

# Practical strategies to ensure the best experience every time for autistic people

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#### Autism facts

Over 700,000 people in the UK are autistic.

More males are diagnosed than females but we think autism is under diagnosed in females

The causes of autism are still being investigated – research suggests a combination of genetic and environmental factors

Autism is a hidden disability – you can't always tell if someone is autistic and not everyone will have a diagnosis

Autism is life-long and there is no known 'cure', but we can find better ways of helping autistic people negotiate the world and access the experiences they would like

#### **Foreword**

When you're in an office or a classroom or even your own house, you can feel that sense of being "trapped". Even visiting your local pub with your friends can leave you feeling a little bit tied up and you long for freedom. But when sailing comes along you rapidly come out of that trapped feeling and you're then a completely new person to how most people know you. You have become "yourself".

Sailing is my world, it's my everything, and it is where I am happiest. It creates more parts of me for the better.

When I started sailing, I hated it! I hated the boat heeling over when going upwind. I used to think downwind was nicer and used to ask if we could have the spinnaker up all the time, but then we broached! As time went on, I started loving it. It was the only sport that I began to make friends of my own age and indeed, friends who did not judge me for being autistic. Through the years, it grew into my biggest passion and any sailing event were the highlights of my summer holidays.

Sailing helps me challenge myself. I have to manage nerves, tiredness, I have to rely on my crew, I have to focus, concentrate and think quickly. I push myself. I used to say to my crew 'hold off putting the kite up', but now I call for it the moment we are round the windward mark because I know we've practiced it and thought it all through.

I am proud that much of what I learnt in the early days I taught myself, but I have learnt a huge amount from my sailing heroes, from coaches and instructors. The best of them have been calm, clear and had planned in advance what we are going to do. There is constant communication and reassurance. They take the time to prepare me for big races with practice, practice, practice. They encourage me to think ahead and work out what might need changing on the boat – something that can be hard for an autistic person to do. They have spoken slowly, explained things more than once, have physically shown me what to do, written down tips and used pictures to help.

Sailing can be a very sensory environment – just to touch the water may be a challenge for an autistic person but there are so many benefits – from problem solving skills to learning to accept reassurance from others. People think autistic people aren't good in a group but sailing has given me the confidence to be part of the team on and off the water.

I hope this guide helps volunteers, instructors and coaches see what they can do differently to help autistic people become sailors. If you are open from the start, things can work really well.

Murry MacDonald

Autism on the Water

#### Introduction

#### Connor

#### "I love the spirit of freedom that comes with sailing"

Boating is fun, social and challenging. Activity outside and on or near the water is good for you physically and for your wellbeing. Learning new skills or doing something you are good at is rewarding. Boating can build character and develop key life skills.

Many autistic people miss out on these benefits because organisations, instructors and coaches aren't always aware of the impact of autism such as heightened anxiety in social situations, experiencing the sensory world differently, repetitive behaviours, difficulties with flexibility of thought and communication.

No two autistic people are the same so taking the time to get to know the person will enable the person to enjoy the many benefits of boating and bring the strengths they have to developing a lifelong love of being on the water.

A person centred approach is needed, one that is based on:

- Asking, not assuming
- Listening
- Assessing what is needed and adjusting plans
- Doing delivering a session, running an activity
- Reviewing reflecting on what happened and what you will do next time

This resource is a guide and offers some practical strategies for delivering boating activities for people on the autism spectrum. It is a guide only, and there is no 'one size fits all' solution. It's all about the person and what is important to them.

#### Logan

"When I come sailing I am me, not what other people want me to be. The rest of the time you spend trying not to be you, just to fit in. I enjoy sailing, it gives you freedom. If you've had a really rubbish day and feel irritated you just have to go sailing and you are fine"

#### What is autism?

Autistic people increasingly say that the way their brain functions and processes information is different which can lead to strengths and challenges when relating to other people and engaging in a complex social world. Autism is a lifelong disability and a spectrum condition. All autistic people share certain difficulties but being autistic will affect them in different ways.

Autism is often diagnosed alongside other conditions. It's important to support people with more than one condition in a way that meets all their needs, while understanding that the needs arising from autism are distinct.

Autism is one of a number of conditions where a person's neurodevelopment is different, including Attention Deficit Disorder, Attention Deficit Hyperactivity Disorder, Tourette's, Complex Learning Disabilities, Dyslexia, and Dyspraxia.

#### Strengths a person may have

There are lots of strengths associated with autism that can be very useful in boating. Everyone is an individual of course, but below are some attributes autistic people can have that may benefit their boating.

- Problem solving: A logical and structured approach to tasks quickly spotting where things can be improved
- **High levels of concentration** the ability to focus on detail and work without distraction, but with consistency and accuracy
- **Reliability and loyalty** very conscientious and committed, punctual, honest with bags of integrity. The potential to be a very committed sailor.
- Technical ability very knowledgeable, developing highly specialist skills, able to see things others can't

Of course, some things are more difficult. People may struggle to turn detail into a coherent whole, put plans and words into action and to self-initiate tasks. It takes time and a lot of effort, particularly in relation to:

- Communication
- Social interaction and relationships
- Social imagination and flexibility of thought
- Sensory sensitivities

The way we organise activities for the majority may disable autistic people who engage in a different way and who would benefit from a personalised approach.

#### Communication

Communication is a two way process. Autistic people may have differences with both verbal and non-verbal communication. They may:

- have a literal understanding of language
- have a restricted vocabulary
- not realise an instruction to the group includes them
- find it difficult to use or understand facial expression, tone of voice, and jokes and sarcasm
- find it difficult to give attention to others around them
- use eye contact differently from social conventions
- repeat words and phrases
- use different intonation
- not use speech
- communicate in a way that doesn't fit the social context
- find it difficult to sequence communication

All in all, these differences can make it very hard for an autistic person to understand the message someone is trying to communicate, particularly if too many unclear non-verbal hints are used and people do not state things clearly and directly. Communication will take longer.

#### Social interaction and relationships

People with autism say it's the way others engage with them that makes life difficult. The differences an autistic person experiences may cause them to stand out in social situations and find building relationships, navigating the social world and reading other people difficult, including:

- Joining in with small talk, the give and take of informal conversation, discussing things you aren't interested in and finding the right things to say – it is easier to go straight to a topic of interest, repeat what has been said, talk at length about your own interests or ask for information
- Being overloaded by other people it's easier to seek time out alone
- Seeking comfort from others
- Adapting use of language in informal situations
- Following the conventional rules on eye contact
- Finding out how other people are feeling and responding in the right way, not misinterpreting others' actions
- Forming friendships
- Expecting others to realise their own thoughts and feelings
- Understanding sarcasm, facial expressions and body language
- Sustaining attention

The rules of physical boundaries and touch in boating change depending on a range of factors – for example whether you are ashore or afloat, the size of the boat, the team work needed, the conditions and the task at hand. It can be difficult for an autistic person to navigate this.

#### Social imagination and flexibility of thought

Many autistic people describe high levels of anxiety around change – the world can seem unpredictable. For example, where activity takes place, the equipment used, changes in coaches / instructors, or new situations and skills to learn can all be confusing. Routine and structure can help, along with advance notice of change and a clear understanding of the purpose of what they have been asked to do and any rules that need following.

Thinking hypothetically, or imagining situations and considering potential outcomes can be challenging. One result is that making choices can be hard – concrete binary choices are easier. An inability to predict what may happen can impact on a person's sense of danger.

People describe having intense and highly focused interests which can be fundamental to their wellbeing. They may have a single focus and find it hard to pay attention to multiple things at once.

Differences with social imagination are not the same as a lack of imagination, and many autistic people are highly imaginative. This can lead to over analysing or dramatising a situation.

#### Marie, Logan's Mum.

"Logan finds disruption stressful, large groups overwhelm him but because he loves sailing he has learned to deal with change and crowds. When he first started he wouldn't speak to anyone but now he is much more confident"

#### Stress and anxiety

Anxiety can be triggered by sensory difficulties, by a loss of control, challenging social situations, or new environments. Stress can come from routines being disrupted, people not doing what they said they would, plans and timetables not being followed, not knowing what is going to happen next, getting to new places, trying new situations, new food, or having to wear new clothes and equipment.

It can lead to people physically tensing up, being restless, getting tired, being irritable, edgy, showing aggression or running away.

For most non autistic people, levels of anxiety are low so when something stressful happens anxiety may rise a little but the brain is able to process this and anxiety levels quickly return to normal.

Autistic people describe high levels of anxiety just from the impact of the different ways they experience the world around them, so when they come across a new stress or sensory input, anxiety increases and the brain struggles to process it to the point where it is hard to function properly.

While sailing and boating can help as a release, clearly if the environment is not right it can be a trigger as well.

#### Ben, 2019 RYA Sailability Sailor of the year

"The thing is with autism you get a lot of anxiety. Sometimes I'll come home, I've had a really stressful day at school and I just get out on the water and forget all my worries and it's a load of fun sailing around and going fast"

#### **Sensory sensitivities**

Many autistic people describe being either over sensitive or under sensitive to sounds, touch, tastes, smells, lights, colours, temperature or pain, often causing reactions that are incomprehensible to others. Too much or too little information can cause stress and anxiety. People may be fascinated by particular sensory stimuli. Self-stimulating behaviour such as repetitive movements or sounds can be used by the person to manage under or over stimulation, or their anxiety, and so are really important to them.

Equally, what is going on inside a person's body may be harder to interpret for an autistic person – am I nervous or excited, hungry or thirsty, do I feel unwell, am I in pain, am I cold or hot?

The table below shows how this **may** impact on a person

Sense	Function	Over sensitive	Under sensitive
Touch	Assess various conditions, the feel of the boat. Recognise and feel pain.	Can be painful Dislike having things on their hands and feet Only tolerate certain types of clothing	Hold objects or others tightly A high pain threshold Chew objects Enjoy heavy objects on top of them
Sight	Defining parts of the boat and the controls Identifying people Judging distance and space around the boat.	Objects, bright coloured walls and bright lights may jump around Images fragment Easier to focus on detail Difficulty sleeping	Objects appear quite dark or lose features.  Some things may be magnified, others blurred.  Poor depth perception.  Clumsiness.
Sound	Communicate with people around you Assess the environment Supports balance.	Hard to filter out noises and focus on what is being said Sounds may be distorted or muddled	Seeks noisy places or objects / actions that make loud sounds
Taste	Meals are an important social time and food fuels us	Flavours are too strong, so limits a diet	Prefers strong flavours and spices May try to taste non-edible items
Smell	Assessing the environment Alerting us to danger	Overwhelmed by every day smells and tries to avoid them Misses out on smells that alerts us to danger	Seeks out strong smells Misses out on smells that alerts us to danger
Body awareness	Assessing where our bodies are in relation to the boat and how different parts of the body are moving	Fine and gross motor skills are harder May need to move their whole body to look at something	Stand too close to others, struggle to recognise personal space Hard to avoid obstructions around the venue or boat Can bump into others
Balance	Maintaining posture in the boat Assessing how fast our bodies move Keeping our body in the right place to perform tasks	Hard to control movement, to stop quickly Even harder if the head is not upright and feet are off the ground	May need to move to get enough sensory input – rock, swing or spin

## **Practical Strategies**

#### A person centred approach

Taking the time to get to know the person, what is important to them and for them is key to ensuring they have a positive experience on and off the water.

Remember it is important to have discussions about what an individual needs in a safe and private environment. People don't want to stand out so offer reassurance that they will be welcomed and the activity is suitable. If need be, and the person is OK with it, talk to others who know the person well.

A conversation can help you gather helpful information and find out

- What people appreciate about the person?
- What is important to them and for them?
- How to support the person?

The prompts below are from a sailor's perspective.

#### Ask me

- How I communicate, make choices and learn?
- What is the best way to give me key information?
- How you will know I am listening and engaging?
- How you will know if I need a break?
- About anything that may impact on my ability to communicate on the water –
  you may need to tell me about the sounds, the smells, and the activities I can
  expect
- What is important to help me plan the day and know what's next?
- Whether anything impacts on how I perceive risk?
- How I experience and feel pain and extremes of temperature?
- How I see and hear and how this might be affected on the water
- About my balance, spatial awareness and awareness of where my body is in space?
- How you will know if I am hungry, thirsty, in pain or not feeling well?
- About my sensitivity towards touch, taste and smell?

#### Come up with a plan for me to:

- Get familiar with:
  - o the boat and the equipment I will need to wear
  - the controls for steering and the sails
- Get in and out of the boat, and my mobility and balance once in the boat
- Avoid dehydration, keep up my energy levels and deal with any noise
- Prevent stress and anxiety, for you to know if I am becoming over anxious and how you can help

#### Tips for getting it right

Remember, what works with one person may not work with another, and what works one day may not work the next. Treat everyone as an individual, every day, and ask what the person will find most helpful. But the following tips may help.

#### Communication

- Speak slowly, calmly and clearly, with light cheerful speech don't shout
- Use my name first repeat instructions to me without re-wording
- Check sensitively if I have understood instructions given to a group
- Simplify language and reduce sentence size.
- · Use language that is clear, precise and concrete
- Make the end goal or purpose clear but...
- You may need to give instructions one at a time and break them down
- Reduce the number of steps needed to achieve success early and add in more steps as my confidence and competence builds
- Give me time to process information
- If I am not looking at you, don't assume I am not listening don't insist on eye contact
- Avoid irony and sarcasm
- Avoid relying on too much body language and facial expression
- Use visual aids or pictorial cards to back up communication
- If you use humour don't forget to smile
- Offer clear choices

#### Social interaction

- · Be gentle and kind
- Be patient
- Invest in me for the long term it will take me time to feel secure, develop trust and build rapport with others
- Don't assume I can see things from your point of view
- Don't assume I am disinterested just by the tone of my voice
- Give me reassurance and positive feedback
- Celebrate my strengths and successes
- Don't assume you can touch me let me know it may happen

Don't assume that I will socialise during breaks and unstructured times

#### Flexibility of thought

- Explain clearly what the plan is for the session / day use visual support
- Use visual planning tools and pictorial boards
- Avoid questions like "What can you do differently next time?" and asking me to imagine possible outcomes
- Avoid problem solving scenarios provide specific answers and information
- Demonstrate one step at a time break tasks or sessions down
- Don't generalise be specific
- Allow time –I may need to get familiar with the venue, the boats and sailing clothing first. It may take me days to achieve what others do quickly
- Try to avoid too many big changes and prepare me for upcoming change
- Teach skills and concepts in context, in the place where I will be practicing
- Describe new situations outline how and why people may react and explain why people may be feeling a certain way
- Explain the rules and any 'grey areas' within the rules

#### **Sensory sensitivities**

- Be aware of my sensory sensitivities and how the boating environment may impact on me – work out what you can change
- Think of positive sensory experiences and build these into the session, introducing them slowly if needed to give me time to de-sensitise
- Allow me to use equipment that helps me manage my sensitivities for example, ear defenders
- Prepare me for what the sailing environment is going to be like noises, smells, sights, balance, and body movement.
- One person talk to me at a time
- Encourage activities that use movement around the boat
- Break tasks and activities down into small, manageable steps use visual clues
- Control noise from flapping sails, shrouds and engines
- Use coloured tape to indicate where I need to move to in the boat, or safe places for me to be.
- Colour co-ordinate ropes and controls

- Use visual supports to back up verbal information
- Gently warn me if you are about to touch me

#### Stress and anxiety

- Recognise positive behaviours and when I am happy praise achievements but be aware of generalised praise. What does 'good job' mean?
- Offer tangible evidence of achievements and good work
- Recognise when stress and anxiety is being communicated
- Be neutral when dealing with negative behaviours don't personalise it
- Be consistent, stick to the rules you set and provide predictability
- Don't make promises you can't keep
- Remind people what they should be doing
- Use problem solving phrases
- Allow people to have a break

#### "Treat everyone as an individual. Everyday".

#### Tools for improving the communication environment

- Use symbols, pictures, photos, and video to support communication and meaning
- Sequence information with visual timetables to get across what is going to happen in a particular timeframe or to breakdown the stages on how to complete a task
- Use portable choice boards to introduce regular opportunities to choose, link cause and effect, establish rapport and develop dialogue
- Produce **social stories**™ to introduce a new situation, outline how and why people may react in different situations and explain why people may be feeling a certain way.
- Use what to expect videos or leaflets beforehand, signs to help new
  participants find their way around whether they are new to a venue or not, and
  name badges where people may be anxious around unfamiliar people and
  where a good rapport is needed quickly

"A young autistic girl had come to a group for a few years and enjoyed it. A new volunteer went up to her and said "hello Rebecca, are you ready to sail". This made Rebecca extremely anxious - a 'stranger' knew her name and she didn't know his."

For more information about these tools see the RYA's "Improving the Communication Environment". Download from Club Zone on the RYA or at the Training Support site

www.rya.org.uk/the-club-zone/Pages/inclusion-equality

www.rya.org.uk/training-

support/Documents/Improving Communication Environment%20v1.0.pdf

### **Autism related sailing projects**

RYA Sailability - Find your nearest place to get on the water

Where's my nearest

Autism on the water - <u>www.autismonthewater.co.uk</u> | <u>www.facebook.com/autismonthewater</u>

#### **Further information**

National Autistic Society - autism.org.uk/about

Positive Autism Support and Training - positive Autism Support Autism Suppo

#### **Sources**

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## Notes







