



# Anxiety Related Absence A guide for practice

# **Anxiety Related Absence: A guide for practice**

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# Introduction:

This guide is intended for practitioners supporting autistic children and young people who are anxious about attending school, and their families. The information may also be useful to families looking for ways to understand why their child is anxious and think about approaches which might help.

The information is relevant for individuals with existing anxiety related absence prior to COVID-19 and also where this is newly emerging. Traditional approaches to understanding and supporting anxiety have commonly been found to be ineffective in resolving this experience in autistic learners.

Throughout this guide we take the 'social-pragmatic' perspective that autism is lifelong and meaningful support occurs best in naturally occurring environments of home, school and the community, rather than through interventions delivered individually or in groups outwith everyday contexts. The responsibility for changing does not lie primarily with the child or young person but with those around them.

The guide highlights the mindset with which we can approach autistic learners, the importance of considering the 24 hour life of the child/ young person and family and some key things that can be put in place at any stage, whether recognising early signs, or whether this is an entrenched problem.

The guide includes reflective questions and ideas for further professional learning.



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# Understanding anxiety related absence

# How this guidance was developed

This guidance has been developed through review of published literature, national and local guidance and in consultation with the autism community including: autistic people, parents of autistic individuals, professionals from health, education and third sector. It is intended to help school staff and other agencies, working in partnership with parents, to frame their thinking and to apply good practice.

# What is anxiety related absence?

Anxiety related absence occurs when children and young people are either reluctant to go to school, have reduced attendance or are not attending. Although there may be an identifiable event which signals a turning point, it rarely happens suddenly. There are usually signs that being in, or transitioning in and out of, the school environment causes anxiety prior to absence being an issue. There may be a build-up:

- May plead not to go
- May make excuses
- May be late
- Increased periods of absence
- Mixed attendance
- Complete absence

Anxiety related absence is more common in adolescence, however there are often signs at the primary school stage. It occurs more frequently and arises earlier in autistic learners compared with non-autistic learners.

- Generally there are multiple sources of anxiety, co-occurring with a lack of strategies to address these. It is often a mistake to put it down to a single issue; there are usually a number of contributing factors.
- It is really important to acknowledge that anxiety related absence can have a significant impact on the wellbeing of the whole family.
- Early intervention, as soon as there are signs of anxiety over going to school, is recommended.
- Any planning must consider the 24 hour life of the child.



# This guide will consider existing and emerging anxiety related absence

# **Existing**:

Learners for whom absence from school was an established pattern prior to the COVID-19 context may now have experienced a different way of learning outwith school. From this they may have developed an awareness that learning from home is possible.

# **Emerging**:

Learners who prior to COVID-19 were attending school regularly. During this time away from their school, reasons may have emerged which could make returning to the school environment particularly difficult.

# Terminology

We are using the phrase 'anxiety related absence' because the language we use is really important. In the past anxiety related absence has sometimes been called 'school phobia' or 'school refusal'. These terms suggest that the solution relies on the child or young person changing rather than a shared understanding of the impact of the environment on the individual. Anxiety is affected by a range of factors within the child or young person and external to the child or young person.

This guide will include further information about things you might notice that might indicate anxiety, how you might think about this for individuals in different contexts, and steps you might take.

An additional point to note is that anxiety based absence could be one indication that autism assessment might be helpful.



# **COVID-19 Context**

COVID-19 has brought about a renewed focus on the issue of anxiety related absence. Many of us are experiencing different responses to the sudden changes to our routines and environments, including extended time away from our usual school or workplaces.

During this time we have also gained understanding that some autistic learners have enjoyed aspects of being at home (e.g. reduced sensory processing demands, more options for movement, learning chunked down, having more opportunity to have time doing activities which are personally motivating) whereas others have found the change very difficult (perhaps not being able to think that 'school work' should be done at home, reduced structure within the day, lack of access to usual regulation activities, like parks, sports, respite). The experience may have affected daily routines, such as eating and sleeping.

Having been in the home environment, wearing comfy clothes, sitting on a range of surfaces, with less noise and fewer people, the return to school will require children and young people to acclimatise to a range of changes (e.g. new morning routines, travelling to and from school, uniforms, school seating, new expectations, noise and busy environments, remembering the names of people in school).

Whilst we are writing at the time of COVID-19, many elements of this guidance could apply at any time.

# What might you notice that are signs of anxiety in autistic individuals?

"The opposite of anxiety is trust" Prizant (2015) and where individuals lose trust that people and environments around them will be suitably predictable and desirable, it can take time to rebuild that trust. We may need to wait and be persistent with strategies identified and applied.

"Anxiety is what we feel when we are worried, tense or afraid – particularly about things that are about to happen, or which we think could happen in the future. Anxiety is a natural human response when we perceive that we are under threat. It can be experienced through our thoughts, feelings and physical sensations." Mind (2017).



# How is anxiety expressed?

- Anxiety can be expressed in an overt way (e.g. a worried expression and body language, refusal or protesting actions)
- Autistic individuals may have strong and specific interests, which other people may describe as obsessions or enthusiasms. These may be more apparent when anxiety is raised
- As a response to stress, anxiety, feeling out of control or unhelpful thoughts, children and young people might try to alleviate their anxiety by performing compulsive rituals (e.g. counting or washing their hands repeatedly)
- Others may withdraw or become selectively mute (not speaking at all in some circumstances)
- Individuals may also appear smiling and quiet or not overtly anxious
- Masking and camouflaging (Mandy, 2019) are recognised experiences in autistic individuals, which are used to 'appear fine' but actually can add to feelings of stress and anxiety
- Just because an autistic person doesn't look worried, does not mean they are not worried



# It is important:

- for people who know individuals well to 'listen' to what they say <u>and do</u> and to observe whether they are initiating and participating confidently
- to be aware that individuals might be using self-regulation or coping strategies in the context of the underlying anxiety
- that rather than trying to stop the individual engaging in the observed behaviour, we support them to learn helpful self-regulation and mutual regulation strategies
- to understand that by the time an individual states that they do not want to go to school, they may have used other ways to express their anxiety that have not worked for them

# **Reasons for anxiety**

Individuals have different reasons for feeling anxious. These are some common considerations for autistic children and young people:

### Separation anxiety:

When children are worried about being separated from caregivers, leading to distress in leaving parents to go into school. In autistic children, this can emerge later than in peers and can last longer, so that it stands out as different. They may have a strong urge to be near their parent/carer. They may feel a lack of control over their parents or siblings being at home when they are not or doing things they do not know about. They may not have a strong sense of time or when they will be reunited with their family. Strategies used with typically developing children experiencing this (in the early years) may not be appropriate in an older autistic child. After a prolonged period at home, it is possible that this will be a stronger anxiety than previously.

### Transition anxiety:

For some individuals, it's not just the transition between home and school that can be a source of anxiety but any change, particularly if it is unexpected or unclear. Sometimes small changes can be as difficult as bigger changes. There might be a sense that something is different but the child or young person can't work out what it is or explain how it makes them feel – a constant sense of discombobulation.

### 'How long will this last' anxiety:

Some individuals will not easily read the signs to tell when something will start and finish. This means that it's hard to start, it's hard to focus, and they might not know if it will ever end. It might prevent them from doing the activity or they may present an action that distracts from or prevents the activity from happening at all. If they do engage in the task, they might find the news that it is ending unexpected – again creating anxiety and reducing desirability of such activities in future. They may learn not to trust. It may be easier for individuals not to agree to do things, if doing them is so unpredictable.

### Social anxiety:

This manifests in different ways at different ages/ stages. At first we might notice that the individual is anxious or uncomfortable being around some other people/ in groups/ in busy and noisy social environments or with less familiar people. As they get older, they might worry about what other people think of them without having a sense of how they can influence that. They might feel like they 'get it wrong' around some people. Some individuals might misinterpret other people's thoughts, words, feelings, actions and intentions. They might appear to be very self-conscious, making it difficult for them to participate in class and socialise with peers.

# Specific phobias:

Children and young people may have a strong and seemingly irrational fear of particular things (e.g. hoovers, spiders, rain...).

# **Generalised anxiety:**

Individuals can worry about a wide variety of everyday things. Sometimes they might worry particularly about performance with school work or struggle with 'perfectionism'. Some of this is developmental, such as worrying about being first in the line or winning and losing – but if children continue to focus on this as they get older, other people find it unexpected. Autistic children and young people may also be 'rule followers' and have a tendency to 'police' other people who they perceive as not following the rules. There are any number of potential disrupted expectations that could happen in a day that we could worry about (e.g. Will I get pizza for lunch or will it be finished when I get there? Will Miss Jones be wearing that perfume I don't like? When is the bell going to go?).

Some individuals are sometimes described as 'catastrophising', when they have a big reaction that can seem to be out of proportion to the size of the problem. It is common for autistic individuals to find it hard to grade the size of a problem, or to match the size of a problem to the expected size of their reaction.



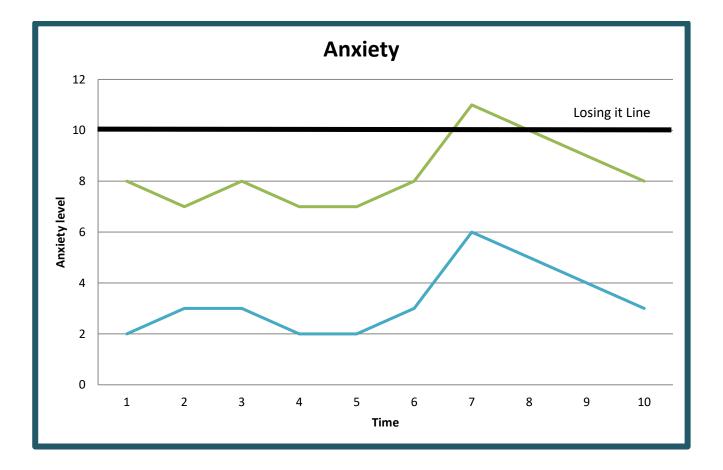
# Understanding why autistic learners might be anxious (Losing it Line)

Why would an autistic child or young person be anxious? If...

- your working memory means you don't know how long something is going to last and you can't hold information in your head for long
- your concept of time means you are unsure about how long things are going to last and what is going to happen next
- you struggle to imagine what might happen next and are unclear about the expectations of those around you
- you don't share the perspectives of others and haven't fully understood what you are expected to do
- you are fearing your own sensory reactions
- you tend to focus on detail and miss the bigger picture
- you regularly experience misunderstandings and feel that you never seem to get it right

# We might equally ask why wouldn't an autistic child or young person be anxious?

Here is an analogy to explain how anxiety builds up, which we call the 'Losing it Line'. This graph shows anxiety levels over time.



# Understanding the 'Losing it Line' graph

The Y axis marks level of anxiety and the X axis is the passage of time. Each point on the coloured lines represent a different event in the day.

The blue line along the lower part of the graph represents most people on an average day with nothing big or significant going on in our life to cause major distress.

- 1. You might get up on the morning worried about the day ahead.
- 2. You calm yourself down by thinking calmly about the day over a cup of tea.
- 3. You set off for work and there is a diversion on the road.
- 4. You start to get anxious about being late and take a detour.
- 5. Lots of others have taken the same route and now you are stuck in traffic and are very late.
- 6. Suddenly the car behind bangs in to yours!
- 7. No one is hurt but it will take the rest of the day for you to return to the level you were at the beginning of the day.

For all the reasons we have already talked about, autistic children are likely to start their day at the higher level – the green line.

- 1. They may waken up anxious.
- 2. Their parent calms them down by looking at their home visual timetable for the day.
- 3. There is none of their favourite cereal left but they find an alternative they like.
- 4. They set off to school later than usual so someone else gets to the front of the line first.
- 5. Someone else gets the coat peg they had wanted.
- 6. Someone brushes past them and brushes them softly on the arm.
- 7. That's it, they've lost it, they are on the ground kicking and screaming. They are 'over the losing it line!' The adults are all saying, "There was no reason at all for that! It's come from nowhere." But it hasn't.



We can't take away all the sources of anxiety for the child or young person but we can try to reduce them. The <u>Key Messages</u> in this document are all designed to do this. One of the simplest ways to do this is to make the child or young person's day predictable.

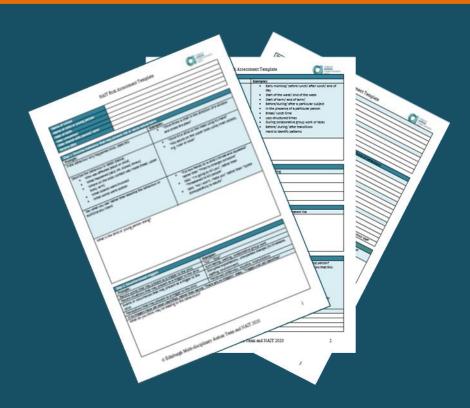
Whilst anticipatory approaches are essential to prevent getting to this point, some children and young people, at particularly difficult points, may 'cross the losing it line'. In these situations:

# Once a child or young person has gone over the losing it line:

- Stop talking
- Walk away observe from a safe distance
- Remove any furniture or objects which could present a risk
- Consider evacuating other people from the immediate area
- Wait give time and space to recover, it may take longer than you imagine

# After the event, the adults should:

- Reflect later (we don't recommend 'post match analysis' with the child or young person)
- "Ask Why?" (Prizant, 2015)
- Think about prevention what could be done differently to avoid the same circumstances leading to a similar response in future? Consider carrying out an autism informed <u>risk</u> <u>assessment</u>



# Understanding the family perspective

Although anxiety related absence is perceived as a school problem, it is important to consider the 24 hour life of the child and the impact on the family.

The first and most important step is to take time to listen to the family perspective. Discrepancies between behaviour at home and school are common and may be indicative of a problem building up. It is not uncommon for autistic children and young people to 'hold it together' in one context and for the reaction to be observed at a later time and in a different context. If a parent is regularly reporting distressed behaviour at home, this can be viewed as a need for reasonable adjustments to be made at school.

# Parents report:

- Anxiety and challenges have been building for quite some time before they become apparent at school
- Morning routines can be extremely stressful and earlier practical help would make a difference
- Actions that focus on the child or young person changing don't work if the support and expectations remain the same
- Feeling judged, blamed or viewed as not trying hard enough to get their child to school
- Simply advising the family to get their child to school is not supportive or helpful
- A perception that other people think that, 'the problem is at home'
- Financial impact, e.g. it can affect whether or not they are able to work
- Feeling that, even if the child or young person has gone to school, they may receive a phone call at any time
- Children and young people returning from school in a stressed and anxious state
- Feeling that they cannot leave the house during the day, often leading to isolation
- A loss of connection with other parents in the school community
- Impact on their mental health and wellbeing
- Siblings lives can be adversely affected

She hates not understanding something but equally doesn't often see the point in learning something she doesn't see a benefit for... I remember she only got in consistently for the computing...nothing else, so I guess interest in a subject made all the difference.

> Everyone tried to fit her into a box – rather than try and create a box for her.

She moved to a new school in P4 and struggled to build friendships and we had a worsening of behavioural issues at home and these behaviour problems at home started to present at school.



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# **Peer relationships**

It is helpful to understand each individual's perspective on friends and peer relationships and whether or how this might affect motivation to attend school.

Children and young people experiencing anxiety related absence may or may not have strong peer relationships at school and this may or may not be a concern.

- Reduced attendance can have a negative impact on previously good social connections and shared interests because peers carry on without them, make new friends or develop new interests
- Some children and young people experience peer rejection, bullying or feeling excluded by peers and this can be a factor in their reluctance to attend, which it can be helpful to focus on in planning
- For some individuals currently, they are neither seeking friends in school, nor are they feeling excluded or bullied and peer relationships need not be a priority for support
- Some individuals find friends with shared interests outside of school and benefit from opportunities for engaging in preferred activities with others who like the same thing

# Socially seeking

For children and young people with strong social connections and a good friend or friends at school, peers can be a key factor in feeling motivated to attend.

I have found it easier to get into school if I had something to look forward to. Either that or if I could see people I liked to hang out with.

He hasn't really missed his friends and in fact his self-sufficiency has been a real strength at this time.

# Content in their own company

For others peer relationships may not be as important.

# **Peer rejection**

Some individuals may experience isolation or feel that they are not accepted or even that they are rejected by their peers at times. This can be experienced as a mild or a significant problem and can take many forms, for example:

- Teasing (verbal)
- Bullying (physical, cyberbullying)
- 'Reputations'
- Responding to rumours and gossip

Approaches to address 'peer rejection' depend on the type of rejection. The <u>PEERS UCLA</u> programme (Laugeson & Frankel 2011) offer some suggestions about how to handle different types of rejection. Autistic children and young people may need support to:

- a) know what kind of rejection they have experienced
- b) learn how to handle teasing themselves
- c) have a plan for dealing with a 'reputation'
- d) seek and receive direct support to address physical or cyberbullying

# Teasing

Typically advice given to children and young people who are being teased is to ignore it, walk away or tell an adult. However, PEERS researchers found that 'socially successful' young people do not walk away or ignore someone who teases them and they do not 'snitch'. They react as if they are not bothered and give a short verbal comeback, such as saying 'Yeah, right!' or 'Whatever!', or use nonverbal signs such as shrugging or rolling eyes.

# Bullying

It is crucial, that when teasing moves towards bullying the child or young person should seek support from trusted adult(s). Bullying is a serious issue and must be treated as such. There may be a need to help an individual to understand the differences between teasing and bullying.

# Cyberbullying

Because IT (and consequently cyberbullying) changes constantly, it is important to reference up to date guidance and seek current advice within your local area. Some consistent key points are to support the child or young person to:

- get help from a trusted adult
- block and report 'trolls' and save the evidence
- 'lay low' online for a while
- avoid responding to inappropriate communications

# Reputations

Things may have happened in the past that have influenced how their peers view the child or young person. Peers may feel nervous around them, or scared that they might cause a distressed reaction. Advice from the PEERS team is for the individual to 'own' their past reputation (e.g. 'Yeh, I used to get really upset when people did that. I'm older now and I don't do that anymore.'), then to 'lie low' and allow a period of time for others to get to know them anew.

# **Minimising Rumours and Gossip**

It can helpful to advise the child or young person to ignore the source of the gossip and not to confront them head on or try to disprove the rumour. They (and their friends) can try to act amazed that anyone would care or believe the gossip (e.g. "I can't believe anyone would believe that!").

# Additional sources of information about peer relationships

It is important to acknowledge that individuals have different levels of motivation to have friendships with peers and there are many ways a friendship can operate. When supporting children and young people with a current interest in forming and maintaining peer friendships in school, <u>Social Thinking</u> resources may also be of interest.

# What steps can we take?

In order to successfully address anxiety related absence, whether this is emerging or existing, there is usually a need for a team approach, clear planning and commitment to consistent implementation and review over time. This part of the document outlines the steps that can be taken.

This guide is intended to complement the **GIRFEC** National Practice Model.

The first five questions all practitioners need to raise when they are concerned about a child or young person are:

- What is getting in the way of this child or young person's wellbeing?
- Do I have all the information I need to help this child or young person?
- What can I do now to help this child or young person?
- What can my agency do to help this child or young person?
- What additional help, if any, may be needed from others?

The wellbeing indicators are also used when a plan is being constructed or reviewed, to summarise the child or young person's needs.

Use this anxiety related absence guide alongside your local planning process involving the team around the child or young person. It is important to base plans and actions to support anxiety related absence on observations and information gathered and to take account of:

- Child or young person's views
- Family views, needs and context
- Universal supports already implemented
- Key Messages for Returning to School (see below) being applied
- Targeted supports in place and how well these are being implemented (see page 22)
- The child or young person across naturally occurring environments (home, school and community)

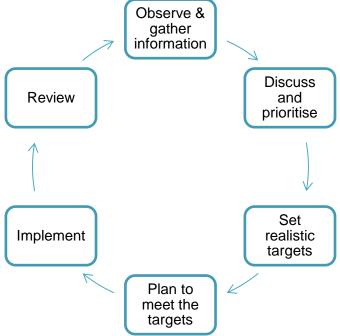
There are Reflective Questions on page 21, which can be used to support planning.

# A planning cycle

The planning process starts with observing, listening and gathering information. The team around the child then discuss strengths, concerns and priorities.

• We recommend setting no more than four realistic targets; these should take account of the priorities of the child or young person and their family.

- Targets should focus on adaptations to naturally occurring environments and routines.
- The next step is planning how these targets can be met and only at this stage, think about what resources are needed to implement the plan.
- A common mistake is to look for a quick solution, such as a putting a supporting person in place before the plan and their role in it has been defined.
- It is tempting to think that simply referring to an outside professional or agency will solve the problem. Whilst additional advice and expertise can inform the planning process, it is important that the overall responsibility for supporting the child or young person to and in school remains with those working in the school environment on a day to day basis.
- At the implementation stage, good communication to enable consistency and persistence with the plan is essential.
- Aim for each strategy to be in place and consistently applied for a reasonable length of time before reviewing. The caveat to that is, if it is causing distress to the learner an early review will be required.



# **Staged intervention**

School staff are not expected to have all the answers. Collaborative working with health professionals and other partners can enhance the planning process. This is particularly helpful where health professionals can bring their specialist lens to planning environmental adaptations.

Historically, health professionals operated an 'extraction model' offering clinical appointments with a focus on 'within child' changes. However, the recommended approach is now a 'natural environment model' which involves working collaboratively with those in the child or young person's day to day life with a shared responsibility for all aspects of the planning cycle.

Although adapted Cognitive Behaviour Therapy (CBT) based approaches are recommended for a small number of autistic young people, this is not recommended as the first line of support to address anxiety related absence for most autistic children and young people.



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# **Universal Supports**

The term Universal Supports describes the approach to creating an inclusive classroom environment that seek to meet the needs of all learners. There are many resources and approaches to support good inclusive practice as a focus in every school. Good inclusive practice is a good way to ensure adjustments are anticipatory. Avoid introducing more specialist interventions before the basics are in place and being consistently applied.

The CIRCLE resource (<u>https://www.thirdspace.scot/circle/</u>) provides a helpful framework, through 6 key considerations:

The Physical Environment: The way school looks and how they use materials and move around

**The Social Environment:** Relationships with people the child or young person already knows but hasn't seen for a while, peers and adults, new people, people in each class, new social rules and expectations, new ways these are communicated

**Daily Routines at home and school:** Washing and self-care, packing bag, going to and from school, mealtimes, break times, lining up, different school activities, Assembly or PE

Social Routines: Greeting people, games and interactions with others, leisure activities with others

**Motivation:** Predictability, seeing the point of what they are expected to do, current likes and dislikes, the things they are allowed to do or not to help them enjoy the day, experience success and have fun

Skills: How the child or young person communicates, moves, learns, attends, remembers

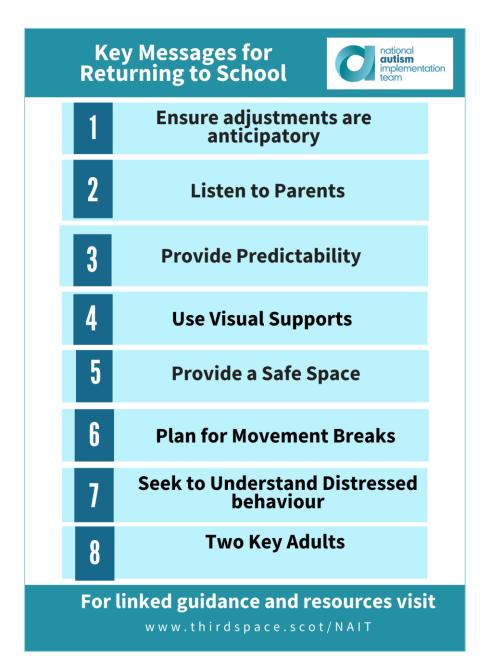






# **Key Messages**

Resolving anxiety related absence can take time and planning should be individualised. Some key strategies are commonly helpful. The NAIT <u>Key Messages</u> below are designed to guide planning for the return to school for autistic children and young people and those with related needs. They are particularly important when supporting this group of learners. Further guidance about each of these Key Messages can be found at <u>www.thirdspace.scot/NAIT</u>. For this group of children and young people we would like to add the importance of 'Environment First'. This means thinking about reasonable adjustments and adaptations to the physical and social environment, before making plans which involve the child or young person learning new skills and making changes.



# Case Study 1 - Ana

Ana is a 16 year old girl who lives at home with her parents and two brothers. She is in S4 of a mainstream secondary school and was diagnosed with autism earlier this school year. She loves reading, crafts and going to the theatre. Her parents report that friendships became difficult in Primary 6 when Ana felt that others were 'picking on her' and reported incidents of bullying.

In early secondary, getting ready for school in the mornings began to take longer and longer leading to regular lateness. Ana talked of not knowing whether certain teachers would be there or not knowing whether particular events were going to happen or not. Small changes to the plan for the day could unsettle her entire day and she would often be absent on the following day or days. Over the course of four years at secondary school, Ana's attendance reduced from 94% to 48%.

Ana enjoys learning and, when in class, she is attentive and works hard. She tends to put homework tasks off until close to deadlines then works late into the night as she is anxious to make her work perfect.

She has a small group of friends at school and talks positively about them, but she often worries about whether she might have upset them and, when things do go wrong, she struggles to find ways to repair the situation. She worries about being viewed as 'stupid' for 'always getting things wrong'.

The team around Ana followed their local Getting it right planning protocols.

# What has helped?

Ana has a white board in her bedroom where she writes the sequence for her morning routine. She ticks each step off as she completes it.

Ana has Two Key Adults in school who she knows she can seek out when she needs support or information. Her parents also know that these are two consistent points of contact.

Each Friday, Ana is given a timetable for the following week that accurately captures classes, teachers, special events (e.g. assembly, fire drill) and personal appointments (e.g. dentist). She knows that other changes might happen but she now knows and trusts that she will be told of these with as much notice as is possible.

Ana's individual subject teachers email her at the start of each week to let her know what they will be learning/ doing in each period. (*Ana: "Now that I know they are learning about photosynthesis I really want to go because I need to know about that."*)

A high backed chair facing a corner in the Support for Learning base has been identified as a Safe Space that Ana can go to any time she feels that she is becoming dysregulated or needs a break from interaction. She regularly spends part of each lunchtime here, calming herself and preparing for the afternoon ahead.

The team discussed the possibility of Ana reducing the number of subjects she studies. However they listened to her views and accepted her personal academic aspirations. This resulted in excellent exam outcomes.



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# **Reflective practice**

However complex the situation seems, there are some important questions you could use to reflect and guide next steps in planning, taking account of the 24 hour life of the child or young person:

Reflective Question	Response
Are expectations developmentally matched?	
Are daily routines at home and school sufficiently predictable?	
Is the child/ young person supported to be as independent as they can be in daily routines?	
Are the school environment and activities sufficiently desirable?	
Are existing strategies and Key Messages consistently implemented?	
Is there consistency from adults across the school?	
Has the child/ young person experienced disrupted expectations?	
What happened and what can we learn from this?	
Does the child/ young person experience success?	
Does the child/ young person have enough opportunities to initiate and make choices?	
Does the child / young person know what they are being asked to do and do they see the point – are their experiences meaningful to them?	
<ul> <li>Have the people around the child or young person understood and made adaptations for differences in:</li> <li>Social communication?</li> <li>Sensory preferences?</li> <li>Thinking style?</li> </ul>	
Are the right people involved?	
Is there an explicitly agreed and effective home school communication system in place?	

# **Targeted approaches**

Big problems don't always need big solutions. It is essential to ensure the simple things that help are in place before reaching for more complex solutions. Where the appropriate universal supports and <u>Key Messages</u> are in place and are being used consistently, the need for a more targeted approach may become apparent. At this point we recommend using the SCERTS framework, for focussed multi-disciplinary observation, planning and review (<u>NAIT SCERTS Publication List, 2019</u>).

**The SCERTS Framework** starts with an easy and quick consideration of the individual's developmental stage, in order that all observation and planning sets out with relevant expectations. These stages are:

- **Social Partner**: have fewer than 10 meaningful words or other consistent intentional communication signals
- Language Partner: use phrase speech
- Conversational Partner: communicate in sentences across several turns

# (Prizant et al., 2006)

Anxiety related absence occurs most commonly in conversational partners but anxiety in school can occur at all stages. The SCERTS framework is ideally placed to allow multi-disciplinary focus on key aspects affecting anxiety related absence:

- Social Communication: How and Why the individual communicates
- Emotional Regulation: Strategies the individual has for 'self-regulation' or things they do to feel calm and happy and 'mutual-regulation' or ways other people can help them to feel better
- **Transactional Supports:** 'interpersonal support' which is the adaptations made by people around the person and 'learning supports' such as visual supports, curricular modification and adaptations to physical resources for learning and how they are presented to support accessibility and success

Within this framework, the team observes the child or young person in usual daily activity, they review observations. They then identify up to four targets and agree how to meet them. Once a target is agreed, the team then considers how best to address that.

It is important at this point to remember that a person is not a strategy. The important things are:

- clarity over adaptations that will be made to make the day predictable and desirable
- what the people will do
- and how to make this consistent.

# Case Study 2 – Alain

Alain is a 14 year old boy who lives at home with his mum. He received a diagnosis of autism when he was three years old. Alain struggled with reading through primary school and has recently been identified as Dyslexic. His mum has a physical health condition and has twice this year required hospital treatment, resulting in him having two periods of kinship care, both with his maternal grandparents. He enjoys Karate and playing on his X-Box.

In primary school, Alain regularly worked in a small group supported by a teaching assistant. He had one close friend with whom he spent break and lunchtime. His attendance was consistently around 80%.

Since beginning secondary school Alain has spent most of his breaks in the Support Base. He talks of having several friends from this group, with whom he enjoys playing computer games.

Alain's teachers report that he frequently shouts out in class and that he openly challenges them whenever he thinks they have made a mistake. He has been sent to Senior Leadership for arguing with teachers on numerous occasions. Alain expresses that he thinks his teachers don't like him and that they don't want him in their class.

In S1 Alain was mostly absent on Mondays. A few months into S2 he expressed that he'd missed too much and couldn't do any of the work. Homework became a source of conflict at home. He then stopped attending school altogether. Alain's Mum reports that she has missed days from work and is at risk of losing her employment.

# What has helped?

Alain has a predictable start to each school day. Two of his friends from the Support Base meet him by the school gate each morning. He then registers in the Base where a consistent adult supports him to look over his timetable for the day ahead.

Alain's teachers reviewed the work he has missed and identified priority areas of learning. He no longer attends modern languages classes and now spends these periods in the base focusing on these priorities. He is no longer given work to do at home.

Alain has a Post-it pad in each class where he is encouraged to write down anything he is worried about or that he thinks might be wrong during the lesson. He is encouraged to give these to the teacher at the end of each period.

Alain has two key adults at school who email his mum at the same time every week to communicate about his week both at home and at school. The two key adults ensure that this is a balanced report that includes his interests, successes and achievements as well as any minor concerns. One of the adults meets with Alain twice a week to check in with him.



# Targeted support at home

# The following strategies can offer support to families

# Listen to parents:

Ask parents about early signs of anxiety and how things have built up; what are their concerns and experiences and what do they notice supports their child or young person to feel calm and happy; what would help them at home?

### Compassionate mindset:

Be aware that there can be a significant impact on a family when the child or young person does not attend school (e.g. unable to work, financial impact, mental health and wellbeing of parents and siblings, reduced peer and social support, feeling they can be called at any time while their child is at school so never 'free', limited opportunities to shop and do household routines if their child won't leave the house).

### No blame culture:

Avoid language which can be perceived as judging, blaming or devising solutions which make it seem like parents haven't tried hard enough to get their child to school or which require the parent to make all the changes, where 'failure' is inevitable.

### Home school communication system:

Agree and implement a mutually acceptable system of communication, which has a predictable frequency with balanced content, so that it happens regardless of positive, negative or neutral events.

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# Shared responsibility and the 24 hour child:

Reassure parents that often there are solutions that can be put in place at school which can reduce anxiety at home, school and across the 24 hour life of the child.

# Seek up to date knowledge about local home and family support which takes account of the needs of autistic children and young people:

Only tell families about support they can access. Families report frustration with being given generic, outdated or irrelevant information or being signposted to supports that exist but they are ineligible for. Check for current information about who supports are for, how they run and how to access them before sharing information with a family.



# Provide early practical support for home routines:

- Simply telling the family to make changes may not work
- Offer support to prioritise one step at a time and some modelling or coaching
- Focus on building independence within routines and limit verbal prompting
- Involve a trusted member of staff or a professional outwith the school team, such as an Occupational Therapist or specialist additional support for learning teacher
- Provide visual supports required to support home routines, (e.g. bedtime, preparing for the next day, getting to sleep in a calm frame of mind, a realistic, predictable and desirable morning routine)

# Post school emotional regulation:



Just being at school and getting through the day can take a lot of effort. When a child or young person comes home they may need some time before they feel calm enough to be with family, talk about their day or do anything that feels demanding.

When children and young people return from school in a stressed and anxious state, parents should not feel that they need to make them do homework or work they have missed. Support families to allow their child 'down time' doing something desirable or indeed, doing nothing.

# Good things should just happen:

It is really important that good things just happen and children and young people do not have to 'earn' positive experiences. Reward charts for attending school or behaving in school can increase anxiety and conflict and are not generally recommended. Adults share the responsibility for ensuring the emotional regulation of the child or young person. This is not something the child holds all the responsibility for. In particular discourage parents from feeling they need to administer any sanctions or rewards at home for incidents and events which have happened at school.

# Practical ideas for separation anxiety:

- Take time to build relationships between key school staff and the child or young person
- Reduce other sources of stress by being organised and prepared
- Create a predictable home routine the night before school and in the morning that focusses on the steps involved in getting ready
- If possible, other family members being up and dressed when the child leaves for school
- Use a 'transition object' this could be a photo, toy or comforting object which reminds them of their caregiver while they are at school (we recommend replaceable items, rather than a favourite object which may get lost)
- A clear and predictable routine for the transition into and out of school that suits individuals
- Use a developmentally appropriate visual timetable, with a clear 'going home' symbol/ words
- Ensure a <u>Safe Space</u> is available at school and that the child or young person knows how to use this
- Some individuals will need separate work to explore and accept that they are not in control of what family members do while they are at school

# Targeted support at school for emerging anxiety related absence

The following strategies may help to address priorities identified in SCERTS focused assessment, in addition to consistent use of universal supports and Key Messages.

Note that this is not an exhaustive list and that one size does not fit all and an individualised approach, taking account of day to day contexts is recommended.

Staff in schools may benefit from additional training and mentoring from health and educational professionals with particular expertise in identifying and implementing stage appropriate strategies for children and young people, when anxiety related absence is an emerging issue.

# Some ways to support Social Communication

### Reduce your language:

- The adults around the child or young person can use shorter, simpler sentences at a slow but natural pace.
- Say things in the order they should happen.
- A good tip is start with '**name** (so they know you are talking to them) **plus action**', for example, instead of 'John it's going to be time to put everything away so that we can get ready for lunch", we could say 'John, drawing is finished' and after he does that 'John, lunchtime'.
- Visual supports and timers can reduce the need for too much language.
- Speech and Language Therapists are a good source of support and information around a range of language and social communication needs.

# Provide a system to get out of class:

- Some individuals can use an 'I need a break' card and learn to give it to an adult or place it on their desk to signal this need.
- Some individuals find initiating communication either with words or a visual support is difficult at times. They need to know they can get up and leave whenever they need to. In order to use this strategy safely, they will need to have a designated individual Safe Space and to have practised going there. They need to be able to trust that all staff will allow them to go without challenge, if that has been agreed.
- Some individuals may need a prompt, e.g. 'Do you need a break?'
- Once in their Safe Space, leave them to decide when they are ready to come out. This may be some time, especially when anxiety levels are high.

# Don't mention being absent:

- As a default, adults should be warm and welcoming and make no immediate reference to the child having being absent.
- If it is possible, agree with the child or young person and/ or family what they would like to happen. They may prefer no-one to mention it in the first few days of return. They may like time with a key adult in school to talk. They may not.

- If the adults agree not to make a big deal of the child or young person being back at school, all school staff should know about this plan and stick to this agreement. Trusting adults to be predictable can reduce anxiety.
- Each child or young person is likely to have a small number of key people with whom they are comfortable talking about being absent from school. Have a plan in place to ensure this is predictable, desirable and matches their communication stage.

# Do what you say you will do:

- Provide and use an individual visual timetable in a developmentally appropriate form.
- Anxiety is the opposite of trust. One of the first steps in building trust is the child or young person experiencing other people being predictable and doing as expected.
- Not following through on expectations agreed leads to disrupted expectations for the child or young person and reduces opportunities for positive social communication and interaction experiences.
- If it is not possible to do this (unexpected change happens!) acknowledge the change, give as much notice as possible and prepare them for the change.
- Using visual supports can help to signpost a change to expectations, the individual visual timetable should be updated as changes become known.

# Support peer interaction:

- Support the child or young person to have something prepared to say if peers ask about their absence.
- Support them to maintain and re-establish links with peers. This might include creating opportunities for them to be with supportive and like-minded peers (e.g. go together to collect resources, or work together on a clear structured task).
- Consider offering support during less structured parts of the school day, through use of the child or young person's interests and motivations (e.g. a lunchtime Star Wars club or book group). Shared interested are a key reason to enjoy being friends with others.

# PEERS ®

• One source of information and training about supporting with developing and maintaining friendships in the school setting can be found at <a href="https://www.semel.ucla.edu/peers">https://www.semel.ucla.edu/peers</a>

# Social Thinking™

 It is helpful for all staff to be aware that the autism and social communication differences are lifelong. <u>www.socialthinking.com</u>



# Some ways to support Emotional Regulation

# Understanding the individual's emotional regulation strategies:

We all develop and use different strategies throughout the day to regulate our own emotions and feel good. These might involve seeking mutual regulation from others (e.g. asking for help, chatting with friends over lunch) or they might be things we do ourselves for selfregulation (e.g. chewing a pen, rocking on a chair, using a fidget object). It is very important to have both types of regulation strategy available. Individuals who are over-reliant on only one type of regulation may be more anxious. The team can take a 'big picture' look at this, to identify:

# Reflective questions

Is the child or young person using self-regulation strategies?
Is the child or young person using mutual regulation strategies?
Does the child or young person know what they can do safely to feel better?
Are visual supports in place as a reminder of regulation strategies
Would it help to introduce some alternative regulation strategies?
Are they able to use their strategies in daily life?
Can the individual differentiate things that are a 'big deal' or a 'little deal'?
Does the size of their problem match the size of their reaction?
Do adults in school pick up on early signs of dysregulation and offer appropriate agreed
supports?

# Start and end of day routine:

A plan is essential and a range of options might include:

- Arrive and/or leave before or after peers
- Arrange for the young person to be met by a peer, buddy or trusted adult at the school gate
- Register at a support base rather than in the registration class
- Having a lateness plan
  - o 'no blame culture'
  - o knowing what to do when arriving late and rehearsing this with the young person
- A 'soft start' to each day that takes account of the child or young person's needs and preferences, e.g. time doing a preferred activity (e.g. Lego, iPad), a predictable movement activity, spending registration time in a support base

# Have a plan for key daily transitions:

Breaks, lunch times and moving between classes or buildings are all transitions which require thought and planning. Some strategies are:

- Planned leaving and arriving at class 5 minutes before the bell to miss the crowds
- Quieter times to take breaks
- Safe, quieter and less busy spaces to spend lunch and breaks
- Structured activities to do in some unstructured times of the day (e.g. chess club at lunchtime)
- Explicit and visual choices to support movement needs at break times and throughout the day

# Plan to meet sensory needs and preferences:

Understanding individual sensory preferences is essential to supporting emotional regulation.

- More information, videos and resources can be found in the Autism Toolbox
- Occupational Therapists are a good source of advice and information
- Be aware of the 'cycle of avoidance'. Think about alternatives or acceptable ways to tolerate the anxiety rather than avoiding it altogether. If you avoid something that makes you feel a bit anxious, this brings short term relief but can lead to increased anxiety in the long term (e.g. wearing ear defenders to block out noise can lead to the noise becoming even harder to tolerate. Using headphones with an alternative noise playing is a better option).
- Take account of movement needs. The <u>NAIT Movement Break Guidance</u> provides broad guidance and ideas for children at early developmental stages. Older children may benefit from planned walks, tailored exercises and activities recommended by an Occupational Therapist.

# Consider introducing Zones of Regulation ®

This approach supports young people to think and talk about regulation. Rather than focussing on teaching emotion vocabulary and pictures, this approach helps individuals to grade their own emotions and sensory responses and link these with practical actions they and others can take to stay or in a preferred 'zone' or to help move out of a 'zone' they don't want to be in.

# Two key adults

- Plan for two consistent members of school staff who are key points of contact for the child or young person and their family
- With a clear and shared plan for how and when the child or young person will access them
- And with a clear and shared plan for how and when parents can communicate with them
- Have a planned check in (e.g. once a day or twice a week) with child or young person
- Key adults check in with all of the child or young person's teachers to support them to continue to follow the agreed plan
- All of the above to happen, even when things appear to be going well
- Regular review, noting and responding to any early signs of issues arising

# Teach and use visual strategies to support grading of problems and reactions:

- OK/ Not OK
- Big Deal/ Little Deal
- Size of my problem, size of the solution
- Emotions Keyring



# Some additional Transactional Supports to support attendance

# Make learning meaningful:

It is essential to ask:

- Does the individual know why they would go to school/ class?
- Are most aspects of the day meaningful to them?
- Do they see the point?

We can:

- Ensure teaching and learning expectations match ability
- Chunk down tasks into shorter manageable chunks
- Ensure tasks have a clear start and finish
- Use timers
- Take a team approach; focus on consistency and predictability across individual school staff and professionals from partner agencies

# Learn from when a child or young person has attended:

When the child/ young person does attend, note what is happening on those days:

- Has this been a particular day, time of day or subject area?
- Are there patterns to when they do not attend?
- Where possible, plan to discretely observe the child or young person within a class/ subject that they do attend and note what strategies and approaches are in place.
- Ask yourself what is predictable or desirable about that setting or context and whether these elements could be adopted by other teachers in other subject areas or across different parts of the school day, e.g. if you note that the child or young person is more likely to attend a class where they sit in the same seat every time or the teacher cues them in by name each time they address them, could these approaches be used at other points in the school day?

# Plan ahead, anticipate and prepare for the return to school after holidays/ a break

- Support the transition back to school with planning, visits and visuals. Resources can be found here <u>https://www.thirdspace.scot/nait/covid-19-return-to-school/</u>
- Plan for steps in transition from home to school

# Expect a return to a full time timetable

- Introduce an adapted timetable in school if needed
- Do not default to a part time timetable. Although this seems like a way of reducing demand and anxiety, in actual fact it should not be the first step. There is no evidence that this leads to full time attendance and it may in fact reduce the likelihood of this.
- Aim to implement changes needed to make school a motivating and positive experience that will make a full time timetable possible
- Minimise the number of changes gradual increases in time at school can be more difficult for autistic learners because this increases the number of changes in routine they experience
- Consider reducing or removing homework expectations

# The end of day is the end of the day

- Aim for the child or young person to leave at the expected school leaving time (not going home early)
- Backward chaining is recommended (i.e. the start time gradually becomes earlier but the end of their day is consistently at the end of the school day) if the child does not attend all day

Have consistently high expectations in terms of attainment and achievement and consider opportunities for wider achievement

- Avoid 'dropping' subjects which could limit SQA and future university or career options
- Consider which subject areas are working well



# **Existing anxiety related absence**

Where a child or young person had anxiety related absence for some time prior to the current COVID-19 context, in addition to the ideas above, you may be considering:

# Flexible timetables:

Each local area will have guidance on the use of part time or flexible timetables. These should not be entered into lightly and always considered with caution.

No reduced timetable should be open ended and there should always be a clear plan and timescale for returning to full time education. As change can be challenging, it is important to limit transitions. Plan for a small number of changes rather than lots of incremental steps. Generally it is best to use 'backwards chaining' where the child or young person gradually moves towards an earlier start but home time is always at home time.

### Late starts:

If a child or young person has particular difficulties getting into school in the morning, as well as offering support with home routines, formalising a late start could be a consideration.

# Homework:

For many autistic children and young people homework is a source of stress and conflict. <u>NAIT</u> <u>Homework Guidance</u> offers information and ideas in this area.

# **Reduced subjects:**

At the secondary stage, be particularly wary of reducing the range and number of subjects a young person attends as such decisions have the potential to limit future academic or career options. Instead focus on what reasonable adjustments can be made to make these subject areas more predictable and desirable to the young person.

# **Blended learning models:**

Through their COVID-19 experience, some children and young people with existing anxiety related absence will have had a positive experience of home learning and will be now aware that this can happen. Some may now view this as a viable alternative to school.

As ever, it will be important to take an individualised approach, taking account of each family context, views and preferences, matching these to national and local guidance.

Where a part time timetable with an element of home learning is being considered, it will be important to be clear about responsibilities, expectations and timescales.

# Monitoring absence

- Keep track of the child or young person's attendance and absence type and frequency and look for patterns.
- Record attendance centrally. Where other groups and agencies are involved in delivering elements of the child or young person's curriculum, ensure that the school retain an accurate overall attendance record.

# Publications and reading:

- Autism Toolbox <a href="http://www.autismtoolbox.co.uk/home">http://www.autismtoolbox.co.uk/home</a>
- Cerebra Anxiety Guide: A guide for parents: <u>https://cerebra.org.uk/download/anxiety-guide-a-guide-for-parents/</u>
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- Mind (2017) Anxiety resources <u>https://www.mind.org.uk/information-support/types-of-mental-health-problems/anxiety-and-panic-attacks/self-care-for-anxiety/</u>
- NAIT SCERTS Publications List 2019 <u>http://www.thirdspace.scot//wp-content/uploads/2019/09/NAIT-SCERTS-Publications-List-2019.pdf</u>
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autism implementation