



**Theme**  
**Life Beyond  
the Diagnosis**

## **TITLE: SUPPORT FOR THOSE THAT GO UNDER THE RADAR**

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## WHAT WILL WE COVER?

- Recognition, Proper Referral and Diagnosis
- Management and Support
- Questions



## Recognition, Referral and Diagnosis

- The term autism describes qualitative differences and impairments in the following three main areas;
  - reciprocal social interaction and social communication,
  - restricted interests
  - rigid and repetitive behaviours
- This often has a lifelong impact.
  
- These features may substantially impact on the quality of life of the individual, and their family or carer, and lead to social vulnerability.



## Recognition

- In addition to these features, children and young people with autism *frequently* experience a range of
  - cognitive
  - learning
  - Language
  - Medical
  - emotional and behavioural problems






## Recognising the spectrum...

- The clinical picture of autism is variable because of differences in the **severity** of autism itself, the presence of **coexisting conditions** and levels of **cognitive ability**, from profound intellectual disability in some people to average or above average intelligence quotient (IQ) in others.



- Anyone who meets the criteria for having autism spectrum disorder (ASD) will be further diagnosed as having ASD level 1, ASD level 2, or ASD level 3, according to criteria outlined in DSM-5.

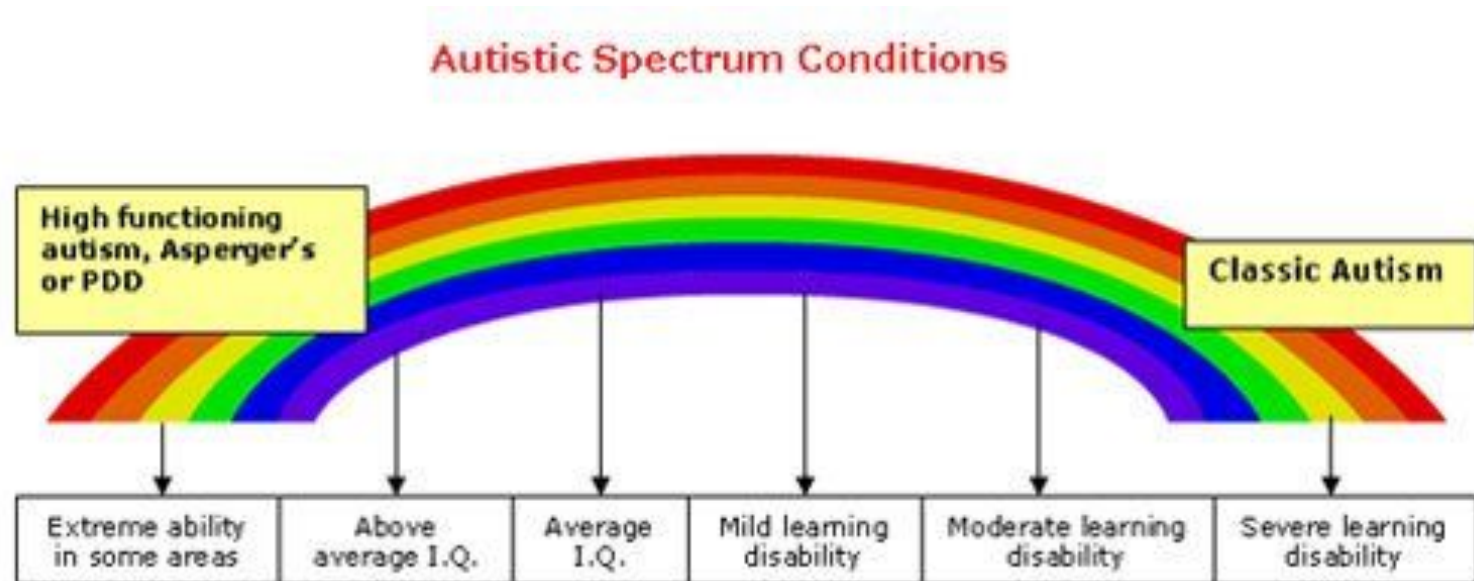
## The Three Functional Levels of Autism

ASD Level 1 Requiring Support	ASD Level 2 Requiring Substantial Support	ASD Level 3 Requiring Very Substantial Support
		
<p>difficulty initiating social interactions</p> <p>organization and planning problems can hamper independence</p>	<p>social interactions limited to narrow special interests</p> <p>frequent restricted/repetitive behaviors</p>	<p>severe deficits in verbal and nonverbal social communication skills</p> <p>great distress/difficulty changing actions or focus</p>

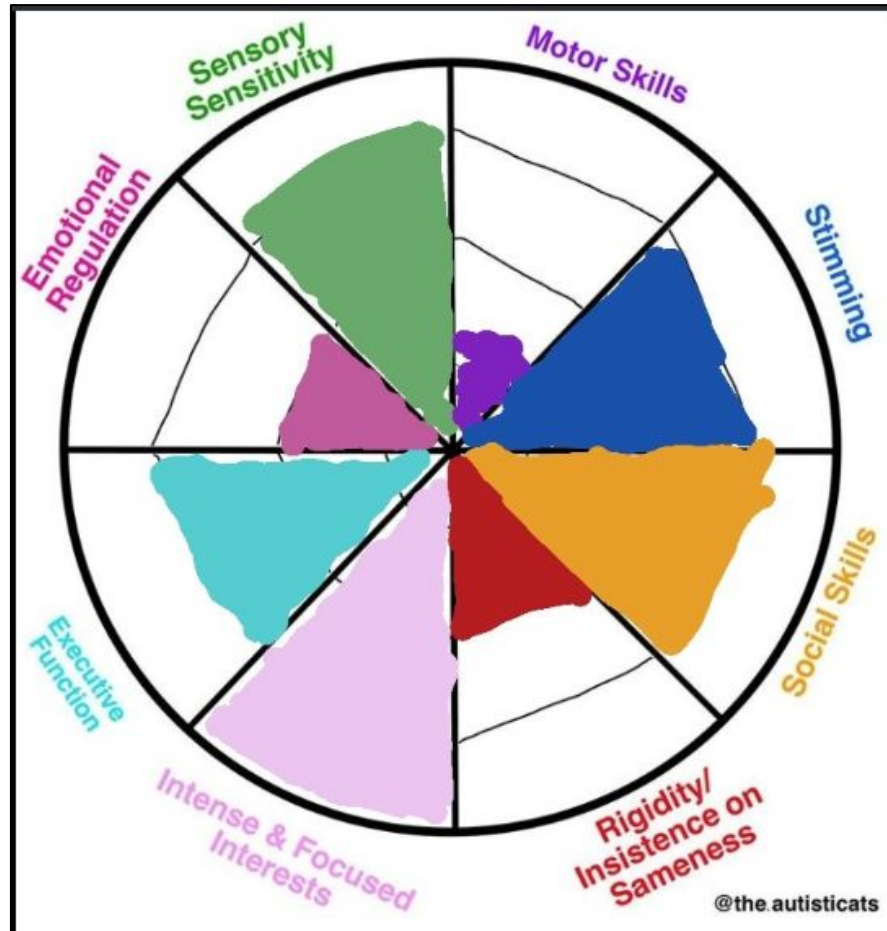
**verywell**



## Is this a good way to visualise the spectrum?



# A Visual Spectrum





## We recognise it... What next?

- There are many claims of a 'cure' for autism, all of which are without foundation. However, there are interventions that can help some of the core features of autism, some of the symptoms, behaviours and problems commonly associated with autism, and support families and carers.
- There is also evidence for treatment strategies to reduce behaviour that challenges.
- Today we are going to examine the different ways that we can provide support, treatment and help for children who typically fall through the gap LEVEL 1 & LEVEL 3



# The Importance Of A Diagnosis

- The nature and course of autism
- The nature and course of behaviour that challenges in children and young people with autism
- Recognition of common coexisting conditions, including:
  - Mental health problems such as anxiety and depression
  - Physical health problems such as epilepsy
  - Sleep problems
  - Other neurodevelopmental conditions such as attention deficit hyperactivity
  - Disorder (ADHD)
- The importance of managing key transition points, such as changing schools or health or social care services
- **The child or young person's experience of autism and its impact on them**
- The impact of autism on the family (including siblings) or carers.



## Cont..

- The impact of the social and physical environment on the child or young person
- How to assess risk (including self-harm, harm to others, self-neglect, breakdown of family or residential support, exploitation or abuse by others) and develop a risk management plan
- The changing needs that arise with puberty (including the child or young person's understanding of intimate relationships and related problems that may occur, for example, misunderstanding the behaviour of others)
- How to provide individualised care and support and ensure a consistent approach is used across all settings
- Skills for communicating with a child or young person with autism.



# Management and support

- We will be examining 4 case studies



**AYO: 3**



**ADE: 7**



**SEGUN: 11**



**NENE: 13**



# Ayo

- Ayo is 3 years old and comes to the clinic with his grandmother. Ayo's family are concerned because he does not turn towards members of his family when they come into the room and despite them calling his name, he does not seem to show any recognition of his name nor of the significant people in his life. Ayo has had a hearing test and all appears to be normal.
- While Ayo is sitting on his grandmother's lap during the consultation he seems to be hearing the whir of the computer fan on your desk and occasionally turns towards the ticking of the clock on the wall. Ayo does not respond to his grandmother's voice and does not show any particular reaction when you call him by name. You wind up a toy in front of him and he immediately pays attention to the winding noise and the subsequent actions of the toy.



# Ayo

## (things to consider)



- Parent-led video therapy is a form of intervention to improve the social communication skills of young children on the autism spectrum, particularly those who speak few or no words.
- The therapy is non-invasive: it involves videoing a child on the spectrum as they play and then using the footage to feed back to parents to support them to recognise and respond to the alternative communication patterns. The therapy focuses on behaviours such as eye-gaze, sharing, showing and giving.
- The Pre-school Autism Communication Therapy (PACT) is the only well-evidenced intervention of this type available in the UK.
- These types of intervention empowers parents to maximise their support of their autistic child, enabling them to develop their own communications skills and ultimately advocate for themselves.
- Currently one in four autistic people speak few or no words throughout their life.
- Language and communication skills have a significant impact on an autistic persons ability to convey their mental and physical health needs and are recognised as a key factor with underlying behaviour that challenges. These skills will likely affect physical health outcomes, their likelihood of social exclusion, their educational attainment and chances of finding employment
- Parent-led video therapies are distinct from other interventions for autistic children. Existing interventions can help prepare children on the autism spectrum for social situations or enable them to functionally communicate their needs. However, PACT is the only well-evidenced therapy that has the potential to improve a child's social communication skills in a sustained way as they develop and therefore alter their longer-term trajectory in life.



# Attention Autism



- Attention Autism: is a learning approach that aims to develop natural and spontaneous communication skills in children with autism through the use of visually based and highly motivating activities.
- **What are the Aims of Attention?**
- As well as the ultimate goal of developing natural and spontaneous communication skills in children with autism, there are several other aims that Attention Autism strives to achieve. These include:
  - To engage attention.
  - To improve joint attention.
  - To develop shared enjoyment in group activities.
  - To increase attention in adult-led activities.
  - To encourage spontaneous interaction in a natural group setting.
  - To increase non-verbal and verbal communication through commentary.
  - To build a wealth and depth of vocabulary.



# Stages of Attention Autism

## Stage 1: The Bucket to Focus Attention

- The first stage of Attention Autism involves filling a bucket with visually engaging toys that aim to help children learn how to focus their attention. The toys will be presented to the group by an adult leader, such as teacher, learning practitioner, occupational therapist or parent. The adult leader will make simple comments about each toy to help introduce them to the children and expand their vocabulary.
- Aim to carry out this session 4 or 5 times a week. Start by showing the toys in the bucket for a minute. If everyone can pay attention for a whole minute, then add an additional minute. When everyone in the group can pay attention for a whole five minutes, you are ready to move on to stage 2.

## Stage 2: The Attention Builder

- This stage involves introducing the group to highly appealing and visually stimulating activities.
- This stage aims to build and sustain attention for a longer period of time.
- Attention autism ideas for activities you could demonstrate during stage 2:
- Flour castles - these can be built like sandcastles. You will need flour, a bowl and any other moulds you wish to make a castle out of.
- Erupting volcano activity - this is a classic science experiment, that is sure to be visually engaging.
- Fishbowl foam - fill a fishbowl with shaving foam and water, slowly drop different coloured food dye in and get children to describe the colours and speeds at which they see it fall.
- Glowing Balloons - blow balloons up and place a glowstick inside each balloon. Turn the lights off for a fun, glowing, visual activity.

## Stage 3: The Interactive Game - Turn-Taking and Shifting Attention

- The adult leader will demonstrate a simple engaging activity and invite children up one at a time to have a turn. This may be the same activity from stage 2 or something new to introduce your group to.
- This will help children to learn how to shift their attention to their own participation and then back to the rest of the group. This will also teach them about the importance of sharing, turn-taking and waiting.

## Stage 4: Individual Activity - Focus Shift and Re-engage Attention:

- In the final stage of Attention Autism, the adult leader will demonstrate a simple creative task and then ask each child will be asked to copy it. This may include building a pattern with different coloured blocks.
- Children will focus their attention as part of a group to watch the demonstration, the shift their attention to work on their individual task, and then finally shift their attention back to the group to show their completed task. This stage also aims to build independent working skills and following instruction skills.





# Using Alternative Communication AAC

she learned how to use  
language to communicate!



# AAC

## Simple AAC

### S how



Point to symbols as you talk  
This SHOWS the learner what to do and models language for them. It's okay to make mistakes and you don't have to point to every single word - just the important ones!

### I nteresting



Remember to keep things fun!  
Relate your teaching to the AAC learner's favourite things to keep them INTERESTED. We all learn more when we are interested and motivated!

### M onths and months



Learning AAC takes time  
Some learners will need MONTHS of modelling, to see and hear their AAC being used, before they are ready to start using it themselves. This is okay!

### P ause



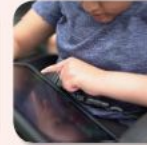
Give learners lots of time  
Learners might need longer to process what you say and respond. A PAUSE also shows it's their turn to talk. It can help to count to ten in your head to make sure you pause for long enough!

### L anguage



Teach different types of words  
Try to remember all the reasons we use LANGUAGE. It's not just to ask for things! So model a range of words and how to use them - to comment, protest, ask questions and more!

### E xplore



Give learners time to explore  
Allowing learners to 'play' with their device is okay! In fact, it's really important that we give learners time to EXPLORE their AAC and see what it can do.

### A lways available



Make sure AAC is available  
AAC users need access to language all of the time! This can be a high tech device, or a low tech communication book. But if they don't ALWAYS have their AAC - they can't learn to use it!

### A dd words



Add new words as you teach  
Once a learner begins to use their AAC, support their language development by ADDING WORDS to what they say. If they say one word, repeat it back and add another word.

### C omment



Swap questions for comments  
Questions can be testing, not teaching. So instead of asking questions we know the answer to, say the answer instead, or just COMMENT on what is happening.



# Ayo (continued)

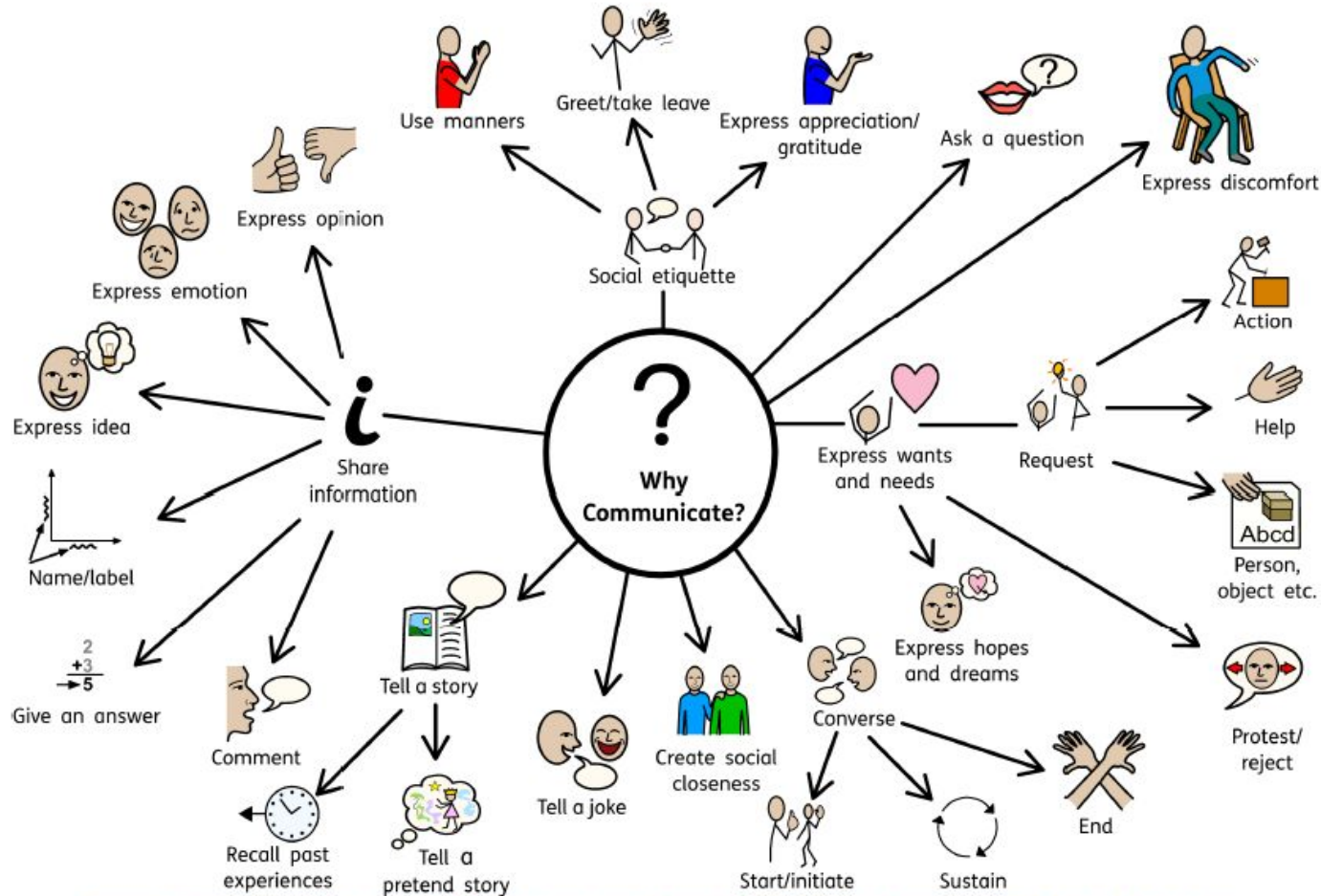
Core vocabulary makes up about 80% of what we say.

For example: like, go, more, want, help, what, here, I, you

I	me	how	who	why	again	please	thank you	problem	now	bad	good
my/mine	am	to	be	feel	give	listen	happy	sad	tired	okay	cool
it	is are	will	come	hurt	hear	know	that	a	the	and	more
you	can	eat	drink	finish	get	love	make	need	all	at	some
your	do	go	help	open	put	say/talk	see/look	first	then	for of	on
here	have	like	play	read	stop	walk	show	wait min	in	up	off
yes	no/don't	want	take	tell	turn	watch	wear	work	out	down	with



# Creating communication opportunities



## Creating meaningful opportunities

- Think of 5 meaningful opportunities that you can create for children to communicate throughout the school day.
- If a child is only requesting then what other opportunities can you create for them to request other than for food or drink.
- LONG TERM AIMS
  - What does the child do outside of lessons at playtime or at home?
  - What will the child do after they leave school?
  - Will the child live independently or in supported accommodating?
  - Will they live with family or friends?



# How many sentences can you making using the core page in one minute?

 top	 page	<p>core</p>		 not here
 I, me, mine	 like	 go, went	 lots, many	
 want	 look, see, show	 more	 1	
 no, not	 help	 stop, finished	 big	
 bad, rubbish	 good, awesome	 oops, mistake, uh oh	 little	
 what	 something's wrong	 got an idea	 let's pretend	



## ADE

Ade is 7 years old and his mother is concerned about his challenging behaviour in school.

- He is very noncompliant and has hit staff and pupils. Ade had early language delay but now uses fluent sentences.
- His school reports indicate that he has some learning difficulties and he has extra support from tutors out of school. His tutors say he is making progress in their lessons but this has not made much impact in school.
- School also describe a failure to develop any peer relationships.
- His parents report that his language is stereotyped and repetitive and that he repeatedly watches the same Youtube videos on games.
- He is very limited in terms initiating social communication and has a restricted pattern of interests, currently an over-focus on gaming.
- He has stereotyped repetitive motor mannerisms and seeks to feel people's clothes. Ade does use eye gaze, facial expression and gesture but is an infrequent initiator of communication.
- Ade shows some appropriate responses to other people's emotions but also often shows an odd response, for example smiles if distress shown. He is unconcerned about adapting his behaviour according to the social context and has some fixed routines, for example reading through all the notices at the swimming pool every time.



## Ade (things to consider)



- Visual support
- Reduce verbal language
- Use of prompting and then fading
- Develop understanding and ability to predict
- Use of structure and routine to develop flexibility
- Interaction work
- Creating communication opportunities
- Work in the child's context
- Joint working – team approach





# How would this work?

- Use minimal language – keep short and specific
- 
- Support spoken language with visual cues (pictures, symbols, objects)
- 
- Give extra time for the child to respond to what you say
- 
- If no response, repeat using the same consistent words. Be wary of re-phrasing again and again – this can lead to sensory overload.
- 
- Refer to the child by name instead of using pronouns (e.g. "Mary's" instead of 'hers', "John" instead of "he" or "you").
- 
- Call the child by name first to get their attention before giving an instruction
- 
- Give instructions in the order in which they need to happen (i.e. "First colouring, then computer")
- 
- Give specific instructions, saying exactly what you want them to do
- 
- Reward positive behaviour e.g. "Good sharing". Avoid vague terms like 'inappropriate behaviour' – instead label what you want to see.
- 
- Use positive not negative instructions e.g. "Keep your space" for a child who keeps touching and going to close to others or "Walking" instead of "No running"

## Assessment of Language Functions

Name:

Date:

Language Function	Suggested assessment	How this function is achieved
<b>Getting other person's attention</b> e.g. saying name	Ensure child needs you + turn or move away, make a puppet go to sleep, ask child to 'tell me when you've finished'	
<b>Greeting / saying goodbye</b>	Observe	
<b>Requesting an object</b>	Work out motivator and put out of reach, use bubbles /songs etc do once and wait, use shopping/ café role play	
<b>Requesting you to do something</b> e.g. help with something or for you to play with him	Give 'sabotaged' item – container child can't undo, blunt pencil, empty cup	
<b>Rejecting/protesting</b> e.g. saying doesn't like or want something	Observe	
<b>Directing another person's attention to something</b> e.g. saying 'look'	Look out of window together or at photos/books	
<b>Directing others</b>	Any activity where child takes turn to tell others what to do, barrier games	
<b>Expressing emotions</b> e.g. happy, enjoying something, worried, scared, upset, proud	Puppets, stories, facial expression/emotion pictures	

<p><b>Giving information</b> telling about something which happened</p>	<p>Plan do and review – photos of activity, retell story</p>	
<p><b>Asking questions</b> e.g. what others are doing, what to do next, where?</p>	<p>Hiding games. Taking turns to ask who? /what doing? questions</p>	
<p><b>Requesting information</b> e.g. about something or someone new</p>	<p>Guessing game – is it...? Does it...? What colour/shape/what do you do with it?</p>	
<p><b>Reasoning / explaining</b> How, why?</p>	<p>What's wrong? That's funny cards</p>	
<p><b>Planning</b> Discussing what's needed for an activity</p>	<p>Let's.....what do we need? How/what shall we do.....?</p>	
<p><b>Conversational repair</b> changing what he says to help <b>you</b> understand</p>	<p>Observe Pretend you don't understand / do something wrong</p>	
<p><b>Requesting clarification</b> Asking when <b>he</b> doesn't understand something</p>	<p>Observe Deliberately say something unintelligible or out of <u>context</u>e.g. 'I broke it yesterday'</p>	

# NeNe

- Nene is 13 years old and presents with her parents at their family doctor with physical symptoms.
- She has a well above average IQ, all early milestones were reached but in retrospect, Nene parents report that there were always problems with social interaction with peers.
- Nene has a liking for routines, and a tendency to literal understanding of what people say and do. Her parents think that Nene is naive and immature compared with her peers.
- In primary school Nene's teacher identified a need for some extra support for learning and she was well supported in primary school, but since secondary transfer NeNe began to complain more frequently of headaches and stomach aches, and does not wish to go to school.
- Nene has never displayed any behavioural difficulties but her parents have long-standing concerns about friendship difficulties with peers. In school, Nene frequently fails to understand task instructions but does not ask for help because she does not wish to draw attention to herself.











## Nene (things to consider)



- Friendships
- Impact of literal understanding on academics
- Ability to discuss emotions – impact on perception of physical ailments
- Problem solving skills



# The Negotiation Canvas

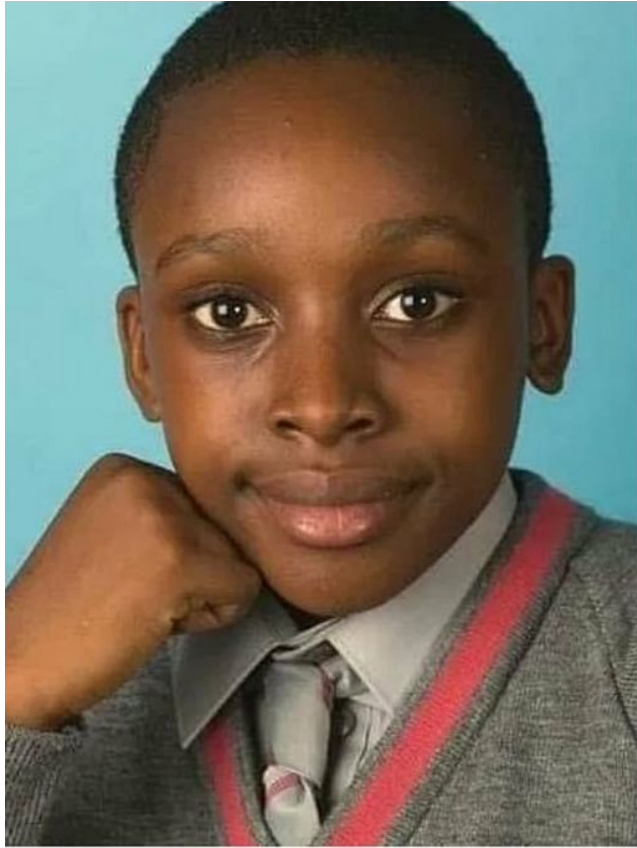
<b>1) MY DESIRED OUTCOME</b>  <i>What do I want?</i> <a href="#">learn more</a> ☺		<b>2) THEIR DESIRED OUTCOME</b>  <i>What do they want?</i> <a href="#">learn more</a> ☺	
<b>3) MY KEY INTERESTS</b>  <i>Why?</i> <a href="#">learn more</a> ☺	<b>7) MY BARGAINING CHIPS</b>  <i>What value can I offer?</i> <a href="#">learn more</a> ☺ ☆☆☆	<b>8) THEIR BARGAINING CHIPS</b>  <i>What value can they offer?</i> <a href="#">learn more</a> ☺ ☆☆☆	<b>4) THEIR KEY INTERESTS</b>  <i>Why?</i> <a href="#">learn more</a> ☺
	☆☆	☆☆	
	☆	☆	
<b>5) MY WALKAWAY ALTERNATIVE</b>  <i>What will I do if we do not reach a deal?</i> <a href="#">learn more</a> ☺	<b>9) POSSIBLE SOLUTIONS</b>  <i>What solutions could work for both of us?</i> <a href="#">learn more</a> ☺		<b>6) THEIR WALKAWAY ALTERNATIVE</b>  <i>What will they do if we do not reach a deal?</i> <a href="#">learn more</a> ☺
	PS 1	PS 2	
<b>10) AGREEMENT</b>  <i>What did we agree to?</i> <a href="#">learn more</a> ☺			

# Segun (Aged 11)

- Segun is 11 years old. His school was concerned because Simon was not able to focus on class instruction and tasks. This prompted referral to the SENCO. Segun was not attaining despite having an above average IQ and language ability. Segun had particular problems with writing and became very frustrated if he made mistakes.
- He was not interested in making friends, and seemed to be “in his own world”. Parents report that Segun becomes frustrated if things are “not right”, and that he has an insistence on perfectionism and routine. He has a focus of interest on the Biafra War – this is the most recent of several intense interests. Segun talks at people about this and does not tolerate interruption.
- He is not responsive to his name being called, seldom chats, responds without looking at people and he spends 1–2 hours daily in his own world re-enacting fantasy with actions.
- Segun has a warm relationship with parents and is kind to his sibling but is anxious that the sibling does not break rules.



# Segun (things to consider)



- intellectual ability and learning style
- academic skills
- speech, language and communication
- fine and gross motor skills
- adaptive behaviour (including self-help skills)
- mental and emotional health (including self-esteem)
- physical health and nutrition
- sensory sensitivities
- behaviour likely to affect day-to-day functioning and social participation
- socialisation skills