

Understanding Behaviour Series



Using Positive Behavioural Support as a model of change with people who have Down's syndrome

Our Resources and Information Team are here to help

Please see our website for up-to-date information: www.downs-syndrome.org.uk
If you would like to talk about the activities or where to start, then please get in touch with our helpline by calling 0333 1212 300 or by emailing us on info@downs-syndrome.org.uk.

Helpline Monday - Friday 10am-4pm | Telephone: 0333 1212 300

Behaviour

Behaviour refers to everything that people do.

We all react to situations and communicate through our behaviour. For people who have difficulties with other forms of communication, behaviour can be the most effective form of communication.

To call something behaviour you need to be able to see it, count it and describe it.

A behaviour (running out of the building) is different from an emotion (feeling scared) and different from a thought/motivation "get me out of here!"

A behaviour is a problem when it is limiting a person's life. Perhaps it is preventing them going to places, socialising, learning and forming relationships with other people. It might be causing harm to them or others around them. Expectations around our behaviour change with age and in different settings. For example, it is fine to run around and kick a ball outside in the playground or garden but not in the classroom.



Behaviour is a form of communication

This booklet will look at how to understand problem behaviours as well as how we can manage and change.

Down's syndrome and behaviour

This quote by David Stein is an important one to keep in mind.

'Most people with Down's syndrome want to be successful behaviourally and make other people happy.'

So why are behaviour issues common in children who have Down's syndrome ranging from minor to very challenging?

There are several reasons for this:

The brain

Learning and retaining information is an area that is different for people who have Down's syndrome and new information is not transferred into their long-term memory and stored as easily or consistently. This means that they tend to learn best by repetition and so routines are very important in understanding their world as well as reducing anxiety.



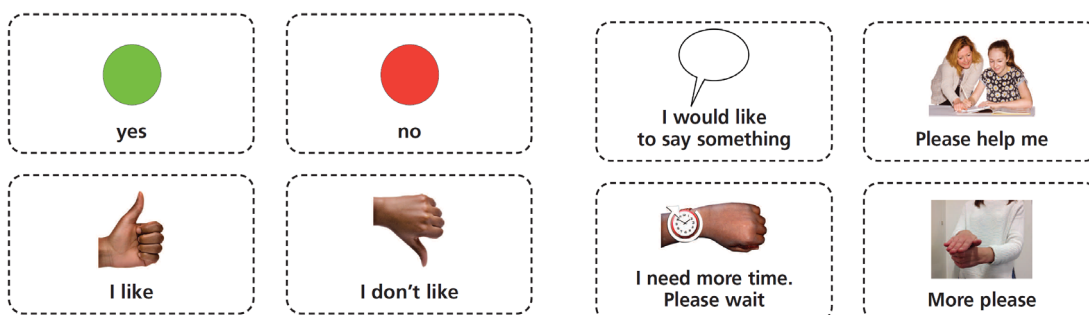
How we learn

There are many ways that people learn new information and quite often people have a strength in a particular one.

These are four commonly identified methods.

- Verbal instruction
- Reading
- Watching
- Doing

People who have Down's syndrome usually have a strength in processing visual information and so will benefit from verbal information being supported with visuals.



Language

A person who has Down's syndrome will usually be stronger in receptive language (understanding) than expressive (verbal) language skills. This can lead to frustration when they can understand but are not able to tell people what they need or want.

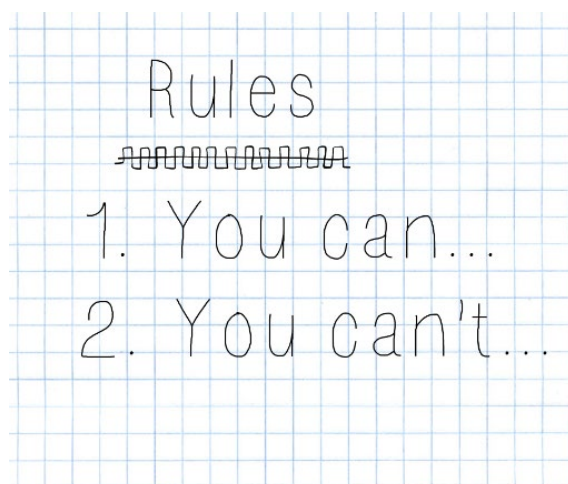
Executive functioning

This is our ability to plan, organise, sequence, remember etc. and is another area that may be weaker in people who have Down's syndrome. This may lead to people needing more time to understand and respond. This part of the brain is also responsible for impulse control.



Understanding the rules

Understanding the rules can be tricky unless the rules are explicitly taught. We sometimes expect children to pick up the right behaviour automatically, but this may not happen.



Common behaviours

The following behaviours are commonly reported.

Stop and Flop or Refusal

This could be dropping to the floor but not always. It is a very common behaviour reported by parents and schools and is more usually seen in younger children.

Running/Bolting

Again, this behaviour tends to be more common in younger children and usually involves a child running away either from or to something.

Hitting/Kicking/Throwing

This could be directed at people or objects.

Stimming (self-stimulatory behaviour)

This includes movements or noises and not problematic in itself unless interfering with engagement in life.

The Groove

Having some sameness, repetition and order helps people to learn particularly as it may take longer for things to be retained in long term memory. At times this need for sameness and routine may tip into becoming problematic and become excessive slowing down, inflexibility or hoarding. It is important when introducing new routines to do so slowly and with sufficient preparation.

Self-Talk

This can increase with age and is more commonly seen in teenagers. In itself it is not a problem as it may be used as a way of processing the day. It may become problematic if it starts to interfere with engagement in everyday life.

Withdrawal

A behaviour that can also increase in teenagers is withdrawal.

You may be seeing one or all these behaviours used by the person you support.

This is not an exhaustive list and there will be other behaviours that may occur that are not mentioned here.

In this booklet we are exploring the importance of why the behaviour is happening rather than just trying to stop it.

Behaviour Learning Theory

Here are some basic principles around managing behaviour:

- Do not reinforce (reward) the behaviour we don't want to see.
- Reinforce the behaviour we want to see.

There are two types of reinforcement

- **Positive** – adding something
- **Negative** – taking something away

Positive reinforcement: adding something such as a reward when desired behaviour is seen

Negative reinforcement: encouraging a desired behaviour to repeat in the future by removing or avoiding something unwanted



Positive Behavioural Support (PBS)

A model for understanding behaviour

PBS is a person-centred way of supporting people who have a learning disability using the principles of behavioural analysis.

It is a collaborative approach that involves focussing on all that is positive whilst keeping the person's needs at the heart of all discussions, thinking and planning.

The person at the centre of this approach is viewed as an individual who is so much more than a problem behaviour.

Developing and building skills for both the person and those around them is key. It is primarily a proactive approach to behaviour. However, if reactive strategies are required, these should be strategies that are the least restrictive in terms of the person's general freedoms and well-being.



Setting

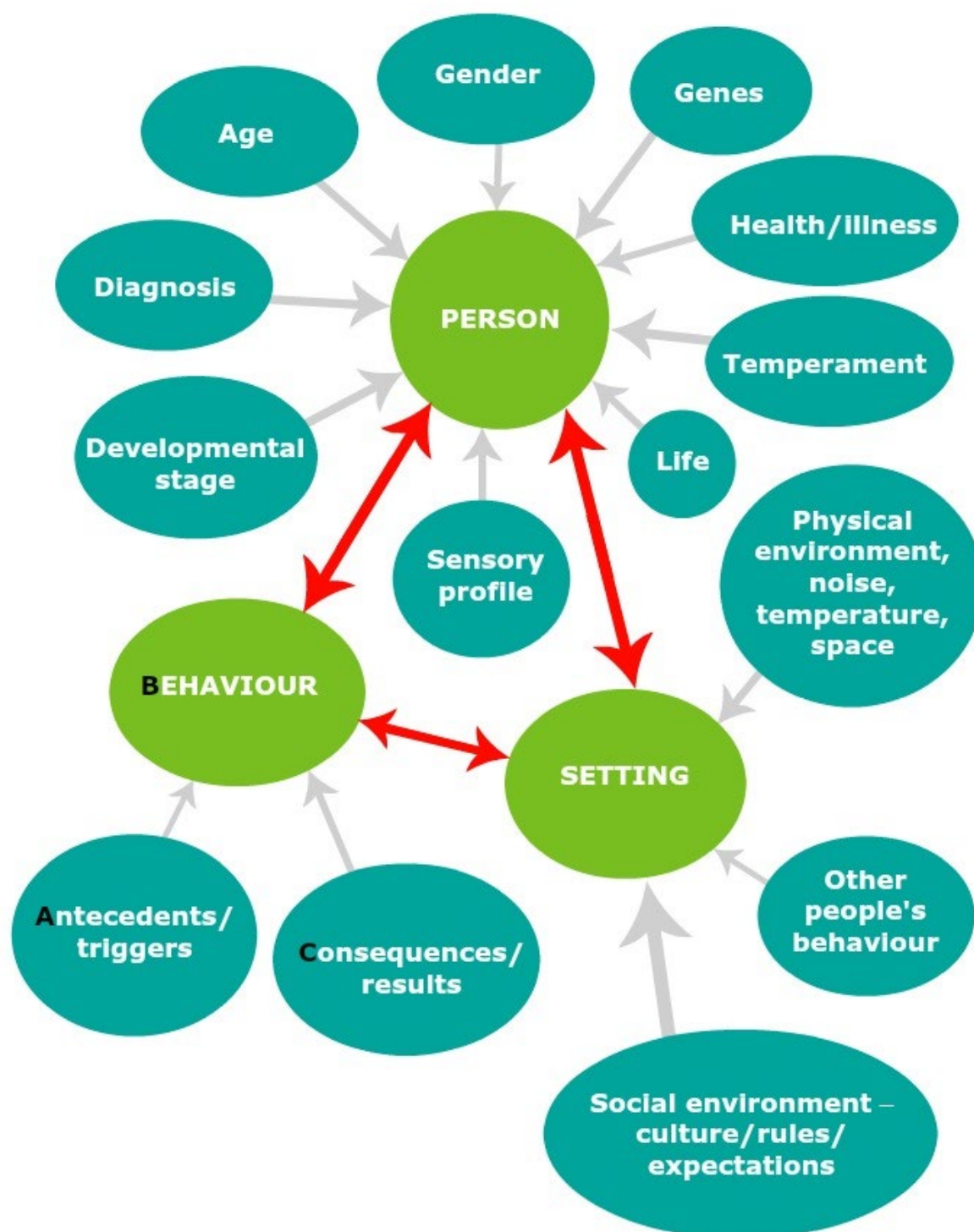
An important part of understanding behaviour is to look at the **environmental factors** and by this we mean more than the physical environment.

We need to look at other people and their behaviour including ourselves as a supporter and consider the rules and expectations and whether they are realistic and consistent.

Is the environment set up in such a way for success?

What we view as inappropriate behaviour may occur for the first time by chance or by imitating others.







On the following page is a diagram that illustrates many factors that need to be taken into consideration when looking at behaviour.



Functions of behaviour

It is helpful to find out what the person is getting from the behaviour and this might not be what you think.

These are some common functions

Pain or expressing emotion	
Sensory	
To get or maintain social connection/interaction	
To avoid social interaction/attention	
To get something	
To reduce demands	

This is not an exhaustive list and there may be many more.


It is a case of being a detective.

How to work out the function – easy as ABC

A good starting point can be to keep a record any time the behaviour/s occur/s as this can help to build up a picture of time/frequency/triggers.

- **A**ntecedents (triggers)
- **B**ehaviour
- **C**onsequence

ABC charts and scattergrams can help to build up a picture.



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ABC Record

Name: _____

Date: _____


	<u>Antecedents</u>	<u>Behaviour</u>	<u>Consequences</u>
Date Time of day	<ul style="list-style-type: none"> What happened just before? Contributory factors? Who? Where? What situation? 	<p style="text-align: center;"><i>Accurate description of the behaviour</i></p> <p style="text-align: center;"><i>How long did it last?</i></p>	<ul style="list-style-type: none"> What did you or others do? (ignore, discuss?) How did you react? How did the person react? What happened after?

Supporting people with Down's syndrome throughout their lives

Behaviour recording – please insert an x when target behaviour occurs Target Behaviour: _____

Date	M	Tu	W	Th	F	Sa	Su	M	Tu	W	Th	F	Sa	Su	M	Tu	W	Th	F	Sa	Su	M	Tu	W	Th	F	Sa	Su
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One behaviour can serve many functions and many behaviours can serve one function so it can also be useful to complete the Communicative Function Questionnaire to get a better idea of the function.

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Communicative Function Questionnaire

Name: _____ Date: _____


Description of the behaviour of concern

1. How often does the behaviour occur (several times a day, daily, once a week)?






2. How long does the behaviour last?

3. How severe is the behaviour?

4. Does the behaviour occur in clusters/phases, or more sporadically?

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Analysing reasons (functions) for behaviour grid

To see if behaviour is maintained or strengthened by.....	Look at the answers to questions number.....
Social attention? 	7, 8, 12, 17
Sensory needs? 	9, 6, 13, 20
Getting things? 	11, 12, 17, 18
Escape/avoidance? 	15, 11, 12, 16
Express emotion? 	15, 11, 12, 16
OTHER e.g. pain, difficulty with change, lack of understanding, need to be in control?	14, 4, 6, 16

A link to the [full questionnaire can be found on the DSA website](#).

Managing Change

When looking at changing any behaviour it is important to prioritise relationships.

Maintaining a positive relationship with your child/the person you care for is the most important thing and should come above any behavioural intervention. The connection you have and ensuring you have some good times will ultimately help in motivating behaviour change.



Consistency

When we are working with a behaviour it is important that everyone is consistent.

Using Visuals

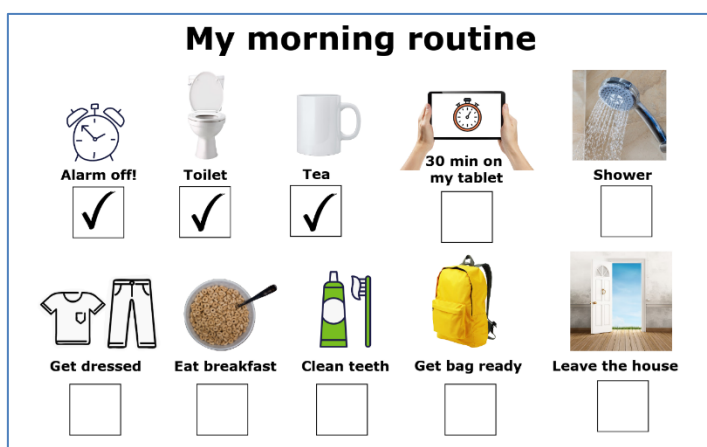
Visuals can be used in a variety of ways. Even when a person is verbal and appears to understand everything, visual support is always helpful, it taps into strengths and can bring clarity to the language which needs to be processed.

Visual timetables provide structure and consistency in a way that can reduce stress for both the person and the care giver. We also know that at times of stress visuals offer much needed support.

Visuals can help with making choices particularly at times when decision making is difficult.

Visual cards can be used to let others know what is wanted

Visuals can also be used to support with teaching new skills. We sometimes assume that a child is going to pick up skills without being taught and although this may happen, it should not be presumed with children who have Down's syndrome.



Using Stories or Videos

These are a great way of teaching a new skill in an engaging way. The idea is to create a story possibly with personalised text and visuals or make a video that will show the person what happens in a particular situation. Family members or school staff can be filmed doing a task although the most effective way of using video is for the person themselves to be completing the activity or task.

Videos are also great for introducing new people and places.

Noticing the Good

Too often we focus on negative behaviours, and we tell someone what we don't like and the behaviour we don't want to see without telling (or even better showing) them the behaviour we do want to see.

We ignore all the positive behaviour and focus on what is wrong. When we pay a lot of attention to behaviours that are a problem, we may end up rewarding the person through our attention.



Using a Token Economy (Reward system)

This simple system of rewarding positive behaviour can be very effective. It should be simple and easy to put in place and it will hopefully reinforce the positive behaviours we want to see. It is a really effective way of noticing the good!

About rewards:

- Can be anything – be creative!
- Avoid food or buying things
- Think about what motivates the young person
- Should be enjoyable
- Think about frequency
- Show appreciation when person makes progress

Below is a simple example of a reward chart.

I am working for...

I am working for...

Or it could be combined with a routine and look something like this:

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Simple visual guide			
Hold Nanna's hand	Wear my Coat	Stop and wait to cross the road	Have a hot chocolate when I get home

Proactive strategies

Predicting difficult situations before they happen is key to this approach.

If a person is using a behaviour to avoid something then perhaps it is about the work or demand being too much and so reducing the demands or simplifying may be enough.

Perhaps the behaviour is a way of being removed to a quieter environment or because they need some one-to-one time. It can be helpful to build this in on to a visual timetable. This could be both at school/college and at home.

Imagine feeling tired and overwhelmed and not understanding when an activity/lesson is going to end? Visuals and timers can help with this or introducing more breaks.

If a person has delayed impulse control (due to developmental delay), understanding this area of need and providing support proactively will help.

It is important to work out the function of the behaviour first (as previously mentioned) as the same behaviour may have very different functions.

Scenario 1

A child throwing his iPad on the floor

The function was to say that they had finished with it

Teaching new skill – parent created a story of what to do when the child had finished using the iPad. The throwing behaviour was replaced with putting the iPad in a designated place

Throwing stopped – there was no reward required as the child simply needed to be taught what to do.

Scenario 2

A child is pulling other children's hair at school

Function is wanting to play with them

Teaching new skill – creating a card that she can use to give to children or an adult when they want to play

Reward given whenever they use the card. The reward could be praise or an extra minute playing.

Reactive strategies

In some instances, a simple redirection will be enough.

Redirection is a prompt or cue to engage in a task so that a reward can be given.

Your message is 'do this instead' and the purpose is to encourage participation.

It communicates that behaviour, which previously stopped interactions or gained inappropriate attention, is no longer effective.

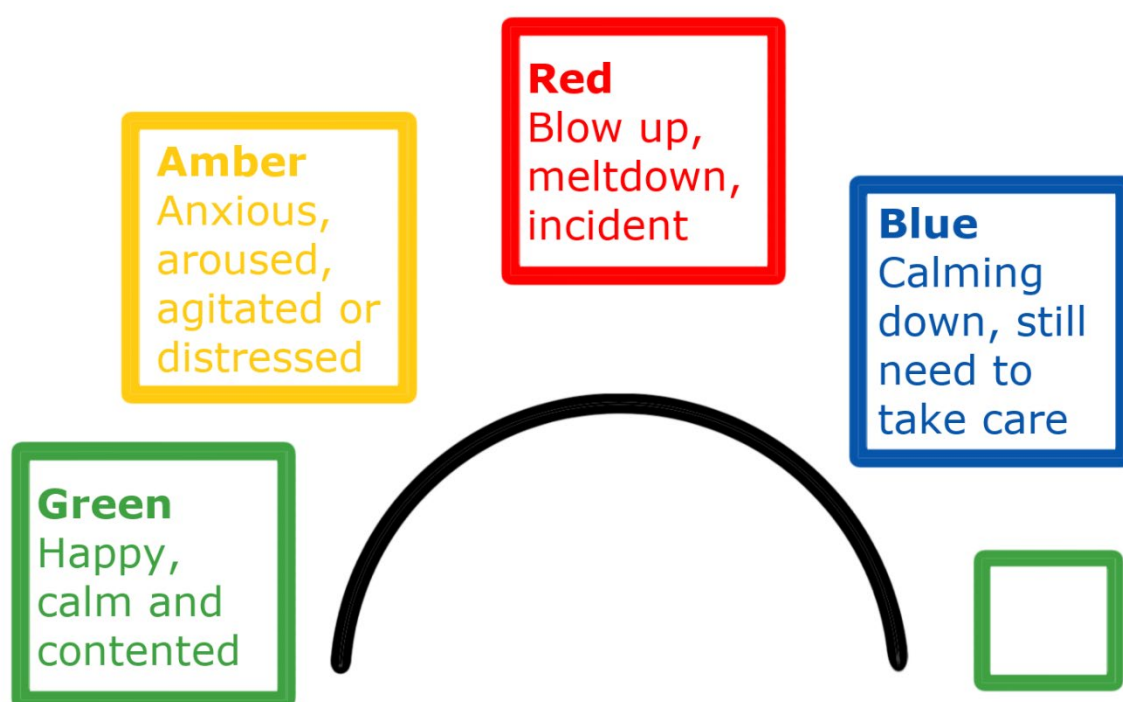
It breaks the unhelpful patterns of interaction and defuses the power or effect of unwanted behaviour.

The Arousal Curve

At times the behaviour is because they have tipped into what we call fight/flight mode or the Red box as seen in the diagram below.

When a person is in the Red box there is no redirecting, reasoning, and calming without time and space to do so. This is because the body releases a lot of chemicals that need to have chance to be processed.

Part of what we want to do is to prevent the person reaching the top of the curve, the Red phase. Once someone has reached Red we can only react to a behaviour. What we want to do is recognise when someone is at Amber and look at how we can help them return to Green.



The ideal situation would be for us all to stay within the Green box and we will look at what might help, however there are times when we move to Amber and at this stage there is still an option to move back to Green if we recognise the signs/triggers.

Case studies

Case Study 1

A 6-year-old girl hitting out at children and adults

Where and when

At school

Frequency

Every day, once or twice a day towards the end of a particular lesson

Problem

Causing anxiety for the other children and adults, limiting positive interactions

Possible Functions

Letting people know had enough of activity/Seeking 1:1 Connection

Proactive Strategies

- Teaching new skill – how to communicate he has had enough
- Introducing card to give when ready to finish an activity
- Visual timetable with 1:1 time built in
- Introducing reward when doesn't hit

Reactive Strategies

- Stay calm
- Don't turn into a drama, don't show emotion
- Pay attention to the person who has been hit
- Give clear instruction

Case Study 2

5-year-old boy running away

Where and when

At school and in the community

Frequency

At least once a week

Problem

No sense of danger and may get hurt

Possible Functions

Running away from something

Running to something

It's fun

Likes the reaction of people

Lack of impulse control

Proactive Strategies

- **Teach skills – use cards**
- **Hold hand or use reins**
- **Lock doors/move handles**

Reactive Strategies

- **Extinction – stay calm, don't chase after, no emotion**
- **If do have to chase, only minimal input**

BEHAVIOUR	FUNCTION	PROACTIVE STRATEGY
Overly focused on playing video games in bedroom for hours	Processing/Winding down Escape/Avoidance Sensory Wanting independence	Setting limits Negotiation – ground rules Environment More structure
Excessive self-talk	Expressing emotion Processing	Ground rules – collaboration Limiting Visuals
Dropping to the floor	Escape/avoidance 'I have had enough' Tired Social attention Don't want to stop/move	If the work is too hard – Simplify More support Offering more opportunity for interaction or breaks Timetable/routine
Physical aggression	I want something Expressing emotion Seeking social interaction	Replacement – teaching new skills/visuals Expressing emotions Picking up anxiety earlier and putting in strategies More structure

Teenagers

In teenage years we may see new behaviours that impact:

- Wanting to spend more time alone
- More self-talk
- Imaginary play
- Repetition such as watching videos over and over

Go back to basics – what is the function?

Be flexible

Strategies

Many of the same strategies will still work and knowing the rules is still crucial

Visual schedules on smartphones/tablets can be helpful and rewards can still be great motivators

DSA resources

ABC Chart: [downs-syndrome.org.uk/wp-content/uploads/2020/09/1b.-ABC-chart-blank.pdf](https://www.downs-syndrome.org.uk/wp-content/uploads/2020/09/1b.-ABC-chart-blank.pdf)

Scattergram: [downs-syndrome.org.uk/wp-content/uploads/2022/03/Scatter-graph-recording-sheet.pdf](https://www.downs-syndrome.org.uk/wp-content/uploads/2022/03/Scatter-graph-recording-sheet.pdf)

Communicative Function Questionnaire: [downs-syndrome.org.uk/wp-content/uploads/2020/09/2a.-Communicative-Function-Questionnaire_noboxes.pdf](https://www.downs-syndrome.org.uk/wp-content/uploads/2020/09/2a.-Communicative-Function-Questionnaire_noboxes.pdf)

Other resources

David Stein *Supporting Positive Behaviour in Children and Teens with Down's Syndrome*

The Down's Syndrome Association provides information and support on all aspects of living with Down's syndrome.

We also work to champion the rights of people with Down's syndrome, by campaigning for change and challenging discrimination.

A wide range of Down's Syndrome Association publications can be downloaded free of charge from our website.

Contact us

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Activities for people
with Down's syndrome

www.dsactive.org



www.dsworkfit.org.uk



www.langdondownmuseum.org.uk

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