

Supporting Swimmers with Down syndrome

**Toolkit for Coaches, Swim Teachers,
Parents and Carers**

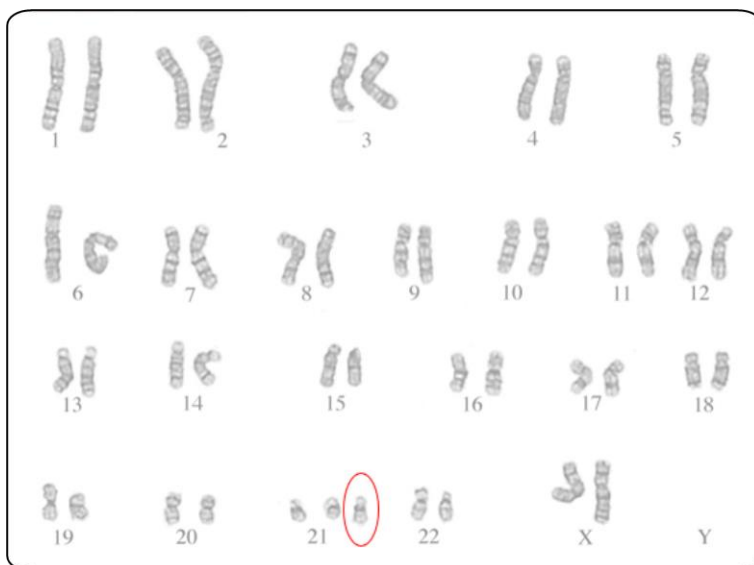




**DOWNSYNDROME
SWIMMINGGB**

What is Down syndrome?

Down syndrome is a genetic condition caused by the presence of an extra chromosome 21 in the body's cells. It is not a disease.



There are 3 types of Down syndrome:

- **Trisomy 21** occurs when every cell in the body has three copies of chromosome 21. This is the most common form of Down syndrome and accounts for approximately 95% of cases.
- **Mosaic Down syndrome** is characterised by a mixture of cells, some with the usual two copies of chromosome 21 and some with three copies. It occurs in around 2% of cases and symptoms can vary depending on the number of cells with the extra chromosome 21.
- **Translocation Down syndrome** occurs when the extra chromosome 21 is attached to another chromosome. This type of Down syndrome can be hereditary.

Everyone with Down syndrome is unique!



- People with Down syndrome are not all the same.
- Everyone with Down syndrome has a degree of:
 - Learning disability
 - Physical impairment
 - Health issues
- This does not mean they cannot learn, especially learn to swim!



“a person with Down syndrome”
OR
“a person who has Down syndrome”

When talking about a person with Down syndrome it is very important that the person comes before the condition.

Strengths

- Good visual memory.
- Keen to communicate despite language difficulties.
- Desire and ability to learn from peers.
- Able to learn from & use sign, pictures, written word.
- Thrive on structure and routine.
- Good episodic memory.
- Kinaesthetic/hands on learner.
- Learn best from pictorial, concrete and practical material.



Implications

- Learn best from watching and doing.
- Want to be part of the group.

Factors that inhibit learning

- Poor short term auditory memory.
- Impaired motor skills – gross and fine.
- Auditory and visual impairment.
- Poor generalisation skills.
- Speech and language difficulties.
- Avoidance strategies.
- Short attention span / easily distracted.
- Consolidation and retention of new skills is problematic.



Implications

- Learning from listening is difficult.
- Consistently inconsistent.

Health Issues

- Visual impairments.
- Higher chance of gastrointestinal tract or cardiac problems.
- Poor immune system.
- At risk of neck instability.
- Low muscle tone and lax ligaments.
- More respiratory illnesses like coughs and colds.
- Higher incidence of hearing impairments.
- Higher chance of Thyroid disorders.



Implications

- More hospital appointments. More illness during early years.
- Likely to miss more sessions due to ill health.
- Tire more easily - likely to be less streamlined in the water.
- Slower to perform physical tasks and perform in less coordinated way.
- Slower with changing and managing equipment.

Strategies to support hearing impairment



- Hearing aids cannot be worn in the pool so need to use visual aids or/and sign language. (Makaton/Signalong)
- Can use bone conductor headphones.
- Swimming pools are not good hearing environments due to background noise. Cue swimmer in and make sure they can see your face before communicating.



Things to know

- 60-70% of children are affected by glue ear. Hearing can fluctuate day to day but worse in the winter months.
- 20% of people with Down syndrome have sensory neural loss caused by defects/damage to auditory nerves.
- Many children and adults will use a hearing aid, softband aid or bone anchored hearing aid (BAHA).

Strategies to support visual impairment



- Many people wear glasses, prescription goggles may help.
- Have the person's glasses to hand on poolside if needed.
- Allow extra time if swimmer finds it hard to switch focus from far to near.
- Have bright coloured focus points like equipment/toys to help switch focus.



Things to know

- 5-8% of typical children of primary school age need glasses whereas approximately 60% of children with Down syndrome need them.
- Poor focussing affects 75% of children with Down syndrome.
- Reduced detail vision affects all children and adults with Down syndrome even if they wear glasses (Acuity).
- Some people find walking up/down slopes and stairs and changes in texture/colour of flooring difficult (Depth perception).

Strategies to support physical difficulties



- All motor skills improve with practice and repetition so provide lots of opportunity to practice.
- You may need to show how to hold the swim equipment correctly.
- If you have permission, guide arms or legs to support muscle memory to kick or pull.
- Be patient, technique takes time.
- Have high expectations.
- Swimmer may need help/extra time to get onto blocks.

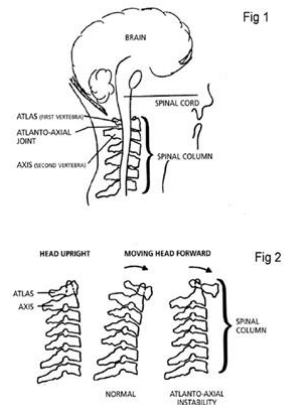
Things to know

- People with Down syndrome are generally short in stature, with short limbs and fingers, a small oral cavity so their tongue may seem large and a flat back of head.
- All gross and fine motor skills are affected. People have low muscle tone and loose ligaments with a poor messaging system between brain and muscles (slow reaction time).

Neck instability (AAI)



- The joints at the top of the spine and at the base of the skull allows us to shake and nod our heads.
- In people with Down syndrome, the ligaments, are stretchier, so joints may be looser and more flexible which can lead to slippage of the vertebrae; these are the bones that surround and protect the spinal cord.
- Problems can develop if a vertebra slips too far and puts pressure on the nerves in the spinal cord. This can be a gradual process or it can happen if a person is jolted suddenly such as when a whiplash injury occurs.
- In people with Down syndrome, the most common place for this slippage to happen is at the first and second vertebrae of the neck (known as 'atlanto-axial instability').



Discussion with family about attitude to risk is very important, especially when teaching the swimmer to dive.

In the unlikely event of a swimmer losing consciousness, care should be taken when handling/moving the swimmer to prioritise neck stability and spinal cord safety. Ensure the head and neck are supported in a neutral position, avoiding hyperextension or excessive flexion.

If you would like any further information on Neck instability, please visit the Down's Syndrome Association's website.

<https://www.downs-syndrome.org.uk>

Strategies to support speech and language



- Say the person's name first – cue them in.
- Allow time to process, up to 10 seconds.
- Use shorter sentences and emphasise key words.
- Total Communication – facial expressions, eye contact, tone of voice, body language.
- It's ok to say you don't understand. The more you listen, the more you will understand.
- Use laminated pictures, symbols, schedules.
- Use sign and gesture.
- Ask others to demonstrate.
- Tell the person what you want them to do, not what they shouldn't do.
- Use the same vocabulary to name activities – continuity is key!



Challenges

- Learning from listening.
- Coping with long sentences.
- Understanding new vocabulary.
- Word finding.
- Forming sentences.
- Speech articulation.
- Understanding instructions.
- Thinking and reasoning.
- Poor generalisation.
- Weak comprehension skills.

The person's expressive language and receptive language may not match. Some people understand more than they can say; others may speak well but not understand everything they hear.

Strategies to support communication



- Check with parents/carers what communication supports the swimmer's needs.
- If they use sign, the swim teacher/coach would benefit from learning a few basic signs such as: again, fast, slow, wait, toilet; for example.
- If the swimmer uses an electronic communication aid, a waterproof cover will need to be used.
- Picture cards can be laminated and added to a lanyard.



Things to know

- Sign, such as Makaton or Signalong, is widely used to support communication with people with Down syndrome especially as children. As their spoken language improves, they will often drop signing but for some adults this remains their means of communicating.



Strategies to support short term auditory and working memory



- Reinforce verbal input using visual and multi sensory strategies – pictures, photos, signing, print, objects, demos etc.
- Limit amount of verbal instructions.
- Chunk instructions or skills into smaller pieces.
- Repeat verbal input given to whole group individually.
- Give time to process and respond to verbal input – 10 sec rule.



Things to know

Auditory memory:

- Weak consolidation and retention skills.
- Difficulty memorising lists, retaining instructions, learning new vocabulary.
- Difficulty transferring recently learnt information/skills to long term memory.

Strategies to support attention span



- Cue swimmer in, get their attention.
- Chunk instructions/new skills into small steps.
- Make the swimming activities fun – use their interests!
- Plan transition between activities.



Things to know

- Short concentration span.
- Difficulty staying on task.
- Difficulty multi-tasking.
- More distracted by other factors.
- Tire more easily.



Strategies to support behaviour

Things to know

- Behaviour can be positive, helpful and useful but it can also be problematic.
- Behaviour is a very effective form of communication.

Functions of behaviour:

- Expressing pain or emotion.
- Meeting a sensory need.
- To initiate or maintain social connection/interaction.
- To avoid social interaction/attention.
- To get something/to avoid something.

People with Down syndrome are very vulnerable to acquiring inappropriate behaviour.

People with Down syndrome are not stubborn.

In order to see a change in behaviour we almost always need to make a change in our own behaviour.

**Behaviour serves a purpose –
What is the person trying to tell us?**

Strategies to support behaviour

- Build a positive relationship.
- Teach swimming lesson rules – reinforce these visually.
- Be firm but fair – Be consistent – Have high expectations.
- Look at what the person is trying to communicate to you.
- Follow a routine or structure, use visual checklists/prompts.
- Make the person feel safe when introducing something new – ensure they experience success.
- Praise – notice the good behaviour.
- Allow swimmer to make choices.
- Boost self-esteem by giving a job.
- Predict difficulties before they happen.
- Redirect - use distraction.
- Provide opportunities for the swimmer to be successful.
- People will keep doing something in a particular way because it is safe, familiar and has worked in the past – don't dig yourself a hole!

Sensory Processing Disorder



The body's eight basic sensory systems work together to provide the brain with the means to perceive, process and react to sensory stimuli and information from outside and inside your body. Sensory processing disorder is a neurological disorder that results from an inability to manage and integrate the information received.

Hypersensitivity – over aroused

- Avoids textures and messy hands.
- Life is too loud, too bright, too fast, too much.
- Rigid about routine.

Hyposensitivity – under aroused

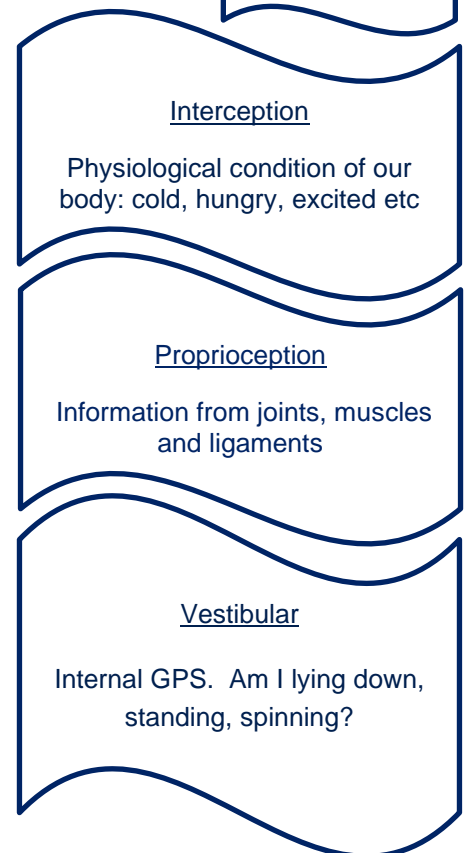
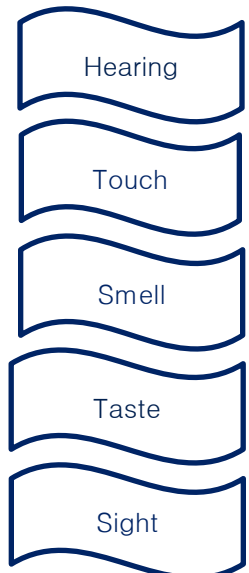
- May not notice being touched, clumsy, heavy handed.
- Doesn't initiate activities.
- Can be passive and in their own world.

Sensory craving – seeking out, often over aroused

- Seeks out movement, frustrated, intense,
- Has to be the boss, struggles with transitions, waiting, taking turns.

Impact in the pool:

- Some swimmers, especially younger or new swimmers, may have difficulty tolerating cold water.
- Swimmers may not be aware that they are getting very cold and are at risk of hypothermia.
- Swimmers will benefit from reminders to drink during longer sessions.
- Swimmers may find it difficult to manage lots of other people in their lane; their awareness of where they are in the lane in relation to other people will be impaired.
- Judging distance and speed in themselves and others is impaired.

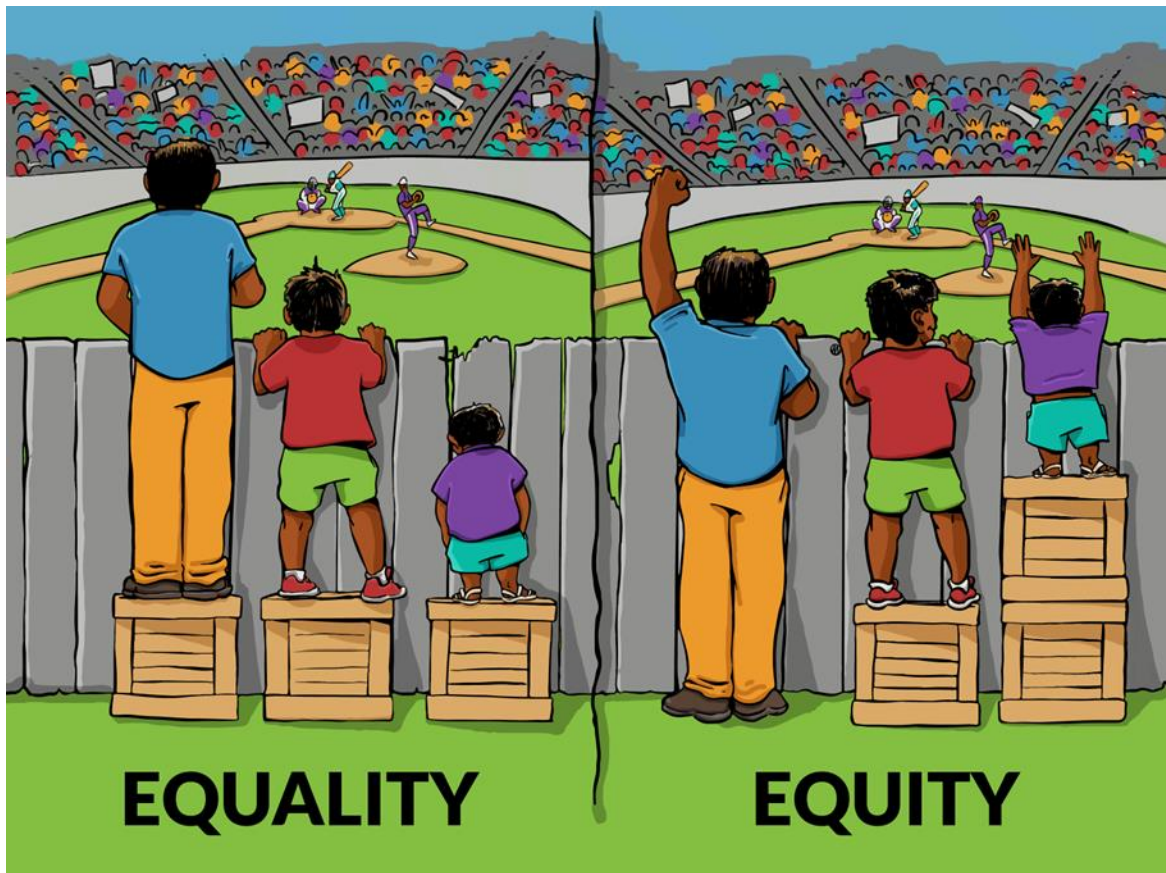


Benefits of differentiation



**DOWNSYNDROME
SWIMMINGGB**

- Swimmers will benefit from differentiation within all session planning.
- Some adjustments will need to be made for the swimmer to make progress.



Key things to remember

- Be confident, enthusiastic and patient.
- Use a structure/format that you follow each week.
- Use your communication skills.
- Have a plan – use visual prompts.
- Use the parent/carer's knowledge of the swimmer.
- Offer choices.
- Regular changes in activity/pace.
- Label routines/activities.



It's really important to have the same, high expectations of attainment and behaviour as the other swimmers in the group.

There is no 'ceiling' on the attainment of skills; learning new skills continues throughout life.

Resources



Down Syndrome Swimming Great Britain

<https://dss-gb.org>
teammanager.dssgb@gmail.com
teamcoach.dssgb@gmail.com
members.dssgb@gmail.com



Down's Syndrome Association

<https://www.downs-syndrome.org.uk>



Down Syndrome International Swimming Organisation

<https://www.dsiso.org>



Atlanto Axial Instability

https://www.downs-syndrome.org.uk/wp-content/uploads/2024/07/16.07.20204_Neck-instability-v9.pdf?_gl=1*182sedl*_up*MQ..*_ga*MTYzMTA1MDY0MS4xNzQwNjY0MjQ5*_ga_GBWXYZMYBW*MTc0MDY2NDI0OC4xLjEuMTc0MDY2NDM4MS4wLjAuMA..

Learning sign

App: MyChoicePad

<https://www.makaton.org>