


Notes to accompany the PowerPoint Slides for the E-learning module for parent-carers: Autism Awareness and Acceptance

NB! Before you start:

- Please note that the PowerPoint which accompanies these notes has been divided into Part 1 and Part 2.
- Remember once the Autism Awareness and Acceptance PPT is open, to then open it up in **Slide Show View**.
- You will need to have a copy of these notes open (preferably a hard copy version), in order to navigate your way through the materials.
- You may also want to consider doing parts of this training with your partner and/or a friend.
- You are welcome to pop an e-mail to sarahs_karma@yahoo.co.uk at any stage should you need clarity on anything or have a specific question you would like to ask.

PART 1

Slide 1: I see your true colours

 You will be able to listen to Cindi Lauper's 'True Colours' by clicking on the speaker icon on this slide.

Lyrics: True Colours

By Cyndi Lauper

You with the sad eyes
Don't be discouraged
Oh I realize
It's hard to take courage
In a world full of people
You can lose sight of it all
And the darkness inside you
Can make you feel so small

But I see your true colors
Shining through
I see your true colors
And that's why I love you
So don't be afraid to let them show
Your true colors
True colors are beautiful
Like a rainbow

Show me a smile then
Don't be unhappy, can't remember
When I last saw you laughing
If this world makes you crazy
And you've taken all you can bear
You call me up
Because you know I'll be there

And I'll see your true colors
Shining through
I see your true colors

And that's why I love you
So don't be afraid to let them show
Your true colors
True colors are beautiful
Like a rainbow

If this world makes you crazy
And you've taken all you can bear
You call me up
Because you know I'll be there

And I'll see your true colours
Shining through
I see your true colours
And that's why I love you
So don't be afraid to let them show

Your true colours
True colours
True colours
Shining through

I see your true colours
And that's why I love you
So don't be afraid to let them show
Your true colours
True colours are beautiful
Like a rainbow

Songwriters: Billy Steinberg / Tom Kelly



Reflection:

Now that you have listened to the song and maybe even read through the lyrics above:

- What, if anything, struck a chord with you?
- How would you link the lyrics of this song to your role as a parent-carer of an Autistic adult child?

Slide 2: Module outline

This is an outline of the content that will be covered over the course of this online module

- Introduction: My true colours
- Making sense of autism
- It is a spectrum
- The challenge of high functioning autism
- Social communication
- Executive functioning
- Interoception
- Girls and Autism
- Anxiety

- All behaviour is communication
- Co-regulation: managing distressed behaviour

Slide 3: Introduction: True Colours

It is always helpful to get to know yourself better. Improved self-awareness will empower you to engage with and respond to others and your Autistic adult child more empathetically.



Complete the **True Colours Personality Questionnaire** (A copy of this questionnaire has been posted together with the PPT and these notes.) This is for yourself only. It may be an idea to 'virtually' meet up with someone else also undertaking this e-Learning opportunity and share your experience of completing this questionnaire.

Reflection:

- What was your experience of this activity?
- What did you learn about yourself that surprised you?
- What about yourself do you feel could do with further development?
- In what ways could you apply what you have learnt about yourself to your parenting/ caring of your Autistic adult child?

Slide 4: Autism – An invisible disability in a visual world



Reflection:

- Think for a minute about what your understanding is of the above statement: **Autism - an invisible disability in a visual world?**
- Jot down on a bit of paper and/or talk with someone about, whatever comes to mind.

Slide 5: Autism – What do you see?



Before you continue with this module, complete the **Autism: Fact or Fiction Questionnaire**. (A copy of this questionnaire has been posted together with the PPT and these notes.) The idea is for you to get a sense of what you already know and understand about Autism.

You will have an opportunity at the end of the module to revisit this questionnaire and based on what you have learnt and/or had confirmed, amend any of your answers using a different coloured pen.

Slide 6: Autism – The disability or the individual

This is a photograph of my son, William. He is now 22. This photograph was taken last winter.



Reflection:

- Looking at this picture, jot down, without too much thought, your impressions of what you see?
- How would you describe William, if you were looking at him on the soccer pitch?

Slide 7: William at 10 years old

This slide depicts William's experience of the world, using many of his words as compiled by me, his mum.

Slide 8: William at 18 years old

This slide depicts William's own words as displayed on his WhatsApp profile some time back.

Slide 9: Autism and Parenting

This is just a reminder that as parent-carers you are the experts on your own children and a valuable resource for professionals and others who provide support to your Autistic adult child and to your family.

Slide 10: Autism-challenges of parenting

This is just a further reminder above all else, to be kind, because many of us are fighting battles that we may know something about and others we couldn't even begin to imagine.



Reflection:

- Based on the knowledge you already have of Autism, what do you think could be some of the challenges parents face on a daily basis?
- How do you think you could contribute to alleviating some of these challenges for yourself and other parent-carers of Autistic adult children?



Read an extract from my story: mum to an Autistic son:

Daring to cross the bridge



Imagine two worlds: a rickety wooden bridge swaying precariously between them. Dangerous in its height above the lashing waters, its distance across and the brittle timber of its design give rise to the fear that has been lurking in my belly!

My son is on the one side and I am on the other. I beckon to him, cajole and plead with him to take that first step and to walk across, to enter my world where people engage and live together.

Yet he vehemently resists, withdrawing, remaining firmly where he feels safe; he in his world and I in mine. I grow weary with trying. My dreams shattered, shrouded in hopelessness I begin searching for answers. Yet, it seems there is none to be found.

From my side of the bridge his world appears lonely; my heart aches. Why won't he venture over? Tentatively I decide to walk across to him, but he refuses to let me in. Crushed I return to my world and he remains steadfastly in his.

Then one day he calls to me! Overcome with joy, my fear aside, I run across to meet him. For a brief moment, the sun shines across the waters, its gentle warmth against my face. I glimpse the boy inside. He is funny, articulate and insightful!

Just as suddenly, the sun moves behind the clouds and the waters grow dark and menacing. It is time to go back. Each day I wait, longing to be invited over to him once again, to feel the sun against my face and to see the boy inside.

So many years have been consumed in search of suitable schooling, to no avail. From schools simply unable to meet his needs, to others completely unwilling to entertain the notion of accommodation, we travelled across the country, searching!

So many education support professionals have been consulted, but not one has communicated with any other. Psychologists, psychiatrist, speech therapist, social worker and occupational therapist.

All their recommendations leading nowhere, amounting to nothing. Now, so many years later, depleted and disillusioned, my son has been an out-of-school youth statistic since he turned 15 in 2013.

Slide 11: Crossing the bridge

What often strikes me as interesting, is the amount of effort put into encouraging Autistic individuals to understand and fit into the neurotypical (a phrase used to describe typically developing individuals) world and how little time is given to empowering neurotypical people to understand the world of Autism .

For the next section of the module, I would like to invite you to cross the bridge and step into the world of Autism.



Reflection:

How could you consider contributing to increasing Autism awareness and acceptance i.e. to engage with and support neurotypical individuals to appreciate that being Autistic is about being different (and what that means), but by no means less?

Slide 12: Neurodiversity

The takeaway from this slide is that essentially being Autistic is about being neurodiverse; DIFFERENT, BUT BY NO MEANS LESS.



Research:

- Spend 15 minutes or so doing a bit of research on Autistic individuals who are and have done interesting things in their lives.
- Go to <https://www.google.co.uk/> and type in something like, 'Well known Autistic Adults' in the search box and hit Enter on the keyboard.



Reflection:

What, if anything, has struck you as interesting about the individuals you have just read about?

Slide 13: Square peg into a round hole



Reflection:

- Are you aware of times, when you may have unintentionally tried to get your Autistic adult to respond in a way typically expected in a particular situation, only to have triggered a complete meltdown?
- What do you think you could/should have done differently?

Slide 14: Making sense of Autism

This slide highlights the areas of difference all Autistic individuals, to varying degrees, encounter by the very nature of being Autistic.

In addition, rather than view Autism as a DISORDER, I prefer to look at it as a **CONDITION** (a social communication condition) that impacts the way in which Autistic individuals **process information** and **make sense of the world**.

- ▶ Click on the link on the slide to watch the YouTube video, '**Just like you-Autism**'.

Slide 15: It's a Spectrum



Reflection:

If you've met one person with autism, you've met one person with autism."

Dr. Stephen Shore

- What do you think Dr. Shore wants us to understand from his statement above?

Slide 16: It's a Spectrum



Reflection:

What is your understanding of the concept of a spectrum?

Slide 17: Like the Visual Spectrum



Read through the slide content

Slide 18: The Autism Spectrum

Be mindful that individuals who exhibited only:

- Social communication difficulties will potentially get a diagnosis of **Pragmatic Language Disorder** and not Autism Spectrum Disorder
- Sensory processing difficulties will potentially get a diagnosis of **Sensory Processing Disorder** and not Autism Spectrum Disorder
- Neuro motor difficulties will potentially get a diagnosis of **Developmental Coordination Disorder (Dyspraxia)** and not Autism Spectrum Disorder



Reflection:

How has your understanding of the concept of Autism Spectrum Disorder (Condition) changed?

Slide 19: High Functioning versus Low Functioning Autism



Reflection:

What comes to mind when you are asked to distinguish between high and low functioning Autism?

Slide 20: The Challenge of High Functioning Autism

This is William, now 22 years old. He has a diagnosis of what was called Asperger's Syndrome Disorder, now often referred to as High Functioning Autism, but actually referred to as Autism Spectrum Disorder (Condition).

Many times over the years I have had other parents say in response to hearing he is Autistic; 'That's not so bad. At least he is not so Autistic'.



Listen to the WhatsApp voice note he sent to me a little while back while out running. Click on the speaker icon on this slide.



Click on the link on the slide to read the article by Lisa Jo Rudy, "**Why 'High Functioning' Autism is so challenging**".



Reflection:

How would you describe William, based on his voice note and in terms of your understanding of so called high functioning Autism?

Slide 21: The Myth of High Functioning Autism

High functioning Autism can make daily life very challenging. Listening to William's voice note it is very possible not to appreciate the extent of his daily struggles.

These challenges may include some/all of the following:

- Sensory processing

e.g. William often says he does not enjoy being outside when it is very windy; he experiences the wind through his hair as painful

📺 Click on the link on this slide to watch the YouTube Video, '**Sensory Overload**'.

- Executive planning skills

Working memory is an executive functioning skill. William has difficulty holding more than one instruction in his working memory at any one time e.g. if he is asked to go to the kitchen, pop the towel onto the radiator on his way and bring the scissors so that I can continue with my workshop preparation, by the time he has put the towel on the radiator he won't always be able to remember what he had to get from the kitchen.

- Transitions and change

William still struggles significantly with transitions and change, but unlike when he was younger, he is now able to articulate his struggle and has developed strategies that help him adjust to unexpected change.

However when he was younger, transitions and unexpected change were significantly distressing for him e.g. if I were to say we needed to go to ASDA and on route mention that we also needed to get petrol, he would become very distressed and would start literally throwing himself around on the back seat of the car; yelling 'This is going to take forever, you said we were only going to ASDA! You lied!'

- Processing of verbal information

William still finds it extraordinarily difficult to process verbal information. For those that don't know him well, he can sometimes appear rude. Often when he is asked something, he isn't able to respond immediately. You are not being ignored. Essentially, I have come to appreciate that William lives in a '5-minute bubble' i.e. he needs this time to process what has been asked, formulate a response (and he will often get frustrated because he knows exactly what he wants to say, but can't always access the words he wants on demand) and then articulate his response.

William has a sort of back and forth communication style; he will keep repeating bits of what he wants to say, adding the new, next bit, repeating it and then moving on a little further, all the while pacing or walking in circles; moving he says helps him keep hold of his train of thought.

- Anxiety and depression

For most Autistic individuals anxiety is like an unwelcome pal, who tags along, regardless of an invitation. Later on we will talk more about Autism and anxiety in greater detail.

William has often expressed how extremely lonely he is, how he really wishes to have friends, a girlfriend to one day. His loneliness and awareness of his difference; that he doesn't just quite fit in, leaves him feeling sad and struggling with bouts of depression.

- Emotional regulation

Much of the difference Autistic individuals have regulating their emotions has to do with how they process the sensory information within their bodies. This refers specifically to a very little known, hidden sense called Interoception. This is looked at in more detail later on.


Slide 22: Social communication



Reflection:

How would you distinguish between the concepts: communication and social communication?

Slide 23: Failure to communicate

 Use the link on the slide to watch the video, **Failure to communicate**.



Reflection:

What struck you as interesting about how the two women were eventually able to communicate and make themselves understood?

Slide 24: What is communication?

The takeaway from this slide is the need to be mindful that most of what we communicate is not actually through the words we use, but in fact through our tone of voice and our non-verbal communication.

In light of this then, for Autistic individuals, who as you know have difficulties with social communication, which is 93% of any total communication, they then only have potentially accurate access to 7% of what is communicated i.e. the actual words we use and if these words are not clear (we do not actually say what we mean) and/or there is a mismatch between our verbal and non-verbal communication, tone of voice and our words, it can become very difficult for an Autistic individual to navigate the social world.

Slide 25: Behaviour and communication

This is a good reminder that all behaviour is communication. Part of our role as parent-carers is to try to make sense of what the behaviour we observe is in fact communicating. If you like, it is about developing the capacity to accurately read the subtext of our Autistic adult's behaviour in order to be able to respond appropriately.

Slide 26: Executive functioning



Read the article by Judy Eaton; '**Living in a 5-minute bubble: The impact of poor executive functioning skills**' by clicking on the link on the slide.



Reflection:

Taking into account what you have just read, how can you apply what you have learnt to your daily parent-carer role?

Slide 27: Executive functioning

To learn more about Executive Functioning Skills and how they guide everything we do from making decisions, to staying on track with an activity, to planning and prioritizing a task; the ability to make a decision, plan it out, and act on it without being distracted, click on the link on the slide.

Slides 28 and 29: Working memory

Activity:

- Give yourself 60 seconds to memorize the items on this slide.
- Once the 60 seconds is up, click on the slide in order to hide the items.
- Now write down as many of the items as you are able to remember.

Reflection:

- What strategy did you use to aid your memory?
- Did you do this consciously i.e. you were aware you were going to e.g. categorize the items into two groups: all the red coloured items versus all the functional items or was it only on reflection that you realized what strategy you had used to aid your memory?

The take home message is that many Autistic individuals have difficulties with their working memory and with this in mind, it is important to think about how this difficulty can impact on the behaviour exhibited by our Autistic adults and our subsequent reaction to what we see.

Slide 30: Information processing


Reflection:

- How did you experience this activity?
- How did this make you feel?

Your experience of this activity is very much how many Autistic individuals experience the processing of information on a daily basis.

PART 2


Slide 31: Interoception

 Click on the link on the slide to read the article, '**What Is Interoception and how does it impact those with Autism?**' written by Kelley Mahler, an occupational therapist.


Reflection:

What was, for you, the most interesting thing you learnt from reading this article?

Slide 32: Autism and Interoception


 Click on the link to watch the YouTube video, '**Autism and Interoception: the one big thing no one is talking about**'.

Slide 33: Autism and Girls

 Click on the link on the slide to read the article, '**Why many Autistic girls are overlooked**' by Beth Arky.

Slide 34: The cost of camouflaging

Many girls mask their autism, sometimes evading diagnosis well into adulthood. These efforts can help women on the spectrum socially and professionally, but they can also do serious psychological harm.

 Click on the link on the slide to read the article, '**The costs of camouflaging Autism**' by Francine Russo.

Slide 35: Autism and Anxiety

It is important to note that feeling anxious is part of being human and that a certain amount of anxiety is a good thing, however where being anxious can be problematic, is if it is of such a degree, that it begins to significantly impact on one's daily functioning i.e. it significantly hinders or makes it impossible for one to engage meaningfully in life.

As already mentioned for many Autistic individuals anxiety is a daily experience. The Autistic nervous system is often extremely fragile, running naturally on high idle. The day to day processing of information and regulating daily experiences can be extraordinarily energy sapping, literally exhausting.



Reflection:

- What is your understanding of the difference between a tantrum and a meltdown?
- What could trigger a meltdown for an Autistic individual?
- In what ways would your response to a tantrum be different from that to a meltdown?



Click on the link on the slide to read the article, '**Understanding the Difference between Meltdowns and Tantrums**' by Raun Kaufman

Slide 36: The Delayed Effect



Click on the link to watch the YouTube video, '**The Delayed Effect**'.



Reflection:

- Think about a time when you experienced a delayed reaction to the build-up of anxiety and stress; what would have helped you; prevented you from going into 'meltdown'?
- Given what you know about your Autistic adult, what do and could you put in place to minimize meltdowns in your home?

Slide 37: The hand model of the brain



Click on the link on the slide to watch Dan Siegel explain the '**Hand Model of the Brain**' to parents

Slide 38: What happens when we flip our lids

Another really useful way of explaining how the brain works and what happens when we become really distressed is to use the analogy of the '**House Brain**'.



Click on this link: <https://www.heysigmund.com/how-to-teach-kids-about-the-brain-laying-strong-foundations-for-emotional-intelligence-by-dr-hazel-harrison/>

Slide 39: If we flip our lids

This slide describes what happens in our brain when we 'flip our lid' and the two systems are not integrated and able to support one another i.e. the information being processed by the reptilian and limbic brains is not being mediated by the neocortex (thinking brain). Essentially the neocortex has gone offline and we are functioning purely out of our reptilian and limbic brains. When this happens we tend to react in one of four ways:

- Fight
- Flight
- Freeze
- Fawn

Most of you will be familiar with three classic responses to fear (real or perceived) — fight, flight and freeze. From an evolutionary standpoint, these responses have served us well by allowing us to respond quickly to threats and get to safety. However there's actually a fourth response. It's called 'fawn'.

 Click on this link to read more: <https://themighty.com/2020/01/fight-flight-freeze-fawn-trauma-responses/>

Slide 40: FIGHT-FLIGHT-FREEZE Response

 Click on the link on the slide to watch the YouTube video, 'The fight-flight response'.

Slide 41: The Arousal Cycle

This next slide looks at the journey **we all** travel when becoming distressed and exhibiting distressed and sometimes very challenging behaviour.

Looking at the graph, the Y Axis is the Arousal Level (Physiological State) and the X Axis, Time (Not indicated in particular units as this can vary from seconds, to minutes to hours, depending on the individual). The time line can be dependent on the individual's previous experience, level of distress, a number of external factors as well as the response/s from others.

Along the top of the graph are 6 phases and during each phase different things happen.

If we understand and identify where an individual is along the arousal cycle then we are much more likely to be able to disrupt or prevent the cycle from occurring and the subsequent meltdown.

Trigger phase - starts with Anxiety the individual experiences elevated anxiety levels in response to a real or perceived threat.



Reflection:

What do you regard as anxiety provoking?

Many Autistic individuals are likely to have elevated anxiety levels anyway, as they try to deal with daily events. There is usually a trigger event e.g. being spoken to by someone and feeling triggered by a particular tone of voice (incongruent with the actual words spoken), being challenged, feeling threatened etc. but it could also be self-doubt, lack of confidence, fear of failure.

During the initial part of the **Escalation Phase** comes **Anger**, this is generalized and may be experienced as the individual being moody, unresponsive, disrespectful, talking back, but is usually not directed specifically at any one person, there **is often no eye** contact and the body of the individual may well be turned away from you. This will look different for each person. Your knowledge of the individual i.e. your Autistic adult child is key.

Should the individual's arousal continue, then the anger in the escalation phase is will progress into **Aggression**. The difference between the earlier anger exhibited and the current aggression observed, is that the aggression will now be directed at one person in particular; the individual's body posture changes and there may well be eye contact. His/her voice level becomes raised and you might see physiological changes to his/her breathing and exaggerated hand movements. Language may well be directed specifically at you, this more than likely will include some, if not a lot of swearing.

If the escalation phase continues then it leads to what is called **Assault**. This is the start of next phase in the arousal cycle; the **Crisis Phase**. In most cases however, there is not actual physical assault during the this part of the escalation phase, but it often leads to the individual becoming very distressed emotionally, possibly running away and out of room, withdrawing to

what he/she experiences as a 'safe' place.

At this point the individual is in **Crisis** and you now need to think of self-protection and damage limitation. **At this point it is best to remain silent; essentially your words are just white noise. The individual's thinking brain is currently offline and therefore cannot process any verbal information.** During the Crisis phase you should try to ensure the individual remains safe, being ever mindful that his/her level of arousal is extremely high.

As the individual moves out of crisis into the **Recovery Phase**; remember it takes time for the physiological changes that took place in the body to recover and return to baseline i.e. for the individual to feel and be calm. It is essential that during this time the individual is not pressurized or challenged in anyway as there is a very strong likelihood that this will be experienced as an 'additional assault' by the individual, with the potential of sending him/her straight back into crisis. Parent-carers should try to hold off discussing what happened while their Autistic adult is still in the Recovery Phase.

Eventually there is a very rapid fall in the level of arousal and this is what is referred to as the **Post Crisis Phase** which is often followed by a sense of **Exhaustion**. Basically this means the individual is literally physically tired and in some instances may even fall asleep. The body needs time to recover from the physiological changes that took place.

After sufficient time (this varies from person to person) the individual returns to their baseline level, the **Learning Phase**. It is in this phase that any reflection/discussion can potentially take place, but be careful that the cycle does not start all over again. For some individuals an attempt at reflection is experienced as an 'additional assault', which then sends them back immediately back into the Crisis Phase.

Slide 42: Common misinterpretations of observable behaviour

Activity:

- Select any two of the listed observable behaviours in the table on the slide and provide an alternative interpretation/s to the ones given.
- Consider for a minute, what informed your reinterpretation of the observable behaviours you selected

Slide 43: All Behaviour is Communication

The iceberg is a metaphor we can use to help us to remember that there is more going on than the behaviours we can see and react to. We often talk about triggers – and it is true that sometimes it is difficult or impossible to know what the trigger was. However it is important to remember that **there is always a trigger**, but even the Autistic individual may not be aware of what that trigger was. We all, I am sure, are not always aware of what triggers certain behaviours in ourselves!

ICEBERG METAPHOR:

The behaviour you see and react to is the tip of the iceberg - the bit we see, and the bit we react to.

Have a look at the **Carrot and Stick Boat**. Essentially this above the water response can be a behaviourist way of responding to the behaviours we see. We respond by trying to shape the behaviours using rewards and sanctions. This will not work for complex distressed behavior as it does not address the underlying issues. If you ignore them you will not be able to successfully improve things. This is why this type of approach is usually unsuccessful in bringing about long term change.

What we actually need to do is **look at what is going on below the surface of the water** where the real issues are and address what is going on there.

Biological – tired, hungry, sleepy, sensory overload (noise, lights, smells, proximity). Pain – ears, throat, teeth. Need to eliminate the possibility of physical pain first.

Emotional – not able to self-regulate, different motivators, coping with change. **Frustration** – It's a complex thing to first understand your own thoughts, feelings and intentions and to then understand that these could be different someone else's. Can lead to **confusion** and **increasing distress** 'why don't you understand?' The world can become quite **overwhelming**.

Cognitive – understanding, attention, memory, perception of time

Prosocial – social behaviour where the intent is to benefit others –helping, sharing, cooperating etc.

Social – understanding feelings and intentions of self and others

Now take a look at the **Stress Detective Submarine**; this can be difficult in the heat of the moment, but **good knowledge of an individual's needs** is essential, as is **good sharing of information**. The submarine is working away, below the water line trying to find out about the individual, to identify and then reduce the stressors and anxieties. Teaching the individual new skills to manage the barriers they are experiencing.

Thinking in this way allows us to '**stop and think**'; when we see our Autistic adult becoming distressed. We need to identify '**why**' in order to consider '**what to do**' e.g. if the individual is seeking sensory feedback, and the focus is on putting specific communication strategies in place it will be ineffective and possibly even detrimental to the Autistic individual. If we can direct our focus more appropriately, we can avoid hours of wasted, but well intentioned effort.

Slide 44: Becoming a stress detective

This requires of us the capacity to reframe the behaviour we see.

Fight or flight response- this is our innate primitive behavioural response to a threat

Stress and coping- the individual's level of stress and anxiety reaches a point where they have to have emotional release and this is expressed as distress in a myriad of different ways.

Additional Support Needs – e.g. Autism Spectrum Disorder, Language and Communication Impairment, Visual or Hearing Impairment, Cognitive difficulties, Sensory processing difficulties.

Developmental stage – e.g. Terrible 2s, delayed development e.g. Autism is a developmental condition, adolescence and the accompanying significant restructuring of the brain (only fully completed in our mid-twenties)

Reinforcement- the individual (young and old) has had previous behaviour reinforced, either positively or negatively so increasing the likelihood of the behaviour being repeated.

Trauma- behaviour is linked to previous negative experience, attachment issues, and can be triggered by environmental factors like sounds or smells.


Physiological need – over-tired and need to sleep, lack of food/drink

As a way of having primary needs met – this may be part of an individual's past and the nature of their attachment relationship i.e. the blueprint of how relationships work (based on their primary attachment experience) is that they are unlovable, others untrustworthy and unreliable

and the world is an unsafe place.

To gain control – this may be an individual who has been exposed to unpredictable, chaotic situations and as a result tries to control his/her immediate environment to help manage his/her feelings and/or individuals who experience an anxiety driven need to feel in control, thereby avoiding all demands, those imposed by others as well as themselves, in order to better manage the anxiety they feel.

It is important to remember that there can be many different reasons / combinations of reasons for distressed behaviour. It is helpful to stop and consider what is going on when this is observed. This highlights further, the importance of monitoring behaviour over a period of time and to then analyze the findings; to look for recurring patterns that may help to make sense of the behaviour observed.

 Click on the link on the slide to watch the YouTube video, which explains the '**Stress Bucket**' analogy.

 **Activity:**

Using this analogy, imagine your own stress bucket which you carry with you. Slowly it fills up as you experience different types of stress. Sometimes you feel strong enough to carry a lot of stress, but it's important to find activities which help to lighten the load i.e. allow some of the stress to dissipate.

- What helps you to lighten/empty your 'bucket'?
- How can you maintain these strategies when other pressures build up, and you sense your 'bucket' is about to overflow?
- How can you consider supporting your Autistic adult to lighten the load of their stress bucket?

Slide 45: All behaviour is communication

This slide highlights very important questions we need to be able to ask ourselves in the face of our Autistic adult's distressed and sometimes challenging behaviour.

 **Reflection:**

- Think back to a particular incident of distressed and/or challenging behaviour you experienced with your Autistic adult; reflect on what need was being met for your child through his/her distressed and/or challenging behaviour?

Remember what you perceive as problematic behaviour, is for your child, in that moment, the SOLUTION!

- Thinking back to the situation, did your intervention make things better or worse?
- Was there anything you could/would have done differently?

Slide 46: Likely interpretations of observable behaviours

 **Activity:**


Compare what you have written in response to the activity on Slide 42 with what is on this slide, what did you notice about your responses in comparison to what responses were given on this slide?

Slide 47: Trying to reduce distressed and challenging behaviour

This slide just reiterates the need to become stress detectors; move beyond the tip of the iceberg and explore the remaining part of the iceberg beneath the surface of the water.

Slide 48: Reframing behaviour

A reminder; for many Autistic individuals with additional support needs, what appears to be 'won't' is actually more accurately '**can't yet**'.

 Click on the link on the slide to read the article by Dr. Ross Greene in which he explains, '**Kids do well if they can**'.

Slide 49: See a child differently, you see a different child

Activity:

Look at the picture on the slide, what are the two images you can see?

Slide 49: Reframe behaviour

The above phenomenon is called an '**aspect-shift**', and it applies just as much to how we see our children, as to how we see ambiguous visuals.

I can paint you a verbal picture of a child who is resisting tidying her bedroom, there is literally stuff covering every surface including the floor. She comes up with a million excuses why she can't do it, or gives up at the slightest hurdle, and all you see is a child who's too lazy or unmotivated to begin tidying her room. But once you understand the Self-Regulation distinction between *lazy* and *limbic*, and how, when a child's 'limbic brakes' are triggered they block her ability to initiate a task, you'll see a completely different child before your eyes.

But there's one big difference between the above example and the image on this PPT slide. In the case of the vase-faces, all that's involved here is where you *focus* your gaze. But in the case of the child, the second you see a different child, everything about how you engage with that child changes in a split second.

Instead of being frustrated or annoyed, you see before you a child who is over-stressed, unsure where/ how to start the process of tidying her room. Questions suddenly occur to you that you would never have thought of when you saw her as lazy and uncooperative.


For example:

- Why did this problem or task over-stress her?
- Was she overstressed to begin with, and if so, why?
- What can you do to reduce her overall stress load?
- What can you do to reduce the cognitive load of tidying her room?
- What can you do to help her recover so that she has both the energy and the desire to tackle tidying her room in the future?

But there's an even bigger difference between the two examples. In the case of the child, the second you see her differently everything about your body language changes. Your facial expression, eye gaze, tone of voice, gestures, posture all soften as a result of your aspect-shift. And the child picks up on all this. In an instant, she doesn't just mirror, but actually shares your calmness.


What's involved here isn't just a shift in how you perceive a child's behaviour. A child responds intuitively to the change that she senses in you. This is the reason why, when you see a child differently, you quite literally see a different child.

Slide 51: The three R's of how to respond to distressed and challenging behaviour

 This slide is pretty self-explanatory, have a read through the content and consider using this as a framework of how to respond to distressed and/or challenging behaviour.

Slide 52: Attuned communication

At the core of being able to provide good enough parenting/care, is attunement. Attunement is being aware of and able to respond to another's needs.

 Click on the link on the slide which explains **the importance of attunement** as well as ways in which parent-carers can be better tuning into their children's needs.

Activity:


Using your understanding of what you have read as well as your experience of being parent-carers; reflect on how you could respond in an attuned way to the following scenario described below:

You announce to the family you are making toasted sandwiches for lunch. Two days prior to this you had made toasted chicken-cheddar melt sandwiches. You indicate to everyone what options are available, which do not include the chicken-cheddar melt of two days earlier. Tensions rise as your Autistic adult son asks for chicken-cheddar melt and you repeat several times the options available, your own frustration increasing at having to repeat for what seems like the millionth time, what you have already said. Before you know it, what started out as your need to provide some nurture becomes a full scale war of words.

- What do you think went wrong here?
- How could you have, as the parent-carer in this scenario, named out loud, what you thought was going on for your Autistic adult in this situation?

Slide 53: The art of co-regulation

Neuroscience shows that humans develop their abilities for emotional self-regulation through connections with reliable caregivers who soothe and model using a process called 'co-regulation'. Many individuals, Autistic and neurotypical, have difficulty regulating their emotions and impulses. Co-regulation provides a practical model for helping us all learn to manage our immediate emotions and develop long term self-control.

 Click on the link on the slide to read the article, '**Calming together: the pathway to self-control**' by Howard Bath

Slide 54: The power of connection

Be mindful here that connecting with an Autistic individual may look and feel different from how one might connect with a neurotypical individual e.g. some (definitely not all) Autistic individuals struggle to make eye contact while processing what is being said. Therefore it may be less distressing if you were to sit alongside, rather than opposite your Autistic adult child, when wanting to engage in conversation and/or an activity.

 The National Autistic Society Website: <https://www.autism.org.uk/> as does the PDA Society: <https://www.pdasociety.org.uk/> offer lots of valuable information.

Slide 55: The importance of self-care

A good reminder to all of us, is the idea that **one cannot pour from an empty cup**; we need to make time to take care of ourselves and each other.



Activity:

Take some time, to think about what you need to do daily to replenish your inner resources. A very practical, concrete way of doing this could be for you to create your own 'Energy Account'.

Essentially what you do, is on a piece of paper, create two lists: a list of things that sap your energy (withdrawals) and a list of things that replenish your energy (deposits). Assign a numerical value to each withdrawal and deposit to give each a specific weighting e.g. 10 points mean the activity gives/takes a *little* energy and 100 points means it gives/takes a *lot* of energy.

Energy Accounting Activity Example	
Withdrawal	Deposit
not sleeping (80)	walking (20)
school (90)	reading (90)
crowds (70)	painting (30)
noise (80)	origami (50)
brightness (50)	solitude (80)
shopping centers (50)	lisa (80)
swimming pools (80)	cat cuddles (20)
hot days (50)	cross-stitch (20)
rushing (70)	chosen noise (50)
pain (90)	time with mum (50)
change (90)	rug rolling (10)
screens (50)	miss Dani (20)
sport (70)	accomplishing hard things (90)
social events (80)	lego alone (50)
busyness (60)	noise-cancelling headphones (50)
appointments (70)	tactile play (50)


The idea is that when a withdrawal, or numerous withdrawals are made, deposits need to be made in order to prevent the account running into overdraft; thereby enhancing one's potential to respond in ways the children we support, need, particularly when they are expressing and/or showing signs of becoming distressed.


Compiling your 'Energy Account' makes explicit your individual needs, but also helps create an appreciation of how you can maintain a 'balanced account'. With this information you will then be well on your way to thinking about how to schedule time for yourself. You will need to actively think about how this is going to look and when you plan do these things. My suggestion is that you have a weekly schedule

prominently up on the wall on which you can write (using different coloured pens) when you plan do what.

Slide 56: Thank you

In closing, I would just like to thank you for embarking on this journey to learning more about Autism.

 Please would you go back to your completed **Autism: Fact or Fiction Questionnaire** and using a different coloured pen from that which you used originally, amend any of your answers if necessary.

 Lastly I would be very grateful if you would send an e-mail to sarahs_karma@yahoo.co.uk with feedback on your experience of this module:

- What did you enjoy most about this module?
- What did you find difficult?
- What would you have liked done differently?
- What would you have liked more of?
- What do you regard as your key takeaway message/s from this module?

