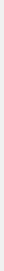

Freddie Adu, Headteacher, Queensmill School

Autism and Anxiety



Anxiety in this Context

Mapping Anxiety in minimally verbal autistic adolescents

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Introduction

Autistic individuals report that anxiety can have a significant impact on their lives and they are more likely to have to manage clinically significant levels of anxiety than their neurotypical peers. The causes of anxiety are often complex and the causal relationships between different types of anxiety and autism are not well understood.

A central focus for school-based professionals is to develop a better understanding of students' anxiety and how best to work together to then manage it. Anxiety has also been highlighted by parents as the most substantial difficulty their children face. Recent research in psychopathology has used a network approach to better understand what are seen as complex, highly connected networks of mutually associated symptoms of mental health difficulties.

Similar levels of complexity can be seen in anxiety and different hypothesised causes of anxiety (HCA - situations, objects or individuals that are perceived to cause increased levels of anxiety). A networked perspective of anxiety was hypothesised to give a better understanding of how to provide more effective support for minimally verbal (MV) autistic students by highlighting HCA that might be central to a network and therefore might be key areas to focus support.

Aim

To examine the viability of using perceived causal relationship (PCR) scaling and network analysis in better understanding and supporting anxiety in MV autistic students.

Method

Participants

Five students (all male) and 5 members of staff from a government funded, special school in inner-city London took part. Students' ages ranged from 14 years 10 months to 16;7 (M=15;4, SD=1;1).

Procedure

PCR Scaling

HCA were identified for the 5 students taking part in the study by the staff teams that worked with the students. PCR scaling was then carried out on these lists of HCA. A single member of staff who worked closely with the student was asked "How much do you think [student]'s anxiety with ['HCA X'] CAUSES their anxiety with ['HCA Y']?" and vice-versa. Answers to the causal association questions were given on a Likert type scale with response options from 0-10, with 0 and 10 denoting "Not at all" and "Strong cause," respectively.

Staff then rated how frequently students experienced anxiety as a result of each HCA. The eight response

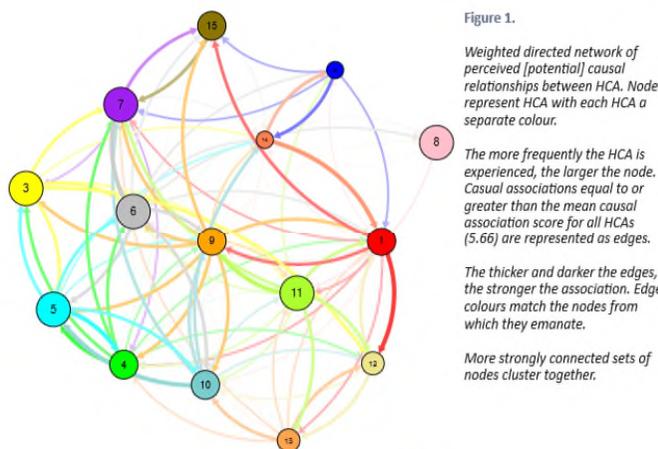


Figure 1.

Weighted directed network of perceived [potential] causal relationships between HCA. Nodes represent HCA with each HCA a separate colour.

The more frequently the HCA is experienced, the larger the node. Casual associations equal to or greater than the mean causal association score for all HCAs (5.66) are represented as edges.

The thicker and darker the edges, the stronger the association. Edge colours match the nodes from which they emanate.

More strongly connected sets of nodes cluster together.

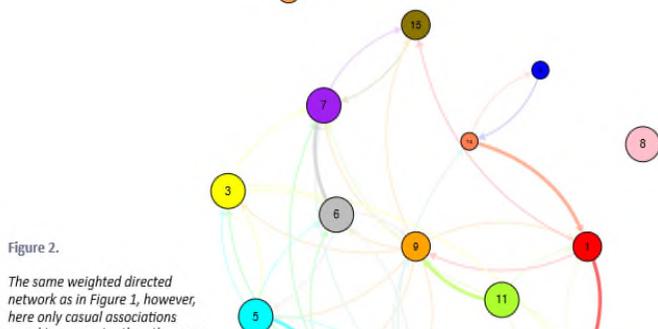


Figure 2.

The same weighted directed network as in Figure 1, however, here only casual associations

Results

PCR and Network Map

To map anxiety a directed network of PCR scores was generated using the R-package qgraph. To examine clustering and centrality in the HCA space, we employed an algorithm that minimizes edge crossing and takes symmetry into account leading more strongly connected nodes to cluster together (see Figures 1 and 2).

1. Uncertainty around food and drink
2. Wanting to vomit
3. Other students
4. Busy places
5. People in his personal/social space
6. When asked to do something he doesn't want to
7. Control of the environment
8. Private time
9. Unfamiliar staff
10. Perceived pressure to choose something
11. Permission to ask for something
12. Waiting
13. AAC system not available
14. Not feeling well
15. Clothing

Focus Group

Thematic analysis was used to analyse the focus group transcript. Four main themes were identified:

The Process

Cumbersome and time heavy to complete PCR; the process of discussing HCAs and relationships was valuable in itself; input of more staff/parents; moderation concerns

The Function

Not to be used for assessment; how does it add to existing documents IEPs/ECHPs; it can

Anxiety in this Context

- We see expressions of extreme anxiety frequently in autism

Under pressure the brain casts around for a coherent pattern, something that it recognises in order to prevent it being tipped into what is described variously as tantrums, losing it, kicking off, meltdown.....it looks for some way of reducing sensory inputs that are so distressing by shifting its point of focus.

Phoebe Caldwell, The Anger Box pain 2014 - Sensory Turmoil and in autism.



Aspergers and Me, Chris Packham, BBC 2017

- Can we manage and detect ongoing but less extreme expressions of anxiety?

Causes of anxiety in autism



- Sensory processing disorders
- Impaired communication
- Social confusion and impairment
- Uncertainty
- Alexithymia (difficulty understanding own emotions)
- Trauma or other recollection of previous discomfort
- Greater demands than capacity to respond or manage

Coping with anxiety



What do people with autism do to cope with stress or anxiety and what is our attitude to this?

- Self-stimming: rocking, hand-flapping, pacing, repeating phrases etc - why?
- Escape
- Self-injury
- Revert to known, predictable patterns of behaviours or interests
- Seek reassurance, often compulsively
- Lash out at others

'When he is walking in the park, Rod will wear ear muffs to protect him from unanticipated loud noises but not at home. However he is so frightened of normal speech and of the difficulties of processing overlapping speech (which for him is overwhelmingly loud) that he will not allow people to come into the house'

Caldwell, 'The Anger Box' 2014

Observing anxiety



‘He finds himself in a severe predicament: on the one hand he has in his brain the message he has learned telling him that he must hold open the door - and on the other, the message that he cannot fulfil the requirement. These contradictory messages place an overwhelming strain on his processing system: his brain becomes a battleground tipping him into a painful autonomic storm (meltdown) that sweeps aside his ability to behave in ways expected of him.’

*(*CP)*

- ‘Johnny is six years old. He is hard to engage because he attacks other children and staff. He is very quick, biting and grabbing and difficult to contain. He tries to push his chin into the face of the other person he is attacking and bite. One of the triggers for his attacks is if attention that has been given is withdrawn without warning’*

*(*SP)*

The Anger Box, Caldwell 2014

Managing anxiety

- At Queensmill, we use the SCERTS model extensively. SCERTS being: Social Communication Emotional Regulation Transactional Supports

(Laurent, Weatherby, Rubin, Prizant, Rydell - 2005)

- This transactional-developmental intervention model provides us with a method determine how we can enable children with autism to better their manage their autism in two essential domains:
 - ❖ Social Communication - Symbol Use and Joint Attention
 - ❖ Emotional Regulation - Self-Regulation and Mutual Regulation

Broadly speaking using this approach we are able to categorise the presentation of each child's autism into:

- ❖ Social Partner: pre-symbolic means to communicate (gestures and/or vocalizations)
- ❖ Language Partner: early symbolic means to communicate (single word speech, echolalia, pictures/picture symbols, signs)
- ❖ Conversation Partner: sentence and conversational level discourse to communicate

Managing anxiety

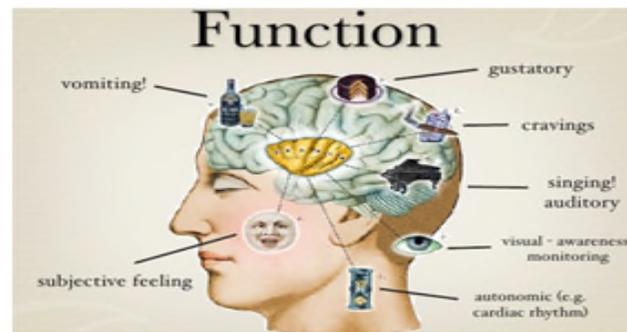


- ‘Emotional Regulation’ is how we describe those behaviours and actions we take to regulate our attention, arousal and in the widest context - anxiety. We have observed that children with autism use a variety of means, some appropriate, many not, to cope with the demands of their environment.
 - Social Partners will, largely speaking use physical means to regulate themselves - rocking, vocalising, escape or ‘shutdown’ as anxiety grows and equally take longer to recover an ‘active alert’ state that is acceptable for the situation. When others offer assistance, this will also be more tactile, physical concrete supports (fidgets, chews, sensory circuits, out for a break) etc
 - Language Partners are able to use symbols such as schedules, ‘first, then, next’ boards, timers, timetables etc as well as being more receptive to distractions like an iPad, favourite toy, activity when offered by an adult
 - Conversation Partners may have greater response to social stories, rules, metacognitive strategies (calming phrases, messages) or approaches like ‘mindfulness’

Our aim is to enable children to achieve greater independence and awareness of their own arousal and anxiety and seek supports (transactional) independently or from others who can help.

Anxiety Awareness

Interoception, the Brain and Autism



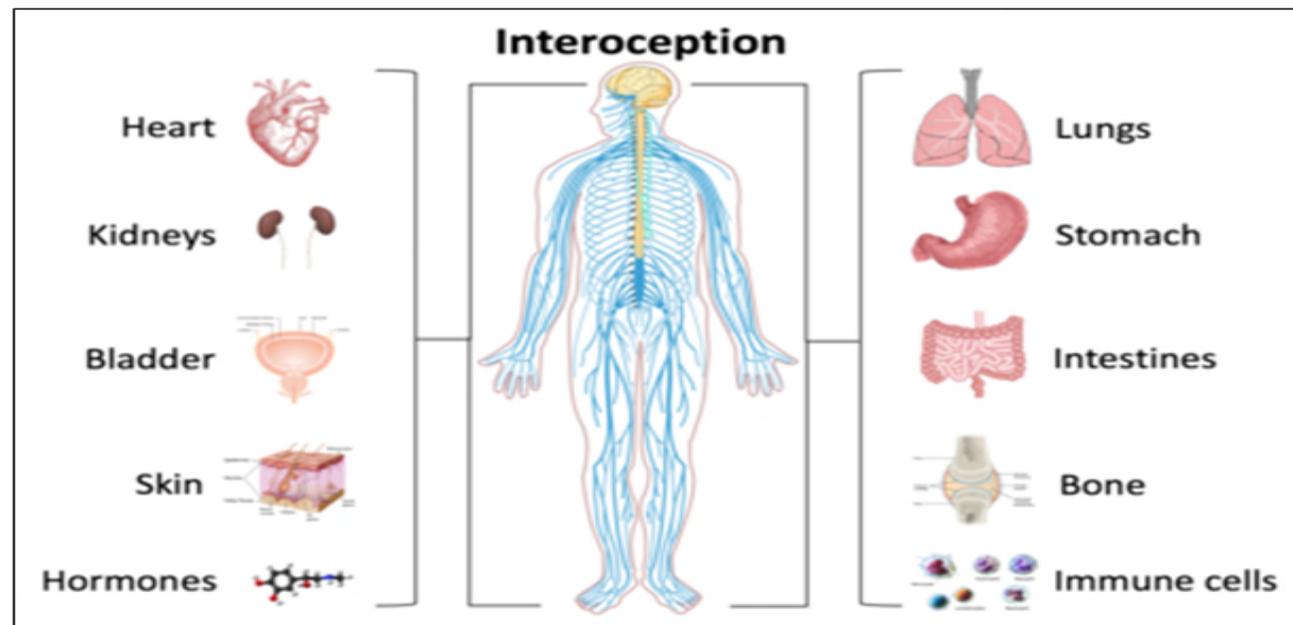
- Fiene and Barlow (2015) were the first to directly look at interoception in individuals with ASD and a number of studies have examined the insula (the brain's interoception centre) in people with ASD.
- Some of these studies show a significant difference between the insula in individuals with ASD and those without ASD:

Connectivity both within subdivisions of the insula and between the insula and other areas of the brain – In a large study, data collected from 539 adolescents and adults with ASD and 573 age matched typical controls indicated a **hypo-connectivity** of the mid and posterior insula in autism (Di Martino et al., 2014)

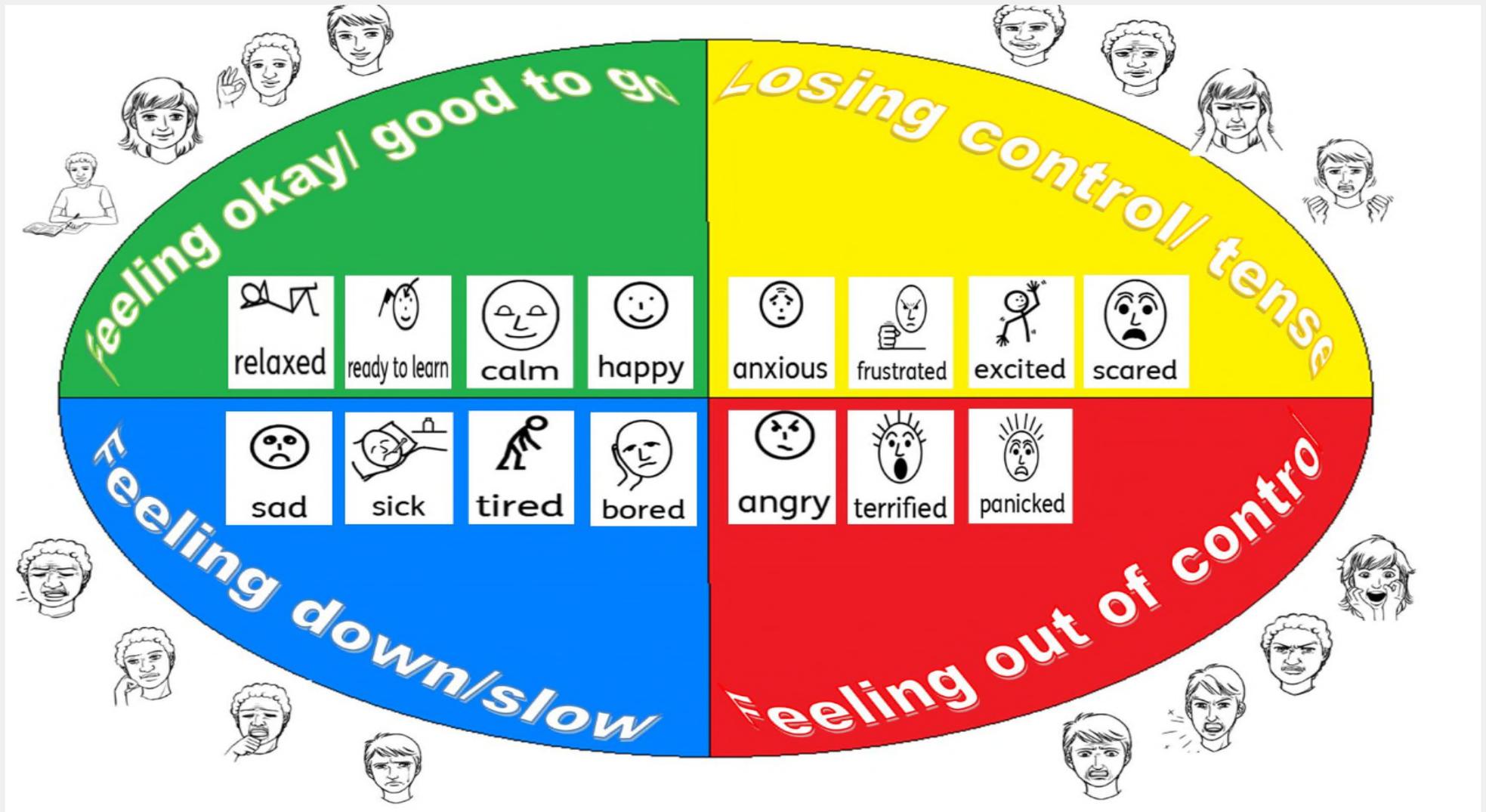
In contrast, one of the first brain imaging studies of the insula of young children with ASD (ages 7-12 years old) found a **hyper-connectivity** of the insula (Uddin, Supekar, Lynch, et al., 2013). This finding suggests that at some point a shift may occur from the hyper-connectivity seen in younger children to hypo-connectivity found in adolescents and adults.

Anxiety Awareness

Interoception - The 8th Sensory system

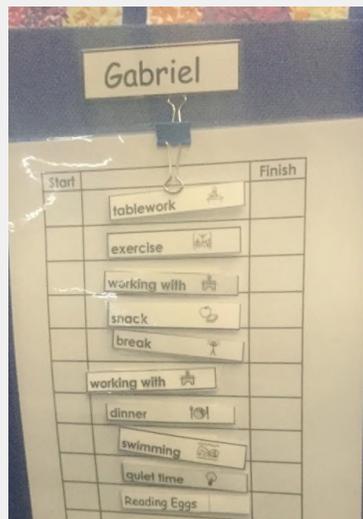


Anxiety Awareness



What does support look like?

- The structured TEACCH (treatment education of autistic and communication handicapped children) provides a predictable, ordered visually transparent environment to help children understand what is around them, the upcoming day, and where they can find resources. This helps to reduce anxiety.

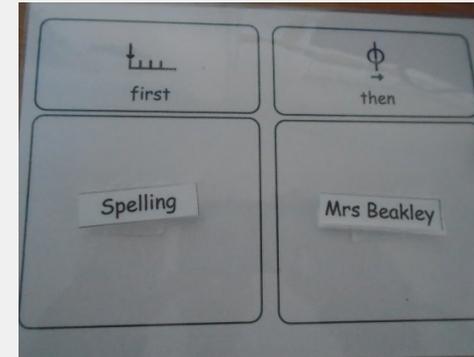
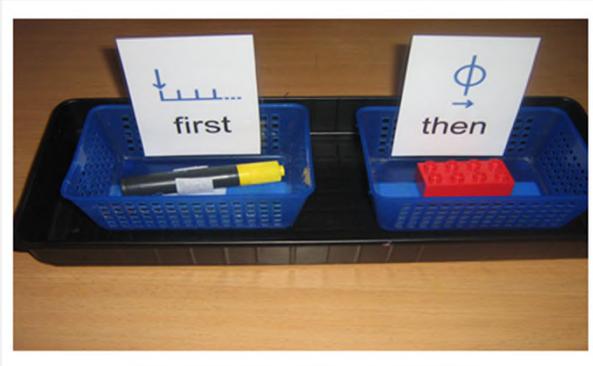


Gabriel

Start	Finish
tablework	
exercise	
working with	
snack	
break	
working with	
dinner	
swimming	
quiet time	
Reading Eggs	



What does support look like?



What am I doing?		
Start		Finish
	Find picture beginning with letter t	
	Get scissors	
	Cut out	
	Get glue stick	
	Stick	

Where possible, making the environment, and sequence of activities predictable and transparent enables the student control and independence in the environment

How do we behave during anxious moments?

Typically these will be during:

- Transitions (within school, within sessions, between settings)
 - In the community
 - Unexpected change
 - Entering new environments
-
- ❖ Give space and maintain your relationship
 - ❖ Reduce language, allow processing time, no raised voices
 - ❖ Provide options (visual is best)
 - ❖ Acknowledge feelings and emotions, providing model of emotional literacy)
 - ❖ Patience
 - ❖ Flexibility
 - ❖ Be creative about options and supports



Solving anxiety problems



- Case Study 1 - (A)

A is 5 years old, non-verbal and joining from a mainstream nursery. Extremely anxious about his new physical environment, routines, peers, expectations and more. A is unable to join his peers in his classroom, preferring corridors and quiet spaces of his choice. Given these huge anxieties and subsequent rigidity, the class team have taken learning to him. Negotiation for control and agenda is constant but gentle, patient and calm. A has only recently (in May) spending full sessions in his classroom with peers.

- Case Study 2 - D

D joins the school in year 7. Her autism is complex and her anxiety extreme and she frequently self-injures. In her previous setting her persistent self injury has been managed with a helmet (to prevent her pulling her hair out) and bandages to prevent her constant scratching of herself and others. D needs two staff members with her constantly. Team reduced demands and simply aimed to discover her likes and interests, sensory seeking behaviours and triggers. Over several challenging months, using intensive interaction, music, sensory soothing resources (TACPAC), and observing her self-soothing strategies (weighted blanket, vocalisations, physical contact of two adults beside her), D is able to learn alongside peers, without a helmet or bandages, following an adult agenda.

Solving anxiety problems

- Case Study 3 - (V)

V is 18 years old preparing to join our post 19 provision. He is non-verbal, communicating via sign. On his first two visits, he is unable to cross the threshold of the reception doors. These transition visits occur with the team showing him visuals of his new environment where he manages to stand and feels comfortable. Being extremely aware and sensitive to his environment, V needs to time to process at his own pace with staff remaining patient, flexible and creative in enabling him to acclimatise. V is now, two years on, accessing a range of environments, including his local community as part of programme.

While flexibility and adjustment of demands and agenda are key, we aim to develop resilience in our students. This occurs by:

- Not shying away from risk
- Assessing autism progress (50% autism specific)
- Endlessly negotiating agenda
- Incorporating special interests
- Adjusting demands
- Planning activities in detail with supports available for students
- Making activity accessible and meaningful to student
- Incorporating technology (PECS via iPad; proloquo2go; visual timetables)
- Integrating rewards
- Celebrating small steps and reinforcing progress in better managing anxiety (self and mutual regulation)
- Integrating calming, regulating activities (Yoga, mindfulness and sensory integration) into sessions and the school day
- Working closely with parents and carers (consistent interventions and programmes between home and school via family support worker) in training and workshops for them specifically.

Questions

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