

# Booklet for Parents



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# Foreword

This booklet is based on the experiences of some of our families. However, names have been changed to protect the identity of parents and children.

The aim of this booklet is to equip parents with practical strategies and suggestions to use with their children. All the ideas in this booklet are based on information given out to parents during our workshops and consultations.

**Note:** Some strategies have been given using family case studies to illustrate how they could be applied. Parents must remember that all Autistic children are very different. So a strategy suggested for one child may not be applicable for another.

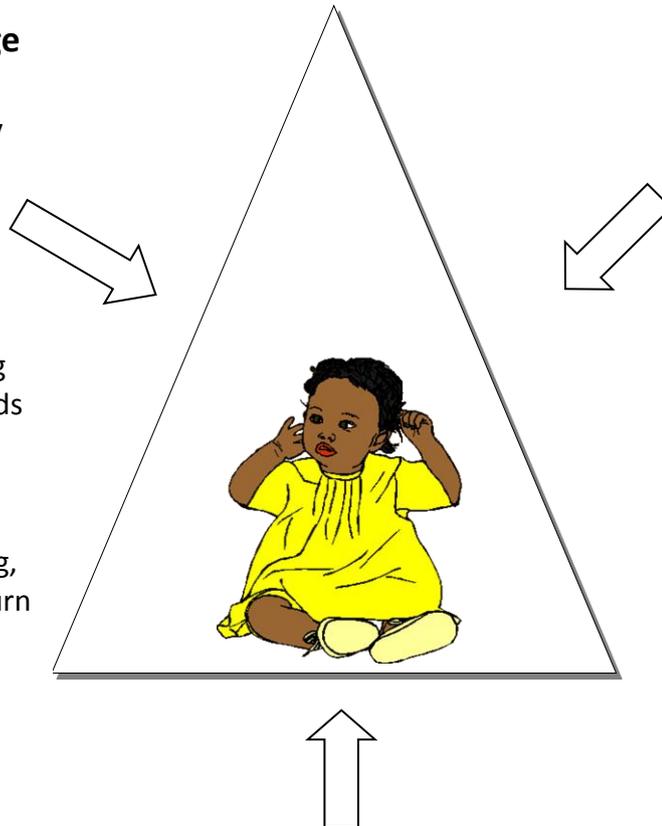
# What is Autism?

Autism is a neurodevelopmental disorder.

Autism is generally described in terms of a 'triad of impairments', which must be present in order to receive a diagnosis. These are:

## Impairment of Social language & communication

- Children with Autism frequently struggle with communication, including understanding spoken language, gesture, facial expression and other social nuances.
- Their difficulties with expressing themselves or getting their needs met can lead to frustration and challenging behaviour.
- Those with more advanced language skills may enjoy talking, but will not be so good at the turn taking involved in conversation.



## Impairment of thought and imagination

- Children with ASD may have an impaired ability to use imagination to problem solve and predict outcomes on a day-to-day basis.
- This impacts upon their ability to engage in pretend play, role play and take part in curriculum activities that involve abstract thinking and the use of personal imagination.
- They are likely to want to stick to rigid routines and to be resistant to change.

## Impairment of Social Interaction

- Children with Autism may try to avoid the types of situations in which typically developing students gain social skills.
- Some use contact with others as a means to an end (e.g. an opportunity to monologue on their subject of special interest)
- Others appear to avoid or not to seek contact with other people
- Children with Asperger's syndrome may want to interact, but lack the empathy and understanding of the give and take of friendship to make friends easily

## Alice's Story

Alice first came to the NEMFLA project in July 2010. Having heard about our services through a friend she made a self-referral. Alice came to NEMFLA, hoping to get support and information on behaviour management, sensory issues and to increase her older children's awareness of Autism.

Alice was a divorced parent with 3 children aged 7, 10 and 14. Her 7 year old son, Yinka was awaiting an assessment as he showed classic signs of ASD including sensory difficulties inappropriate behaviours at times and isolated at school.

There were several school complaints about Yinka's behaviour and the school were finding it difficult to manage him. As a result Alice had to give him support in class every day as he wasn't eligible for class room support due to lack of statement. This impacted on Alice's work situation so she had to close her tailoring business down. In addition, she had very little support from her ex husband who refused to accept that his son could have Autism.

A workshop was organised for Alice and her two other children to help them understand Autism and manage their brother. Out of the first sibling session, we were able to unravel feelings of the children towards Yinka and Alice.

These were some of the things said by Yinka's older brother and sister *"It's unfair".... "Yinka gets more attention..."* Alice's children expressed that were given a lot of errands to do and they didn't feel like they could be trusted.

Alice was set a few actions to do with her children. Set routines for all the children at home. Such as doing activities with her children individually e.g. older son

enjoyed making origami so Alice would spend time doing that with him. Set some time aside for each of her children to ensure they all had alone time with her. Following this workshop the Alice and her children requested further sessions. In total, three workshop sessions were organized with Alice and her family. From the second session onwards her ex husband, Wale came along too. This was fantastic to see the whole family coming together as unit.

As the sessions progressed Alice's children became a lot more relaxed and comfortable to speak freely about issues in the home. Autism was explained to them in detail and ways to manage Yinka's behaviour. Further actions were set for parents such as finding time to help older children with literacy homework, encourage children to write about their day, create chore rota's to share the workload and more positive encouragement. Also, Wale would find a way of alleviating the stress off Alice.

By the third workshop session it was clear that the family were making active steps to work together on achieving actions set during workshops with NEMFLA staff. Wale was more involved and helped more with the children - which had taken some of the pressure off Alice. Now the family have become a very cohesive unit. Both parents have also seen an improvement in Yinka's behaviour since they first came to NEMFLA.



## Sarah's Story

Sarah first came to the NEMFLA project in January 2011. Having heard about our services through her Social worker she courageously picked up the phone and made a self referral.

Sarah's case was quite complex. She moved to Ireland from Africa and there her son John was diagnosed with Autism. John has behavioural issues and can be violent and very hyperactive. He can say a few words but not fluid sentences. Mary didn't know what to do or how to support John, so she left him with social services as a cry for help. This resulted in her son being placed in care for over a year in Ireland.

After a struggle, Sarah came to live in London. Unfortunately, Sarah's start in London didn't start off very well. She had several housing issues and was moved out of several flats due to neighbour complaints about her son's behaviour. Eventually Sarah was re-housed and given a flat. Unfortunately, she had issues moving out of the hostel to get there. Due to the heavy snow at the time John was unable to get to school and her respite carer couldn't look after him. Sarah asked for emergency respite for 2 weeks so she could sort herself and things out. This resulted in her son staying in care once again.

Sarah was distressed and this impacted on her health. She felt very isolated because she has no family in UK and few friends.

### Now...

Sarah has complied with all of the authorities requests to take extra parenting classes, attend parenting courses and undergo various assessments. She sees her son a few times a week. John has made improvement at the school he attends.

After attending several workshops at NEMFLA Sarah was encouraged to try do things for herself. Now, she attends social functions with friends, has applied for some voluntary posts in the community and is looking to start a college course in next few months.

She has attended several workshops at NEMFLA on:

- Behaviour management
- Basic principles of child development
- Personal development
- How to use the internet and computer

Sarah also borrows resources from our toy and book library which she uses with her son.

These resources and workshop sessions have been of great use to Sarah as they have equipped her with several ways to manage her son and have given her the confidence to explore and do things for herself.



**In the next section we will briefly describe some interventions suggested to parents to help them engage with their children. These strategies can be applied to your children also.**

## Fixation

**Sarah identified that John was fixated with Bob the builder cartoon character. This caused immense frustration for Sarah when she would try to engage him with other toys or games. To overcome this Sarah was given a few ideas.**



- If Yinka enjoys this character don't take it away from him, instead engage with him.
- Create different activities around Bob the builder For example: find pictures/worksheets/print outs of Bob the Builder from the internet, magazines etc.
- Cut images into pieces to create a jigsaw.
- Take it in turns to colour in pieces of the picture
- With time introduce new toy/activity to him slowly
- This principle can be applied to other activities/games/objects. Just ensure there is something to replace the item that is being removed.

## Ways to engage your child

**In some workshops with parents the importance of play and engaging with the children was emphasised. Some strategies suggested include:**

- Try and play physical games with your child such as rough and tumble, piggy back rides or peek a boo.
- Take children to play outside (park / garden) as much as possible. This can be for 10-15 minutes at a time. It's important not to stay cooped up inside.
- Have family time where parents and siblings do things together e.g. play board games, trips/outings etc
- Observe your child's playing patterns and turn it into positive play. For example if s/he is throwing toys on the



floor – create a throwing game with bean bags or soft balls.

- Art and crafts using old newspapers, magazine etc, drawing, colouring, painting.
- Try keeping your child active through activities such as bike riding, swimming, football trampolining and many more.
- Enrol them in local or after school clubs such as drama, dance, karate, music, youth etc.
- Be creative with the resources you have. Utilise things at home and turn them into activities and games. E.g. use pot and wooden spoon to create playing instruments.



Whatever game or activity your child is playing...try and join in!

Parents can borrow toys from NEMFLA library. Contact NEMFLA staff for more information.

## Fear / Anxieties

**For children who have anxieties or fears one can try different things to overcome them. For example: Faith's 4 year old son Tunde doesn't like using the stairs.**

- Faith will encourage him and practise walking with him at home.
- Faith will stack catalogues on top of each other to create a stair effect and practise walking up and down them with Tunde.

Introduce children to these objects that make them feel anxious gradually.



## Interaction

**Social interaction can be an issue for children with Autism. We have compiled some strategies to overcome this.**

- Maintain eye contact with your child and come down to their level when speaking to them
- To maintain your child's attention parents can use: balloons, bubbles, musical instruments
- If you have more than one Autistic child try to engage with both children in the same way
- It is important to praise your child when they do something good i.e. with a hug, cuddle.



## Verbal Communication

**Here are some possible strategies to use with children who are non verbal.**

- Make dialogue very clear and appropriate to your child's level of understanding. So they are not confused.
- This is especially important when giving instructions to children. For example, *"Go get my big black handbag on the table near the bed"*. Here you have given a clear and descriptive instruction of the object needed.
- Some children on the spectrum may need a step by step breakdown when explaining things to them
- Be mindful of how you speak to your child i.e. tone of voice and words used, particularly if your child is easily angered.
- Sing with your child as this is a great way of promoting their speech
- Continue to speak to your child even if they do not respond.
- Try recording their voices on a tape/ mobile phone saying short sentences about their daily routine and the

home. For example *"brush your teeth"* *"rice and chicken for dinner"*.

- Play back to child so they can imitate parents.
- Record words said by your child so they can learn to repeat them and say them more often.



What about children who are verbal? Do they display communication difficulties? Yes they do. Some of our parents have reported that although their children are verbal but:

- They talk incessantly
- Speech may be incoherent
- Say inappropriate things

Parent can record their voice and say short sentences (or tell stories for younger children).

When recording parents should speak in a slow and calm tone so their child can copy you when listening back to it

## Learning skills

***Abdul was worried about his Autistic child's progress academically. Here are some strategies we suggested.***

- Set time aside each day to go through school work
- Try to make learning activities fun using coloured pens, paper etc
- Give your child short activities to begin with and increase them with time
- Reward good work with stickers, stamps, verbal praise, hugs etc
- Apply these strategies to other learning activities such as reading, writing, handwriting etc



## Siblings

Some workshops we have had in the past with families concerning siblings include:

- Explaining what Autism is to siblings of an ASD child
- Explaining ways to support their ASD brother / sister in the home
- Finding ways to ensure siblings aren't neglected by parents

Here are some things said by siblings of ASD children during our workshops.

***"I want to play with my brother but he doesn't speak to me"***

***David can be annoying, he lashes out, kicks, spits at us***



## Routine

Children on the spectrum must have routine and structure.

- Build a structure at home for your child i.e. morning routine, after school routine, bed time routine.
- Include your child when making this timetable/structure so they feel a part of it
- Create rotas for chores, activities etc
- Reward your child through praise, stickers, encouragement etc
- Give an indication of time when setting rules so your child knows the parameters



## Sensory

Many children on the Autistic Spectrum experience sensory difficulties. These sensory difficulties can impact: sight, smell, touch, taste, sound, balance and body awareness. These sensory issues can be split into two main areas high and low sensitivity. Although, for some children their sensory difficulties may fall into both areas.

Below are some statements of sensory difficulties observed by some of our families.

*Shaun destroys things in the house.  
He's damaged the panelling under the  
bath with his fists....*

*My son frequently tears his t shirts*

*At times Tunde self harms.....*



*Asha always switches off the lights in the  
corridor and the bedroom.....*

*Bola is sensitive to sounds and doesn't  
like large crowds of children.....*

*Dylan is very particular  
about the food he eats....*

*My daughter always bangs doors at home.*

### Possible Strategies

- Invest in dimmer bulbs or blackout curtains to minimise bright lights
- Slowly introduce different textures in small portions around your child's mouth. This may decrease their sensitivity to different foods
- Remove tags or labels, allow your child to wear clothes they feel comfortable in
- Prepare your child before going to a noisy place or crowded environment

### Further help

1. Ask to be referred to an Occupational therapist who can assist with finding ways to overcome sensory difficulties.
2. For more information on sensory needs please contact NEMFLA to access books from NEMFLA book library.
3. NAS also provides very comprehensive information on sensory difficulties that people with an ASD may experience, ways of dealing with sensory difficulties and professionals and resources that can help.

## Professionals who can help

Once an ASD diagnosis is made parents will at some point come into contact with some if not all of these CAMHS professionals listed below. See a brief description of what each professional does:

Professional	What they do
<b>Speech and Language Therapist</b>	<ul style="list-style-type: none"> <li>• Provide advice and support to parents and carers who have children with communication difficulties such as Speech, talking and interacting.</li> </ul>
<b>Occupational Therapist</b>	<ul style="list-style-type: none"> <li>• Help children to become as independent in daily life by encouraging the development of skills such as feeding themselves, getting dressed and playing.</li> <li>• They identify your child's needs and propose ways for the difficulties to be overcome e.g. suggesting necessary equipment or adaptations in the home.</li> </ul>
<b>Physiotherapist</b>	<ul style="list-style-type: none"> <li>• Physiotherapists help children with movement skills and physical mobility.</li> <li>• Through activities and sometimes equipment, they encourage the development of things such as standing, walking, sitting and balancing.</li> </ul>
<b>Paediatrician</b>	<ul style="list-style-type: none"> <li>• They are involved in assessing the child as a whole, the child's diagnosis, planning and coordinating care and assessing the impact on the family.</li> <li>• They liaise with other professionals and offer advice and support to the family.</li> </ul>
<b>Educational Psychologist</b>	<ul style="list-style-type: none"> <li>• They work with children and young people and they assess their learning and emotional needs using methods such as interviews, observation and test materials.</li> <li>• Interventions are then implemented to support the child or young person</li> </ul>
<b>Clinical Psychologist</b>	<ul style="list-style-type: none"> <li>• They work with children and young people who have all sorts of difficulties such as problems with mood, behaviour and relationships</li> <li>• Clinical psychologists may suggest different types of therapies such as cognitive behavioural therapy (CBT), family therapy and counselling.</li> </ul>
<b>Social worker</b>	<ul style="list-style-type: none"> <li>• They work with you and your family to help keep safe and to keep your family together.</li> </ul>
<b>Dietician</b>	<ul style="list-style-type: none"> <li>• They help you with nutritional advice if your child is struggling with food problems.</li> </ul>
<b>Psychotherapists</b>	<ul style="list-style-type: none"> <li>• They provide in depth therapy to work through your child's feelings and what may be behind them.</li> </ul>

## FAQ's

### **Q. What is a referral?**

A. Referral means how you are put in touch with different services. You can be referred to a health service by: Your doctor (GP), your school, your social worker, a professional working in the health service or anyone else on your behalf.

### **Q. What does CAMHS mean?**

CAMHS stands for Child and Adolescent Mental Health Services.

### **Q. Should I be worried if my child has been referred to CAMHS?**

CAMHS provide assessment and treatment services to children and young people aged 0-18 years where there are concerns about their behaviour or emotional wellbeing. CAMHS services cover children and young people living in the boroughs

### **Q. How will my child's needs be assessed?**

In a statutory assessment process the local authority asks people to give their views on your child. They ask for advice from: you, your child's school, an educational psychologist, a doctor, social services (who will only give advice if they know your child) and anyone else who the local authority thinks it should get advice from to get a clear picture of your child's needs

### **Q. What is a statement?**

A statement of special educational needs (SEN) sets out your child's needs (in terms of their learning difficulties which call for SEN provision) and the help they should have. It is reviewed annually to ensure that any extra support given continues to meet your child's needs.

## Useful contacts

### London Borough

### Children's Centre

#### Southwark

Sunshine House  
Southwark Children and young people's  
development centre  
27 Peckham Road  
London  
SE5 8UH  
**Tel:** 020 3049 8100

#### Lewisham

Kaleidoscope  
Lewisham Centre for Children & Young  
People  
32 Rushey Green  
Catford, London  
SE6 4JF  
**Tel:** 020 7138 1100

#### Greenwich

The Child Development Centre  
3 Wensley Close  
Eltham  
London SE9 5AB  
**Tel:** 020 8294 3118 or 020 82943107

#### Bromley

Phoenix Children's Resource Centre  
40 Masons Hill  
Bromley  
BR2 9JG  
**Tel:** 020 8466 9988

## Resources



### Recommended reading

***The Sensory World of the Autistic Spectrum - a greater understanding*** by Kate Wilkes (2007)

Many people on the autism spectrum experience sensory difficulties or are particularly sensitive to certain sensations. This booklet aims to give a basic understanding of these difficulties and offers coping strategies.

***Understanding Behaviour*** by Fiona May (2006)

This book offers an insight into practical approaches and strategies which can be applied in day-to-day situations. Full of helpful case studies and guidance on behaviour in both children and adults.

***Body Language and Communication*** by Simon Perks (2007)

This is a guide discusses some body language techniques and a number of scenarios where people with an Autism Spectrum Disorder can put these into practice, such as meeting people for the first time, starting a conversation or engaging in small talk.

***What's so Special about Autism?*** By Lorna Wing (2006)

The author discusses the characteristics of Autism and how these affect the services that people with an autism spectrum disorder need.

***I have Autism... What's that?*** By Kate Doherty, Paddy McNally and Eileen Sherrard (2008)

This book helps children and young people with autism discover how they are different. It explores different approaches to talking, playing and learning and offers coping strategies.

These books are available from NEMFLA toy and book library. To borrow any of our items contact us on:

**Tel: 0207 708 3939**

**Email: [info@stmichaelassociates.org.uk](mailto:info@stmichaelassociates.org.uk)**

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*Thank You*

