autism.org.uk Provides a wide range of services and advice
Autism Speaks www.autismspeaks.org

Assistance dogs:

http://4pawsforability.org/autism-assistance-dog https://www.autismspeaks.org/services/service-dogs

Communication Apps:

There are many different Apps on the market today but *TalkRocket Go* by MyVoice Inc seems particularly easy to use either on an iPad or an iPhone.

Developmental delay:

www.youtube.com/watch?v=kSTBSjaQJto www.autismdecoded.com/Learning-Breakthrough™.php www.movetolearn.com.au www.ot-mom-learning-activities.com

Dyspraxia: See TREE FU TOM CBEEBIES on YouTube

Visual problems: www.autismdecoded.com

Auditory Differences: www.soundsriteprogram.com

Eating Problems: www.nationalautismresources.com/autism-eating-problems.html

Anxiety: FREE download http://suelarkey.com.au/wp-content/uploads/2015/11/Power_Of_Preventative_Break1.pdf

Meltdowns: .http://suelarkey.com.au/wp-content/uploads/2015/11/Managing_Meltdowns.pdf
Toys: FREE download of the Top 10 tips for toys that will bring success not a sense of frustration
http://lekotek.org/news/item/200-toys-r-us-2015-toy-guide-for-differently-abled-kids

Weighted quilts/clothing www.saltoftheearthweightedgear.com & www.quietquilt.com www.marpac.com Sleep machines.

Dietary supplements can be obtained from: Nutricentre Tel: www.nutricentre.com Kirkman (U.S.A.) www.kirkmanlabs.com

Osteopathic Centre - www.occ.uk.com

This works with those families who would not normally be able to afford osteopathic treatment. A donation towards costs is requested, but no child is turned away because of inability to pay. www.osteopathy.org.uk Osteopathic Information Service

Sleep problems http://thesleepconnection.com.au Wandering:

http://nationalautismassociation.org/resources/awaare-wandering/naas-awaare-site

Legal advice: http://www.wrightslaw.com/subscribe.htm

Bullying: http://www.free-for-kids.com/help-with-bullying.shtml http://www.educatorstechnology.com/2013/02/6-great-posters-on-bullying.html

Issues with video games? www.aspergerexperts.com/go/videogames-join

Miscellaneous

www.autismvillage.com Autism Village's mission is to apply Internet and Mobile technologies to provide a globally accessible platform which helps the autism community to manage practical day to day problems. Our goal is to improve the futures of all people with autism by making daily life more navigable.

For people with ASD - www.auties.org - offers clubs, support etc Wrong Planet - a web community designed for individuals (and parents of those) with ASD www.wrongplanet.net

E-zines.

http://www.autismfile.com

www.autismlink.com www.autismtoday.com www.futurehorizons-autism.com www.lookingupautism.org www.moautismreport.com
www.autismparentingmagazine.com
www.autismeye.com
www.autismfile.com
www.autismworldmagazine.com
www.positivelyautism.com
www.familytimemagazine.com/the-magazine/guides

Radio & TV

http://autismshow.org

www.autismradio.org

www.blogtalkradio.com (search autism)

www.autism-live.com

www.autismwebsite.com/autism.tv

If you found this book helpful please leave a review and share it with anyone who might find it helpful.

Thank you.

THE AUTHOR

Stella Waterhouse is a writer and therapist who has worked children and adults with autism and other learning differences since the late 1960s.

She was hooked . . . and has been ever since.

Stella wrote her first book on autism, Asperger's syndrome and other sensory disorders in 1990. The published author of several books including A Positive Approach to Autism, she has recently published *Autism Decoded – The Cracks in the Code*. The next book in the series: *Autism Decoded - The Ciphers* will be out later this year.

If you found this book helpful, please leave a review. Many thanks.

Meanwhile don't forget to claim your FREE gift

You can download it from: www.gerrysorrillpublishers.com



Other FREEBIES re AUTISM

Here are some FREE tools to help you on your journey.

Grab the <u>FREE checklist</u> to help you identify whether your child has visual differences.



Have a child with auditory difficulties? Want to help? Get your <u>FREE</u> mini-course about the Auditory Differences and the Soundsrite Program.



Claim your <u>FREE</u> *Dietary Diary* here



Claim your <u>FREE</u> copy of *The Food Detectives Guide* here



Go to: www.autismdecoded.com or use the QR code