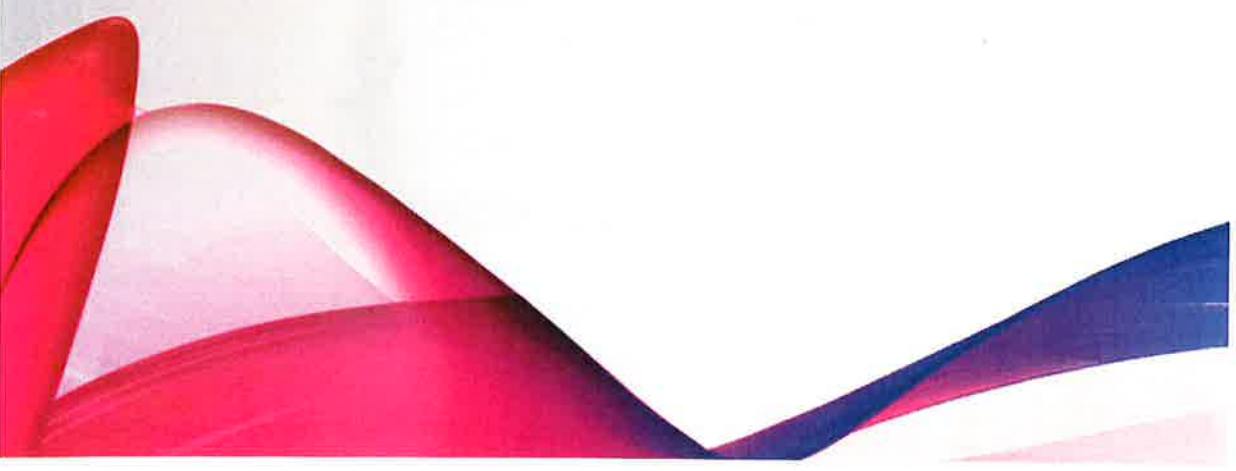
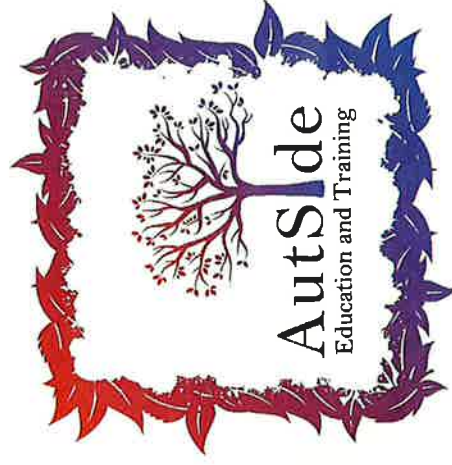


EXTREME DEMAND · AVOIDANT PROFILES AND AUTISM





**Welcome to this family seminar
focusing on Extreme Demand
Avoidant profiles**

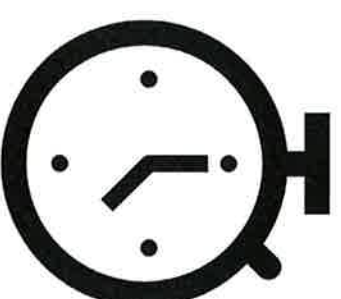
**This seminar is delivered by Autside
Education and Training.**

DOMESTICS

Housekeeping (toilets,
phones, fire alarms)

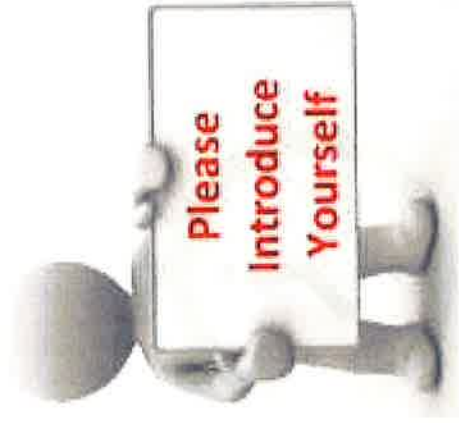


Timings (breaks & lunch)



Confidentiality (what is
said in the room stays in
the room)





INTRODUCTIONS

Please introduce yourself, tell us a little about yourself....



AGENDA

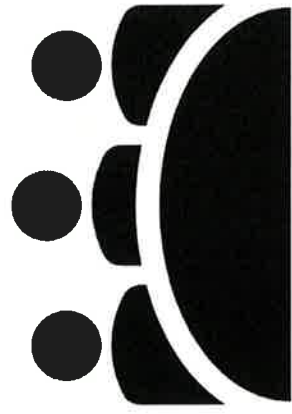
What is EDA?

History of EDA and how our knowledge has evolved

Identifying EDA

Latest research/academic studies and current medical/political position

Management Strategies



ACTIVITY



Autism and Extreme Demand Avoidant Profiles

Activity – True or False?



Individuals with EDA usually have better eye contact than individuals with autism.	F
Rewards and sanctions work well for individuals with EDA.	T
People with EDA are not sociable and prefer to be alone.	F
EDA is the same as autism and or ODD.	F
Individuals with EDA will need support for throughout their lives.	T
EDA is a controversial diagnosis and many professionals do not recognise it.	T
EDA is not in the DSM-V.	T
EDA is also known as Newson's Syndrome.	T
EDA affects the same number of boys as girls.	T
EDA is now recognised as an Autism Spectrum Disorder.	T
EDA was originally part of the "PDD" family.	T
Individuals with EDA experience the same level of anxiety as those with autism and ODD.	F
People with EDA understand social rules better than those with ASC. <i>Surface level</i>	F
Individuals with EDA like routine and sameness.	T + F
Children will grow out of EDA.	F



WHAT IS EDA?

WHAT IS EXTREME DEMAND AVOIDANCE?

- PDA was originally described by Elizabeth Newson in the 1980s
- It is increasingly used to describe a particular ASD profile
- It is also sometimes referred to as Extreme Demand Avoidance – with the term 'Pathological' falling out of favour due to 'perjorative' connotations'
- Its is sometimes referred to as the female presentation of autism in fact PDA diagnosis is stable and equal

INTRINSIC - NOT AVOIDANCE

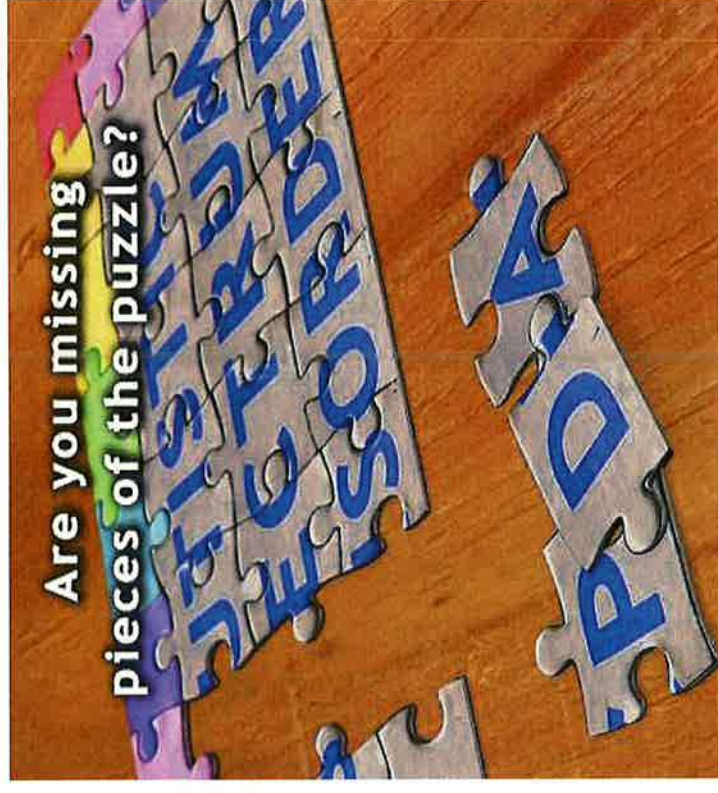
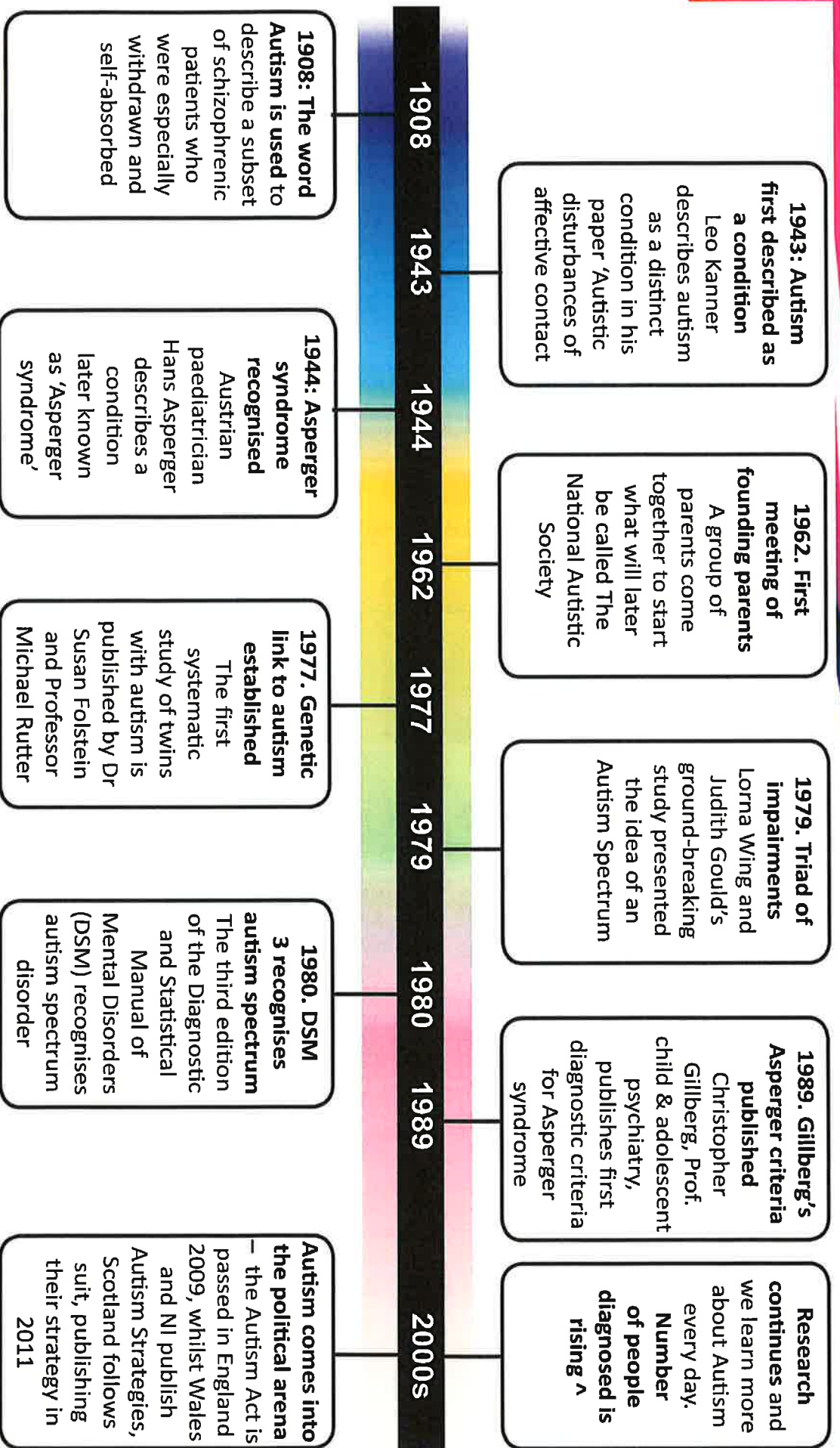


Image credit pdasociety.org.uk





Early work on PDA started by Elizabeth Newson



First Peer Reviewed Publication on PDA published by Elizabeth Newson in the Archive of diseases in childhood

www.adc.bmj.com

PDA information published on National Autistic Society website

www.autism.co.uk



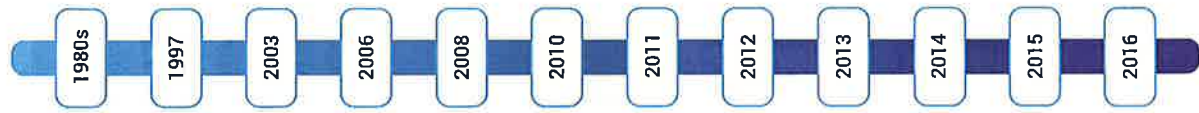
First MAS/NORSACA conference takes place. Launch of book 'Understanding PDA in children'



New Research 2013 - 2015. Researchers: Gillberg, Gould, Gore-Langton, Happé, O'Nions, Viding and others.



January 2015, MAS update their website and publications to include PDA as part of the Autism Spectrum



1980s

1997

2003

2006

2008

2010

2011

2012

2013

2014

2015

2016

PDA Contact Group formed by parents, affiliated to 'Contact a Family'



www.cafamily.org.uk/


PDA paper presented by Phil Christie at the World Autism Congress, Cape Town



PDA Research - led by Francesca Happé - begins at Kings College, London



National Autism Standards Guidance created, based on Phil Christie's 2007 Good Autism Practice publication



PDA Contact Group become PDA Society and new website and forum launched



January 2016
PDA Society awarded charity status

Registered Charity No. 1165038

ELIZABETH NEWSON



"One of Newson's strongest beliefs about her work was that it should "make sense". Many parents would attest to her astute observations and genuine personal commitment – as well as the accuracy of the clinical descriptions that helped them make sense of their child's behaviour."

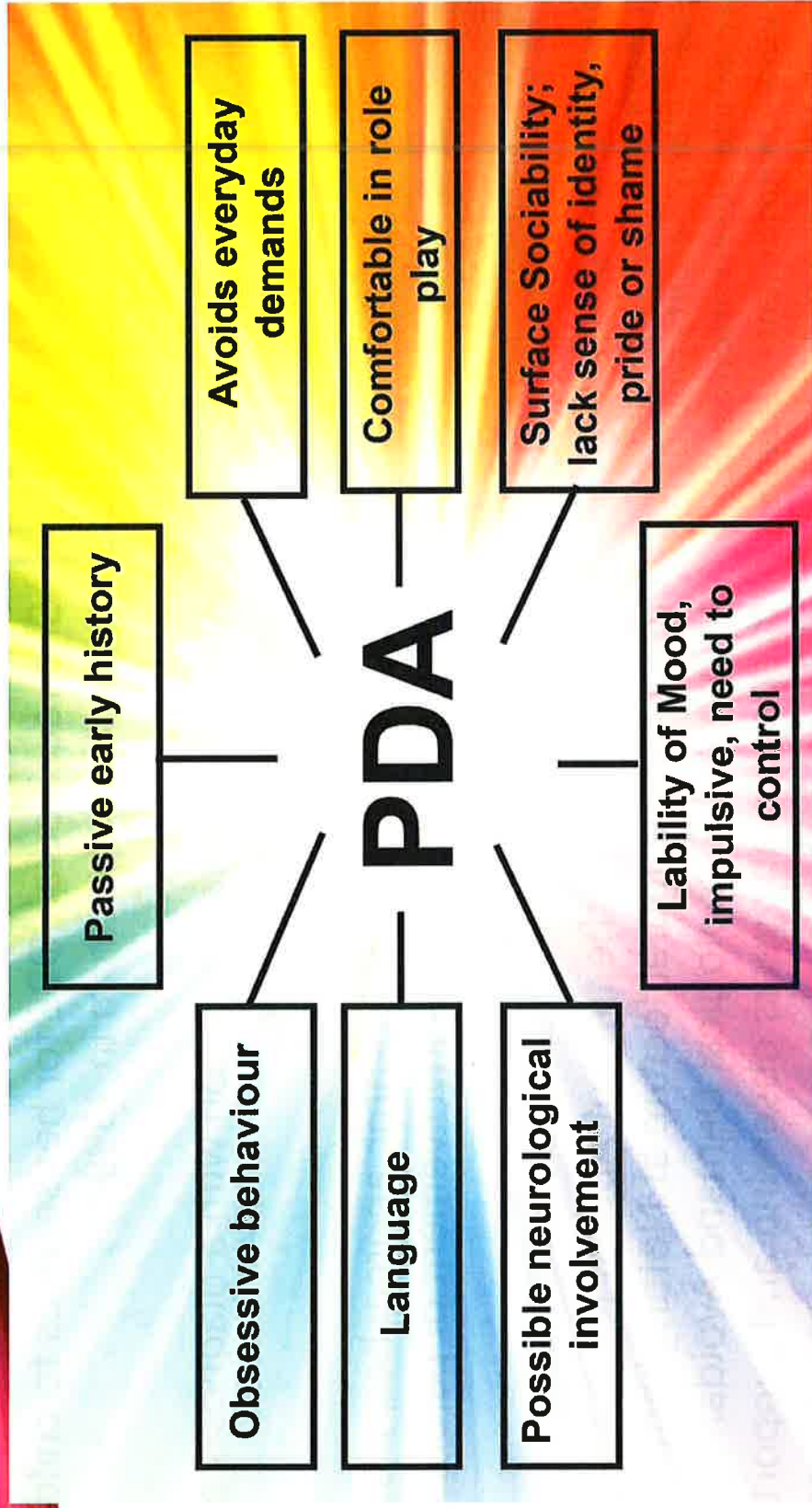
Elizabeth Newson was a child psychologist

She received an OBE for her services to children on the autism spectrum in 1999

She was a parent to a son with a diagnosis of Asperger's Syndrome

She pioneered child centric approaches, play based assessments and the involvement of parents in the process

She worked in the field of Autism for many years and used her inaugural lecture at Nottingham University to present Pathological Demand Avoidance, going on to spend many years observing and supporting children with the proposed syndrome during her time at a diagnostic centre at Sunderland House School, later named the Elizabeth Newson Centre



Newson's criteria of PDA (2003)

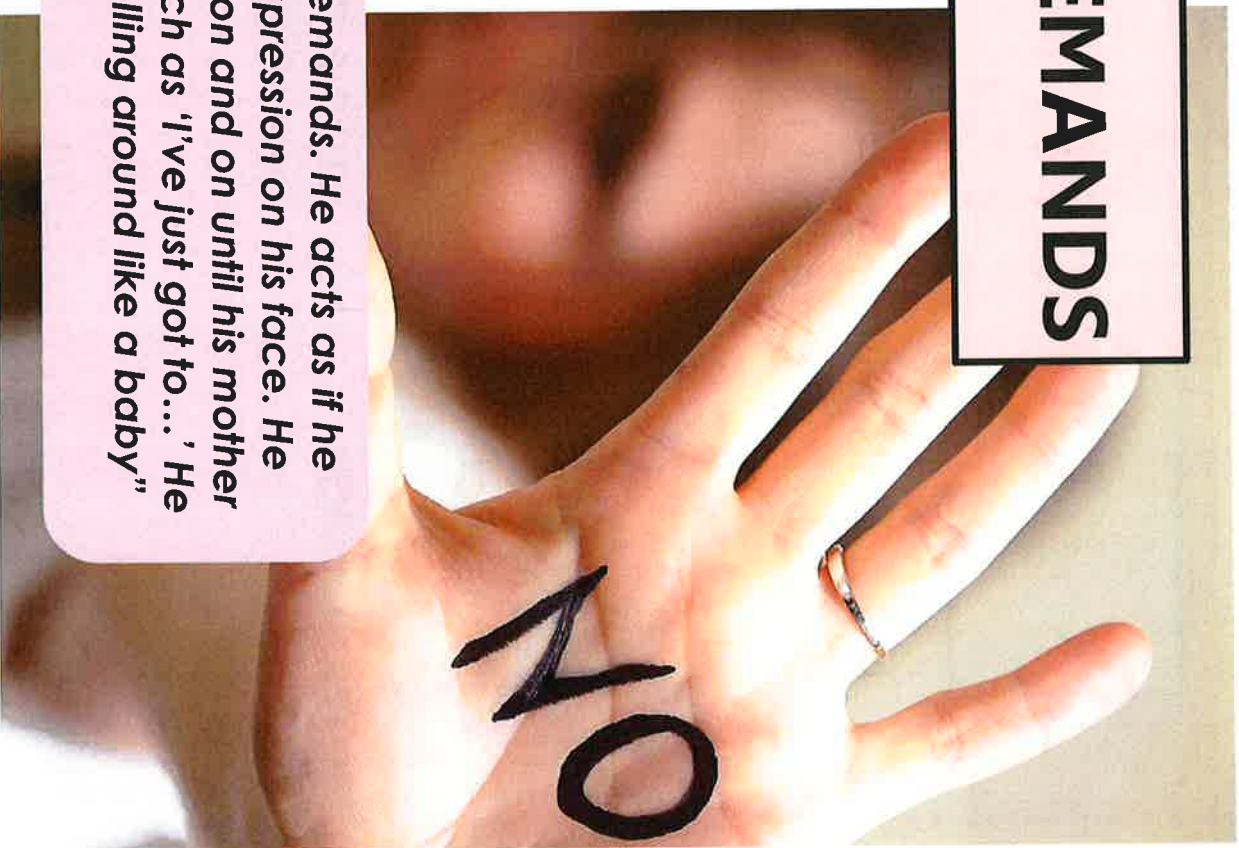
EXTREME AVOIDANCE OF DEMANDS

The most important characteristic in the criteria, present in 100% of cases is an extreme, pervasive resistance/avoidance of everyday demands.

This even relates to demands the individual places upon themselves and demands that are things they would very much like to do.

"He has a wide variety of strategies to avoid obeying direct demands. He acts as if he hasn't heard, carrying on with what he's doing with a blank expression on his face. He distracts by starting to talk about something else and he will go on and on until his mother has forgotten what she wanted him to do. He makes excuses such as 'I've just got to...' He says 'I can't' in a plaintive voice or falls to the floor and starts rolling around like a baby"

Letter from paediatrician



EXTREME AVOIDANCE OF DEMANDS

Individuals will often employ a wide variety of avoidant behaviours which range from aggressive to seemingly skilled manipulation including:

Diverting Attention

- Steering conversation
- Delaying Tactics
- Yes, but later

Excuses

- I'm poorly
- I'm busy
- Pretending unable to do something

Refusal

- Refusing flatly
- Disruptive behaviour
- aggression

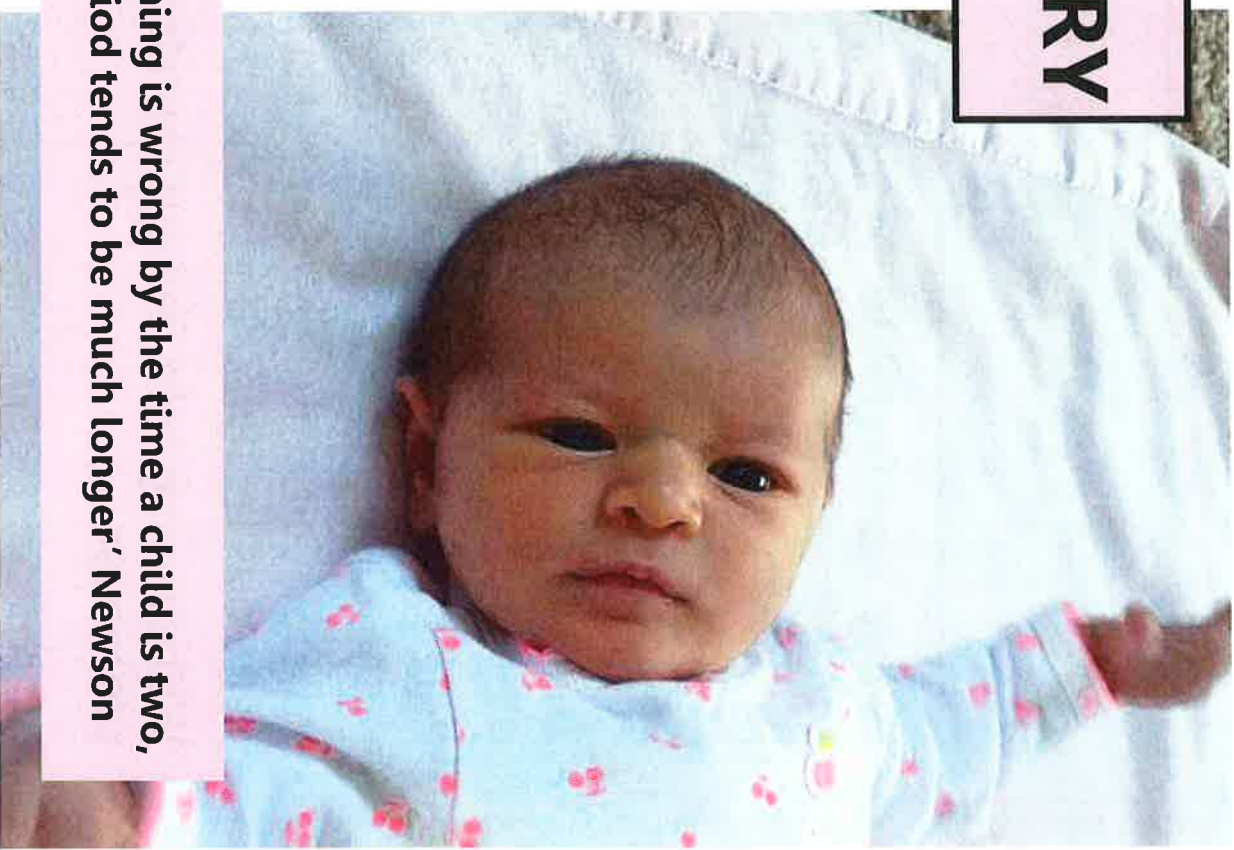
Parrying

- "Come look in my mirror", "but I have my own mirror"
- Disengagement
- Sensible reasons why
- humour

PASSIVE EARLY HISTORY

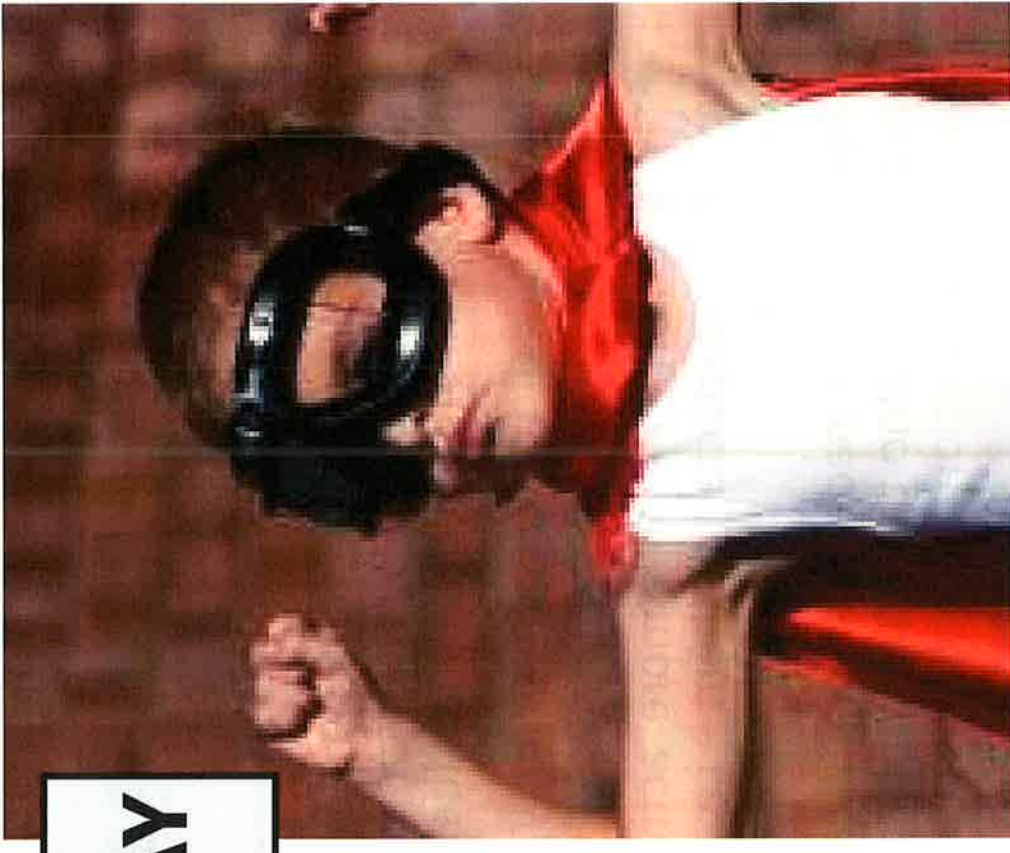
- Newson found that a high proportion of those with EDA were described by their caregivers as passive or placid in the first year of their life
- Nearly half did not reach for their toys or dropped them when they were offered
- The child only became more 'actively resistant' when more was expected of them – i.e. when starting nursery etc.
- Parents often made quite significant accommodations without realising the issues until external demands were placed upon the child

'While Autistic children's parents usually realise that something is wrong by the time a child is two, and often before this, in PDA children the honeymoon period tends to be much longer' Newson



COMFORTABLE IN ROLE PLAY

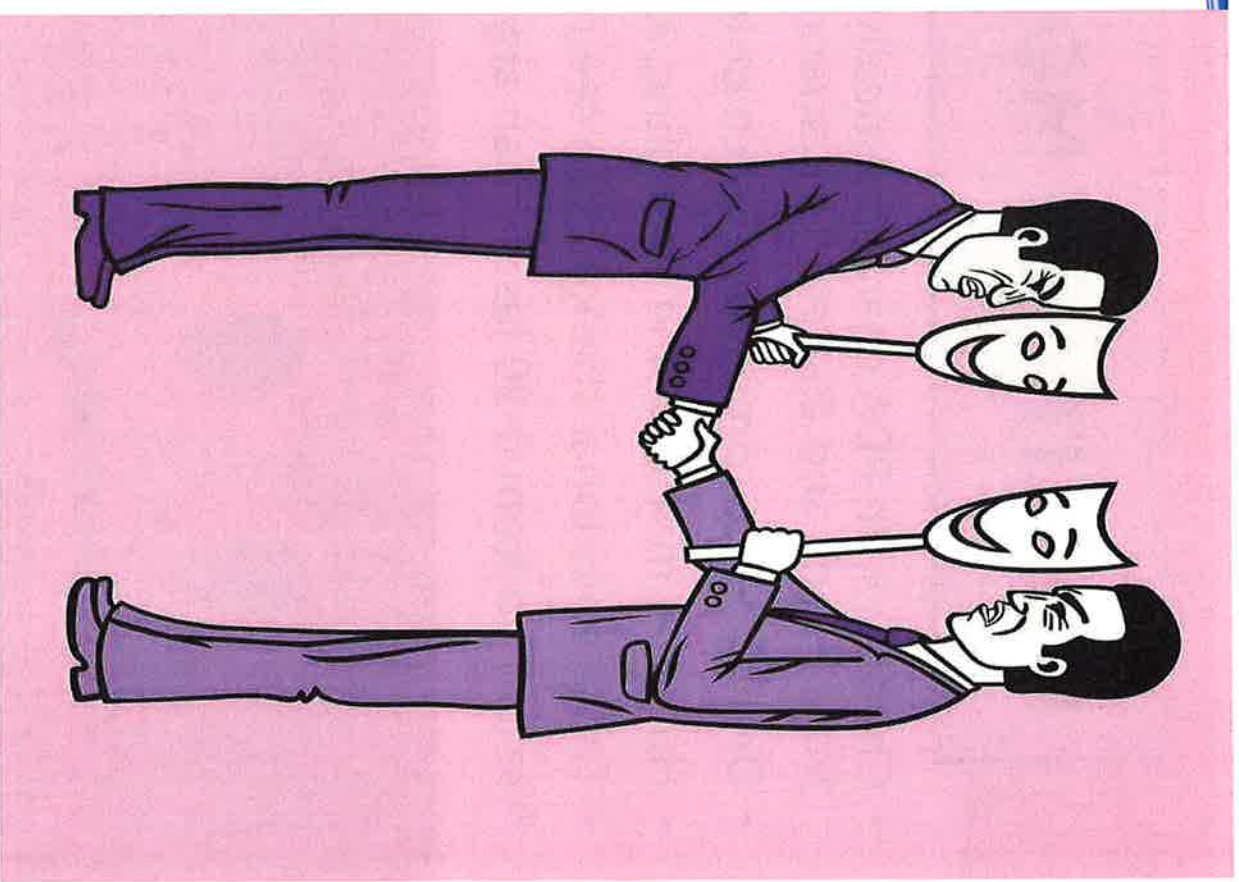
- Being comfortable in role play and pretence, sometimes to an extreme extent and the lines between reality and pretence can become blurred,
- Often adopting the persona of a figure of authority
- This role often requires them to oversee and direct others
- Role play can be used as a strategy to avoid demands
- Role playing the compliant child in school to reduce demands by flying under the radar.
- Withdrawing into fantasy can also be a form of self-protection



- Live through their roles/characters/dolls
- 'used as allies in manipulating others'
- As opposed to repetitive engagement with fictional characters/roles

SURFACE SOCIABILITY

- Children with EDA tend to be very 'people-orientated'
- They have usually learnt many social niceties
- They will often use charm in their repertoire of avoidance tactics
- They can seem exceptionally well tuned into what might prove an effective strategy with particular people
- However this sociability appears to be 'skin deep' which can be very misleading
- Socially naïve in many ways with their surface sociability lacking depth of understanding
- Leads to overpowering, domineering responses

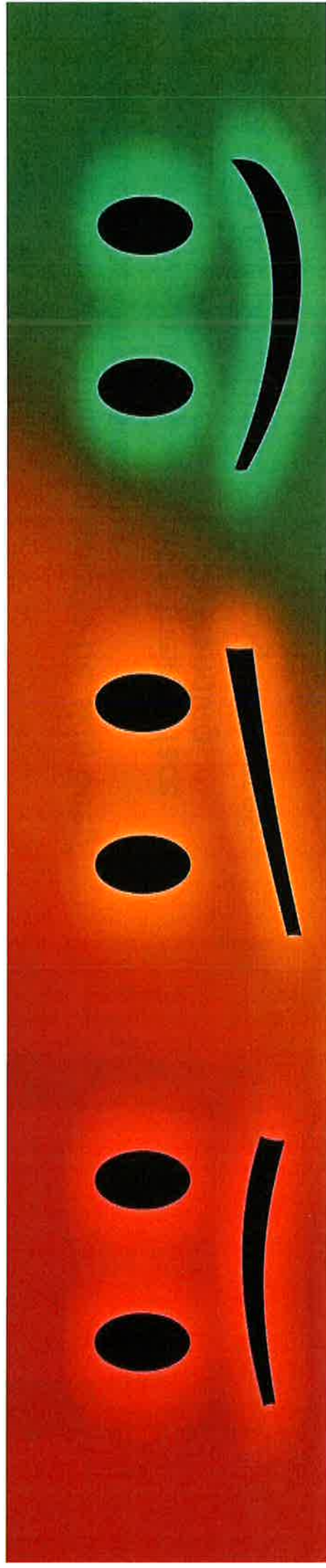


LABILITY OF MOOD

"You are always walking on eggshells"

- Children with PDA characteristically switch from one mood to another very suddenly e.g. from happy and content to distraught
- Described by some as a 'switch going on and off' or 'Jekyll and Hyde'
- Hugging may become strangling, kisses may turn to bites
- These emotional changes can seem very dramatic and unpredictable

"He can go from 0-90 faster than any car in existence – and from 90-0 at the same speed"



OBSESSIVE BEHAVIOUR

- Strong fascinations and intense interests are common in Autistic people – so this criterion alone does not distinguish demand avoidant profiles from classic presentations
- However the subjects of fixations for those with PDA tend to be social in nature and often revolve around specific individuals
- This can result in blame, victimisation and harassment, which can cause real problems both in the education system and in adult life

One teacher, writing about Tom, aged five, described how he, 'is very attached to a boy called Adam. He is only interested in emulating Adam's work and often talks to him and ignores the teacher. He will only eat food if he thinks Adam is eating at the same time.

POSSIBLE NEUROLOGICAL INVOLVEMENT

absences

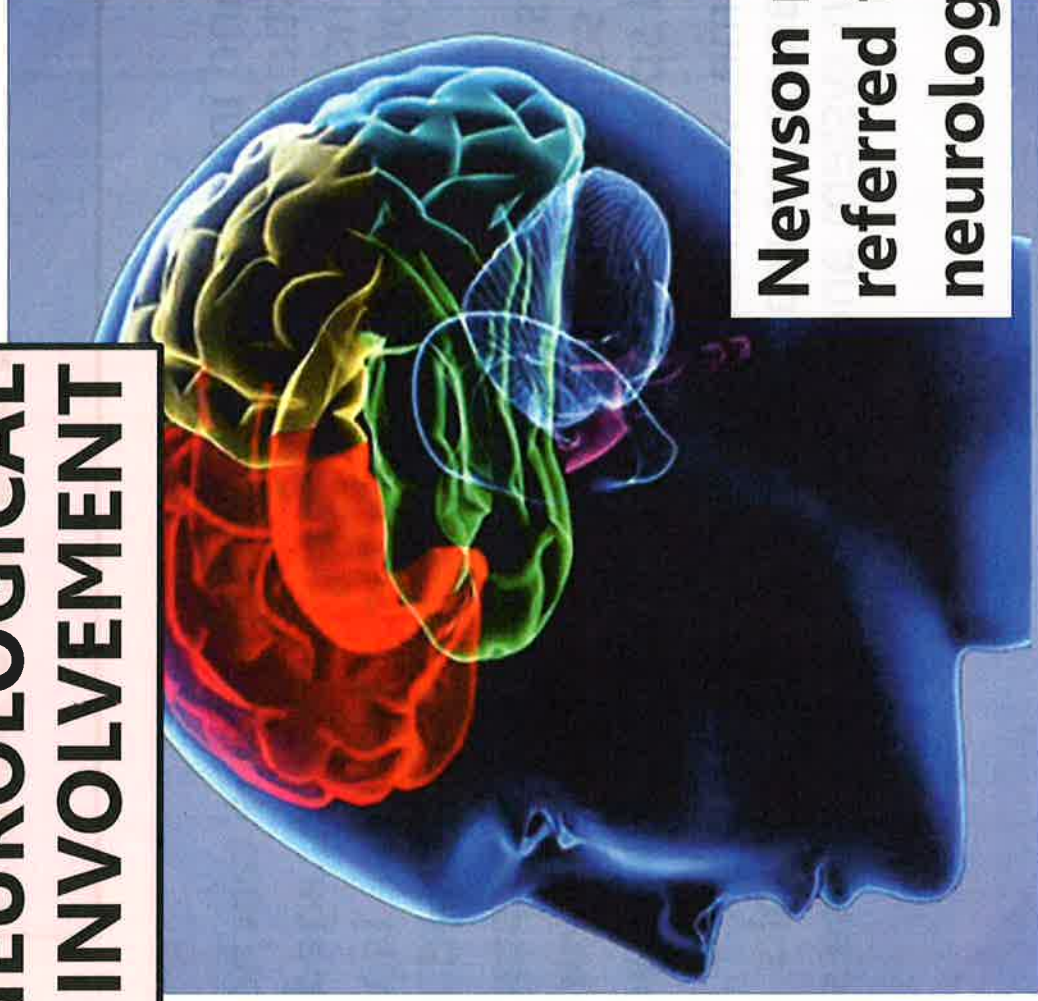
CLUMSINESS

Motor
milestones:
crawling,
walking etc

TICS

**'floppy'
in infancy**

**Newson noted what she
referred to as possible
neurological involvement**



LANGUAGE

- Some early language delay is common, this seems to be dependent on their overall intellectual ability and part of their early passivity
- There is often an accelerated 'striking and sudden' degree of catch up
- Less difficulty generally with eye-contact/non verbal cues and pragmatics of language
- Mismatch between expressive and receptive language (links to surface sociability)

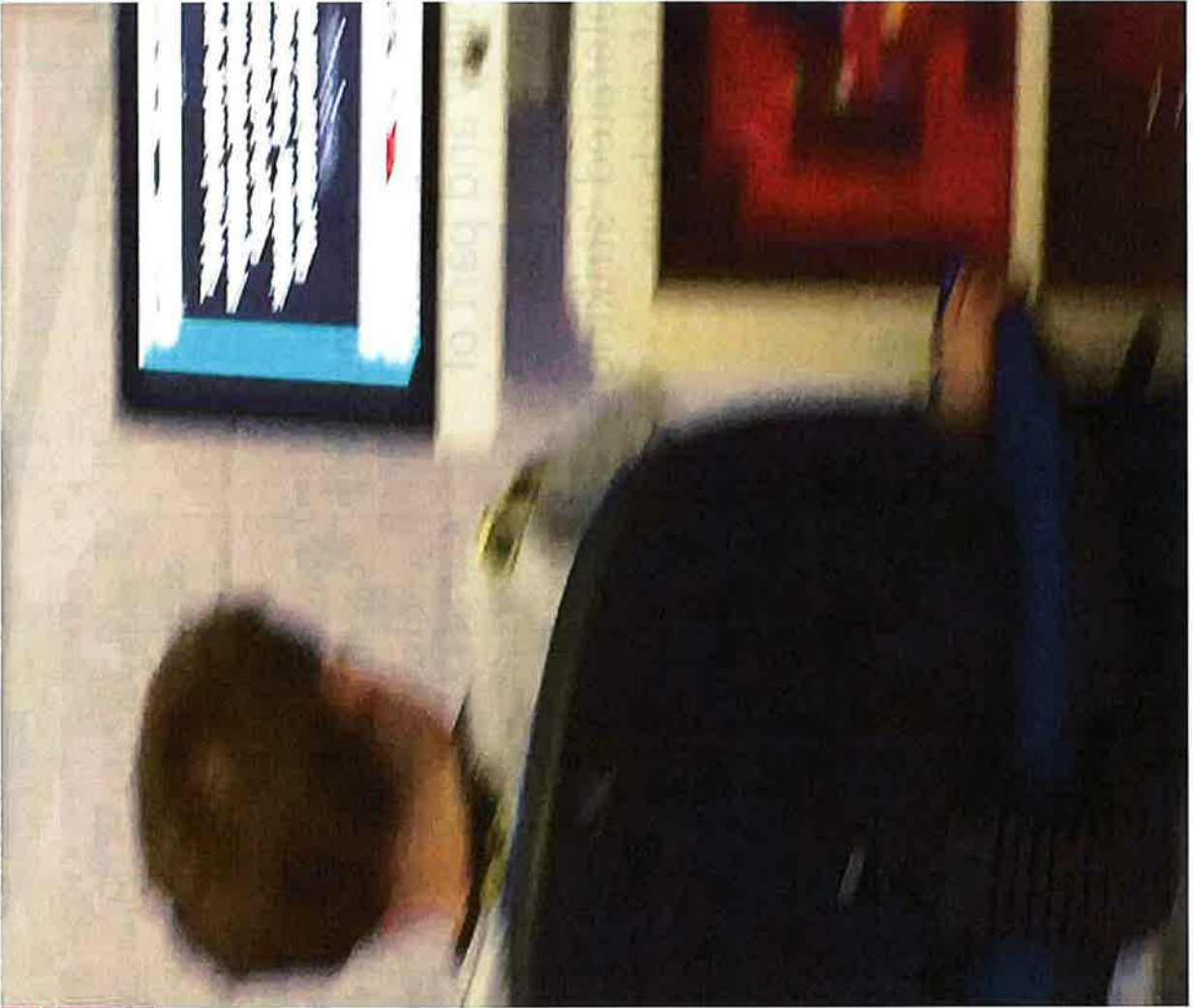
"Many of the children will take an outsider's view of themselves, addressing themselves or commenting themselves. Autistic children can seem to do something similar using echolalia, but this is different:

Susannah uses both gesture and speech to control herself from the outside.

If her mother smacks her bottom, she will smack herself, and it almost seems she is more responsive to her own smack than her mothers"

Newton

LANGUAGE



DIFFERENCES BETWEEN CLASSIC AND EXTREME DEMAND AVOIDANT PROFILES OF AUTISM

Children with EDA are less likely to:

- × Have caused anxiety to parents before 18 months of age
- × Show stereotypical motor mannerisms
- × Show (or have shown) echolalia or pronoun reversal
- × Show speech anomalies in terms of pragmatics
- × Show (or have shown) tiptoe walking
- × Show compulsive adherence to routines

Children with EDA are more likely to:

- ✓ Resist demands obsessively (100%)
- ✓ Be socially manipulative (100% by age five)
- ✓ Show normal eye contact
- ✓ Show excessive lability of mood and impulsivity
- ✓ Show social mimicry (i.e. gestures and personal style)
- ✓ Show role play (more complete than mimicry)
- ✓ Show other types of symbolic play »
- ✓ Be female (50%)

"Although there are obvious differences from a classic ASD profile, our work suggests that those with substantial features of EDA have similar levels of autistic traits to those without the profile"

O'Nions DECP debate

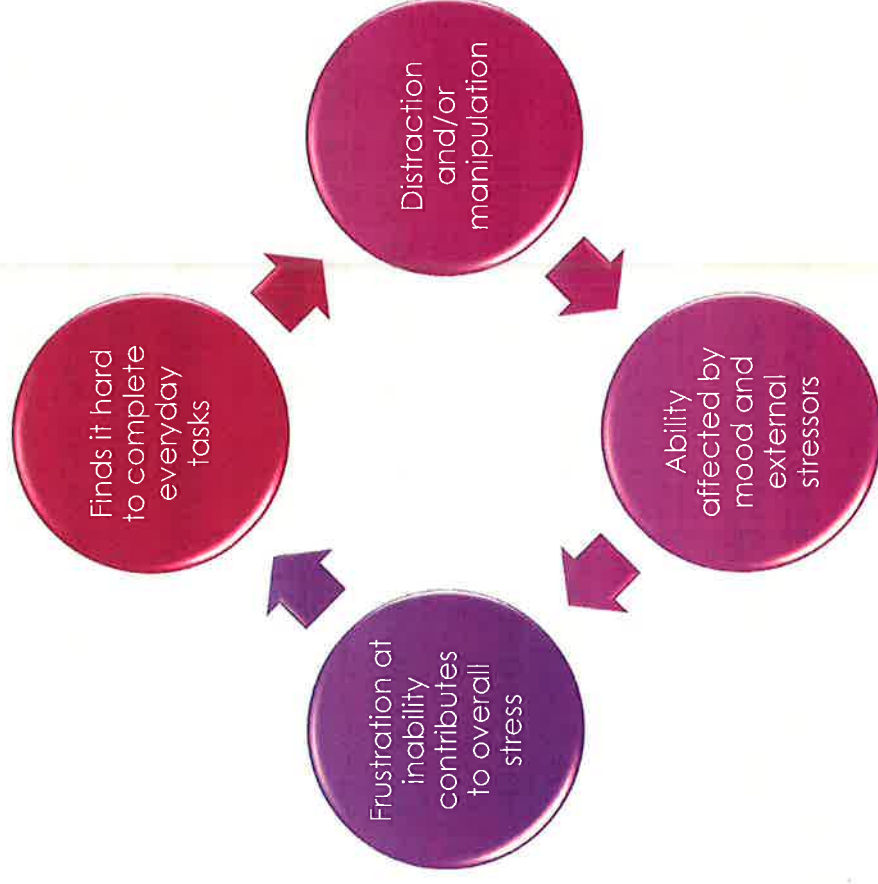
The Anxiety Demand Cycle (Sally Russell)

Research suggests that much like other Autistic profiles, EDA is very much rooted in Anxiety.

Anxiety and excitement sit close to each other on the spectrum of emotions so each can overlap and have the same effect.

(diagram adapted from image retrieved from pdasociety.org.uk)

EDA AND ANXIETY





INTOLERANCE OF UNCERTAINTY

- Newcastle University conducted research which found that IU and anxiety were both associated with PDA behaviour in children, and that IU was even more strongly associated with PDA than anxiety.
- They found PDA behaviour can be understood as an expression of IU and anxiety in this possible hierarchy of responses:

Uncertain situation



Attempt to control aspect of the situation to reduce uncertainty



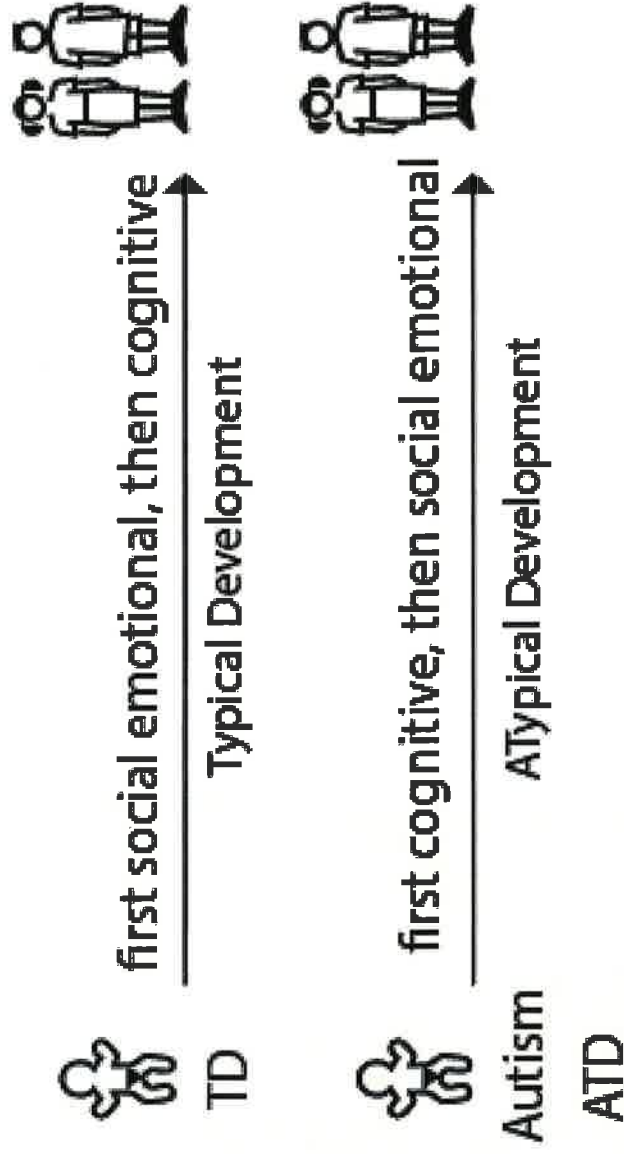
Withdraw to fantasy or mentally disengage (avoid)



Loss of control over emotions and behaviour meltdown



S- MAS1P



Dr. M.F. Delfos

alexaphonia

Me – Other Differentiation

The Socio Scheme

The ME placed in the world

In a physical sense

- body scheme
- body boundaries
- body functioning

In a psychological sense

- me-

Other differentiation

- self-image
- sense of space
- sense of time
- social insight
- empathy
- theory-of-mind
- social functioning

'I have come to see PDA as a failure to code social and personal identity' and 'that loss of sense of self must be seen as deeply destructive'
Newson

PSYCHOLOGICAL REACTION TO BEING DIFFERENT (ATTWOOD, T)

- **Depression**

- Low self esteem
- Defective not different
- Isolation

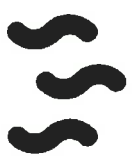
- **Imagination**

- Fantasy World
- Super heroes
- Fiction and Film
- Role play games
- Schizoid PD



- **Arrogance**

- Inflated self esteem
- Comforting over compensation
- Narcissist PD
- **Imitation**
- Expert mimic
- Acting
- An alternative persona
- Dissociative identity disorder



BREAK

CONTROVERSY

Support for EDA from:

- NAS
- Autism Educational Trust
- Autism East Midlands
- Sunderland House School
- PDA Society
- Elizabeth Newson, Phil Christie, Ruth Fidler, Lorna Wing and Judith Gould, Christopher Gillberg, O'nions, Francesca Happe, Vincent Egan,
- Many individuals and parents feel that EDA is a valuable clinical distinction

Criticism of EDA from:

- Damien Milton and Richard Woods – suggest EDA is financially valuable and that it blunts attempts at self advocacy from Autistics who have learnt some social skills – further medicalisation of neurotype
- Green et al 2018– Lancet article – suggest evidence not robust enough and PDA traits can be explained by Autism – current 'best practice' should meet needs although agree need for differentiated management. Demand reduction could 'increase sensitivity' and medication may be effective in reducing anxiety.

RESEARCH SAYS....

"recognition of this subgroup with special problems is innovative and clinically valuable"
(Wing & Gould, 2002)

'a major challenge in clinical practice is that cases fail to respect diagnostic or conceptual boundaries, often presenting a confusing or atypical picture'
(O'Nion et al 2013)

"PDA is not just encountered in asd or odd or as a 'separate entity'. According to my own 40 yrs of clinical experience, it is not at all uncommon in language disorder, adhd (particularly inattentive subtype or add), selective mutism, school refusal, anorexia nervosa, certain behavioural phenotype syndromes (inc. 22q11 deletion syndrome and Marfan syndrome) and epilepsy. It is very likely, a label that would fit almost perfectly with the phenotype of the Japanese 'diagnosis' of Hikikomori'. Pda is already a very real clinical problem, not just in the UK but across the rest of the planet"

Gillberg, 2014



RESEARCH SAYS...

'PDA is a very real clinical problem...intervention and treatment currently rest almost entirely on guesswork, clinical experience and trial and error. It is one of the most difficult to treat' constellations of problems in the whole of child and adolescent psychiatry. Strategies developed for ASD, ODD and ADHD are often ineffective'
Gillberg

"It is important to recognise that these children have a hidden disability and often appear 'normal' to others. Many parents of children with PDA are accused of poor parenting through lack of understanding about the condition. These parents will need a lot of support, as their children can often present severe behavioural challenges" Dr Judy

Eaton

IDENTIFICATION OF EDA



IDENTIFYING EDA

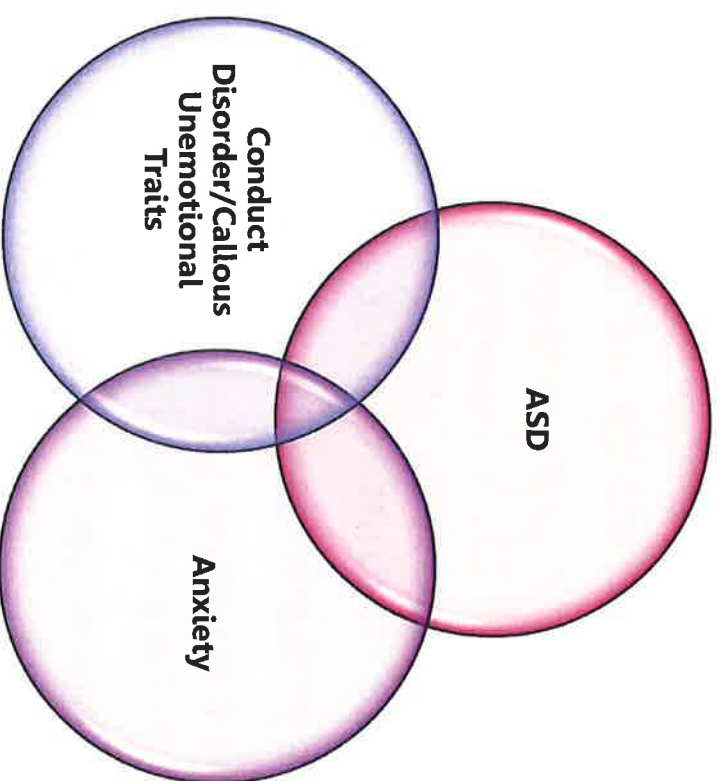
- EDA doesn't appear in either of the diagnostic manuals – the DSM-V (APA) or the ICD-10 (WHO)
- However clinicians are increasingly diagnosing with terminology such as 'Autism with a demand avoidant profile' or 'Autism and ODD/CD'.
- In some areas it can be seemingly impossible to get a diagnosis of EDA. It is down to clinician discretion.
- Perhaps the biggest difficulty is that some of the characteristics of EDA seem to 'exclude' an Autism diagnosis – which leads to no diagnosis and support in some cases.



OVERLAP WITH OTHER CONDITIONS

- Personality Disorders: Anti Social Personality Disorder (ASPD), Narcissistic Personality Disorder, Borderline Personality Disorder
- Attachment Disorder
- Oppositional Defiance Disorder (ODD)
- Conduct Disorder
- Callous Unemotional Traits
- ADHD
- Attachment Disorder

The debate has been strong as to whether EDA is part of the Autism Spectrum or whether it occurs alongside it – with scientists theorising potential ‘double’ or ‘triple hits’ to explain the EDA profile such as Gore Langton and Fredrickson’s suggestion adjacent.





DO WE NEED EDA?

- There is still debate around whether EDA as a classification is needed or if it is covered by Autism & (conditions like ODD/PD etc)
- However it seems these diagnoses fall short in some ways of the full criteria of EDA, leaving individuals, parents/carers and professionals in a difficult position where they do not feel that the diagnosis truly fits their profile of characteristics
- This in turn has implications for support
- EDA can mean that those with the profile are unable to access a diagnosis of Autism compounding delays in assessment and support
- Parents report being labelled with Attachment Disorder/Fabricated Illness/Munchausens By Proxy and this has a negative effect much as the 'refrigerator parent' term historically did for parents of Autistic children

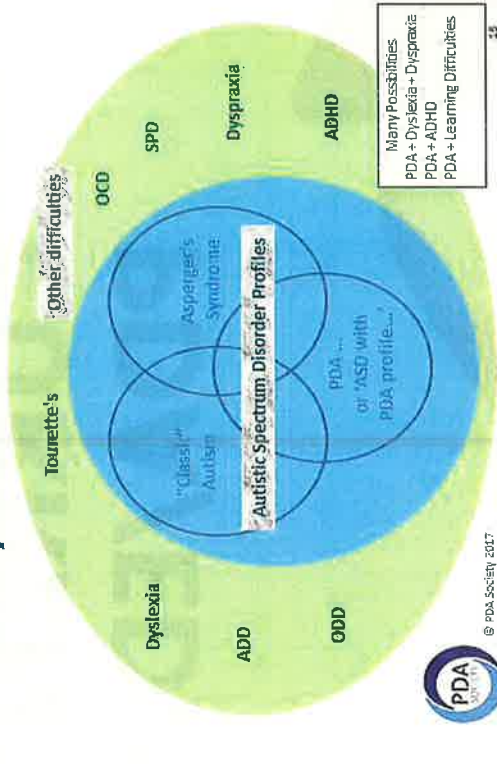
CURRENT VIEWS ON PDA/EDA



CURRENT VIEWS ON EDA

- PDA Society survey 2016 found **half of diagnostic professionals would identify PDA**
- Westminster **petition nearly 12k signatures** (no 202680)
- Scottish parliament debate 2017 found **division amongst LAs and HBs** (PE01625)
- Research by Gore-Langton and Fredrickson (2015; 2016) found this division over recognition **compounded delays faced by the Autistic community** in accessing diagnosis and support, with families feeling increasingly **isolated and misunderstood**
- **Research and guidance remains sparse** (small scale studies which may show confirmation bias) although it **highlights the crisis** individuals with this profile and their close supporters are facing

Every individual is different....





UK GOVERNMENT REVIEW

The UK government have announced a review of services and support for autistic people is covering autistic children as well as adults for the first time:

“The review will inform the new joint adults and children autism strategy to be published in autumn 2019”.

The review looks at several key factors - of most significance here:

- **“improving understanding of autism and all its profiles, including recently identified forms such as pathological demand avoidance (PDA)”**

“As part of this review, the government will collect evidence from autistic children and adults, families, carers and professionals on how to improve services and support”.

“Supporting people on the autism spectrum or with learning disabilities is one of the 4 clinical priority areas in the NHS long-term plan”.

<https://www.gov.uk/government/news/government-review-to-improve-the-lives-of-autistic-children>



EARLY DAY MOTION 1669

Sir Mike Penning MP's [Early Day Motion EDM 1669](#) has attracted cross-party support:

"That this House commends the PDA Society and other PDA campaigners for their Call To Action campaign to raise awareness, recognition and understanding of the Pathological Demand Avoidance profile of autism; and supports their calls for Autism Boards, local authorities and clinical commissioning groups to issue a position statement to help health and education professionals provide the support so desperately needed by children and young people with PDA and their families."

"The lack of consensus on the status of the PDA profile should not be a reason to fail to identify and consider how best to meet the support needs of an individual. It is essential that health, education and social care providers work together to recognise that as young people's needs vary, there must be effective and responsive support for those needs."

Excerpt DHSC proposed update to ministerial statement – PDA Society website

IMPACT ON LIFE





PEOPLE WITH EDA SAY...

"It makes me feel afraid when people look at me, but I don't know why".

"I feel as if there are two versions of me on the inside. Constantly fighting with each other. One that wants to do things but my other self – stops me. It feels like I'm being torn apart from the inside out and the monster that is killing me, on the inside, is me!"

"It makes me feel sad when I get so angry I hit people. My insides feel tight and I can't hear properly. After I don't remember what I've done."

"For me it's like being in a poorly designed, constantly malfunctioning robot. At several points throughout my life, I spiralled into dark depression amidst self-blame and self-hatred."

"Although I am acting angry, what I am feeling is terror."



PEOPLE WITH EDA SAY...

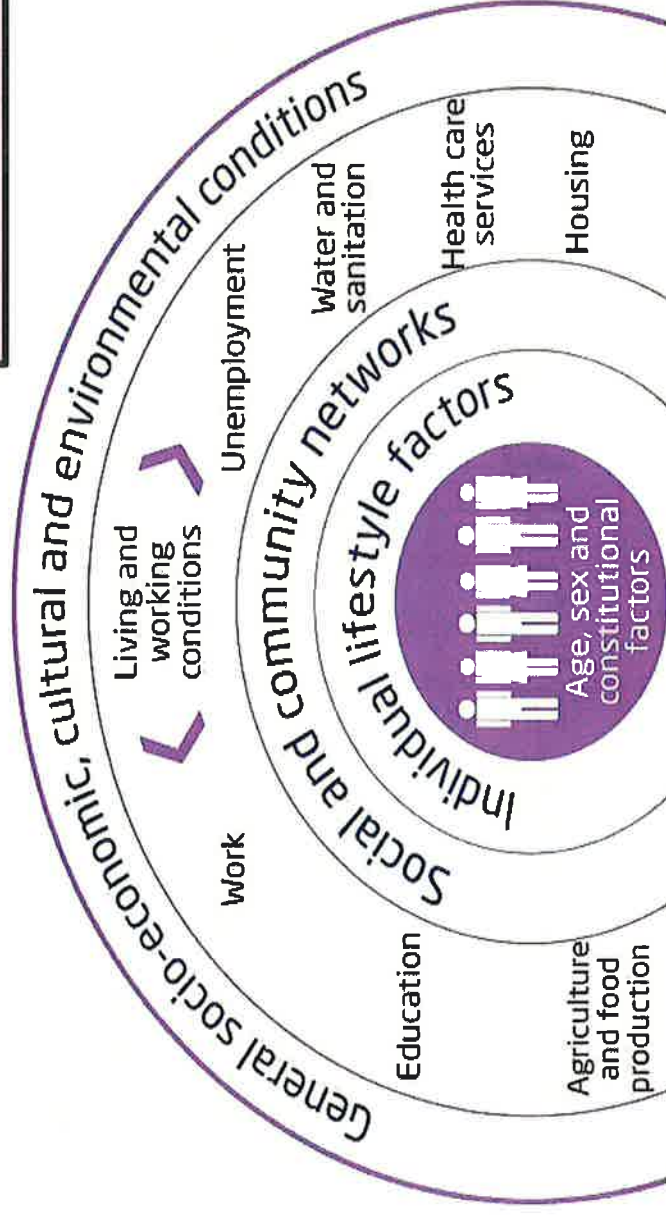
"PDA is irritating because most of the time I want to do stuff but something gives me the urge not to. If I say 'I'm not going to do it' then I CAN'T do it because I've said I won't and I can't back down.

My new technique now I'm older is to think 'try not say anything when I'm asked to do something'. If I can stop myself saying I won't do it then I can leave my options open. That means I can get used to the idea of co-operating and I MIGHT be able to do it"

FAMILIES OF THOSE WITH EDA SAY...

"It was a huge consolation to find a set of characteristics and criteria that seemed to have been made for my child....after years of reluctant trawling through ASD diagnostic criteria and really feeling that something didn't sit right, here was a tailor-made paper on my child"

IMPACT ON LIFE



"PDA is not a lifestyle choice. I make lifestyle choices, but PDA always thwarts them".
Sally Cat



LUNCH

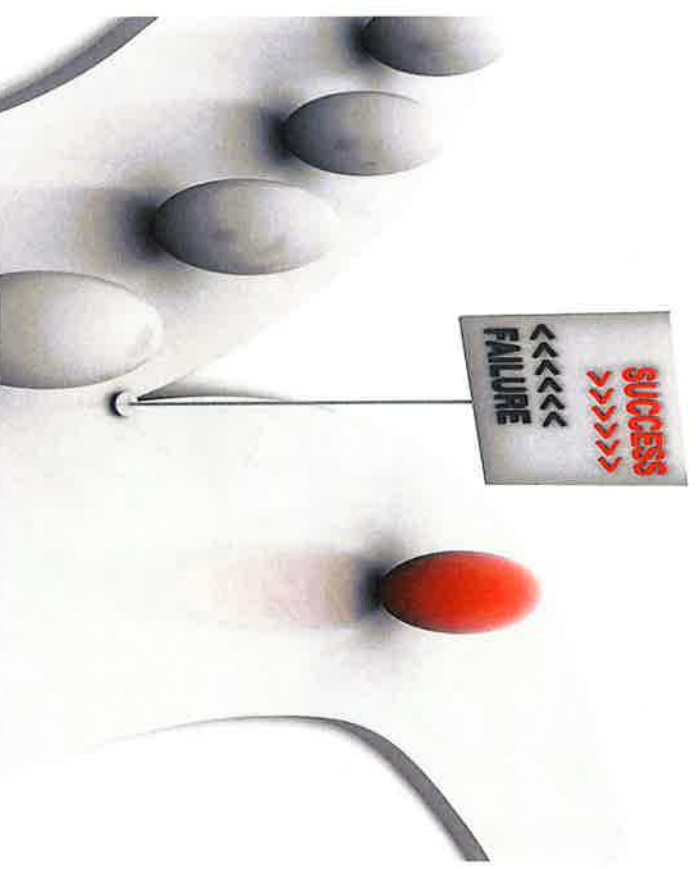


STRATEGIES FOR EFFECTIVE EDA MANAGEMENT

A DIFFERENT APPROACH

- Traditional Autism approaches ineffective at best exacerbate difficulties at worst....
- The rules, structure and strict adherence to routines that are often beneficial for Autistic people may have a negative effect in demand avoidant profile management
- Therefore while some renowned Autism management strategies can be adapted to good effect (i.e. visual supports), differing strategies may be necessary and helpful in EDA management

"There is a real coping problem here which has to be recognised. The problem is an incapacity rather than naughtiness. "Being told" cannot solve the problem and nor can sanctions" Newson





EDA MANAGEMENT STRATEGIES

Key Principles
PANDA
Person Centred
Functional Assessments
Consistency staff/keyworker
Managing Expectations
Anxiety vs Tolerance dials
Sensory Considerations
A Creative Approach
Communication Techniques
Illusion of choice
Indirect demands
Visual Supports
Contingency Maps

KEY PRINCIPLES OF POSITIVE BEHAVIOUR MANAGEMENT FOR EDA

- High level of anxiety
- Sensory difficulties
- Demand Avoidance
- Role playing
- Bossy
- Need for control
- Obsessions



- Callous or seemingly uncaring
- Controlling
- Meltdown or panic attack
- Social / Communication difficulties.
- Fear of failure

Picking battles

Anxiety management

Negotiation & collaboration

Disguise and manage demands ✱

Adaptation ✱



PERSON CENTRED

- Good quality, robust, person centred planning is vital in supporting those with EDA profiles
- Highly individualised to meet specific needs and develop full understanding of specific responses and limits
- Should recognise the need for preparation and planning but understand the need for more enhanced control and flexibility than is typical for classic profiles



Perception of threat.

"PDA is best understood as an anxiety-driven need to be in control and avoid other people's demands and expectations"

Christie

- Important to recognise inability rather than being purposely difficult
- Those with EDA can be labelled as naughty, defiant or even psychotic as it can be extremely hard for staff to recognise and accept that violent, shocking and strategic behaviours are forms of panic attacks, needing reassurance rather than reprimand (Eaton & Banting, 2012)

Forced compliance demands
 x
 voice input.



FUNCTIONAL ASSESSMENTS



OVERLOAD – FIGHT, FLIGHT OR FREEZE

Meltdown	Shutdown
Display extreme behaviour such as: <ul style="list-style-type: none"> Self-harm Shouting Aggression – kicking, hitting, biting EXTERNAL	Complete withdrawal: <ul style="list-style-type: none"> Non-responsive to communication Cease to interact with world Retreat to 'safe space'/hide Lie down where they are Be unable to move INTERNAL

CONSISTENCY OF STAFF/KEYWORKER

Characteristics of the ideal person to work with individuals with EDA:

- To be able to build a relationship of warmth and trust
- Good sense of humour
- Be able to stay calm and neutral
- Flexible
- Creative
- Resilient
- Able to think on their feet
- Be able to show sympathy and empathy
- Ability to self-reflect and stay regulated

Be aware to avoid over-dependence, have a group of constant staff working with the individual with EDA

"I remember the first time someone reached me so that I wanted to try being truthful. He was earnest and genuinely keen to know how I really felt. He was also respectful of me and saw good in me, that I was a worthwhile person"

Sally Cat

*Need changing
to be up-
line
PSD
Snatchers*

** Need calm **

MANAGING EXPECTATIONS



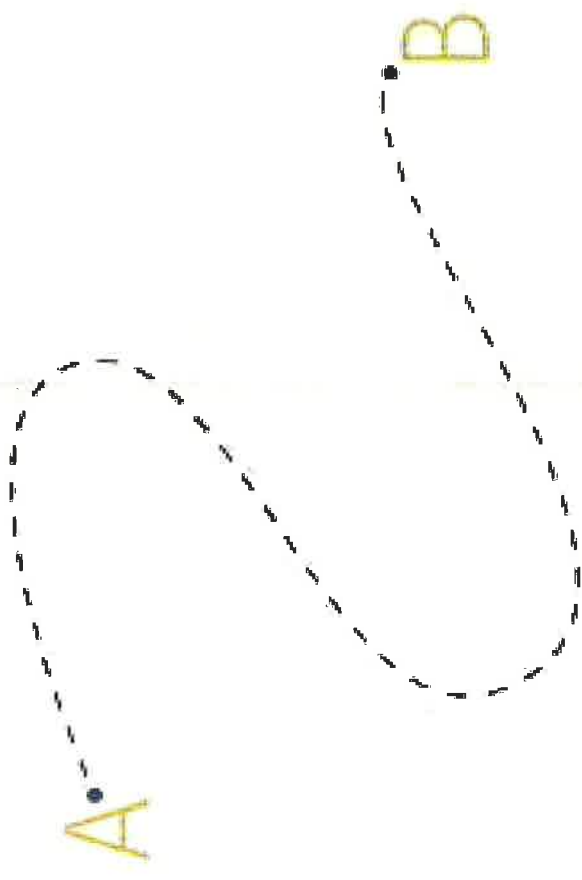
Managing the expectations of the person with EDA and of staff:

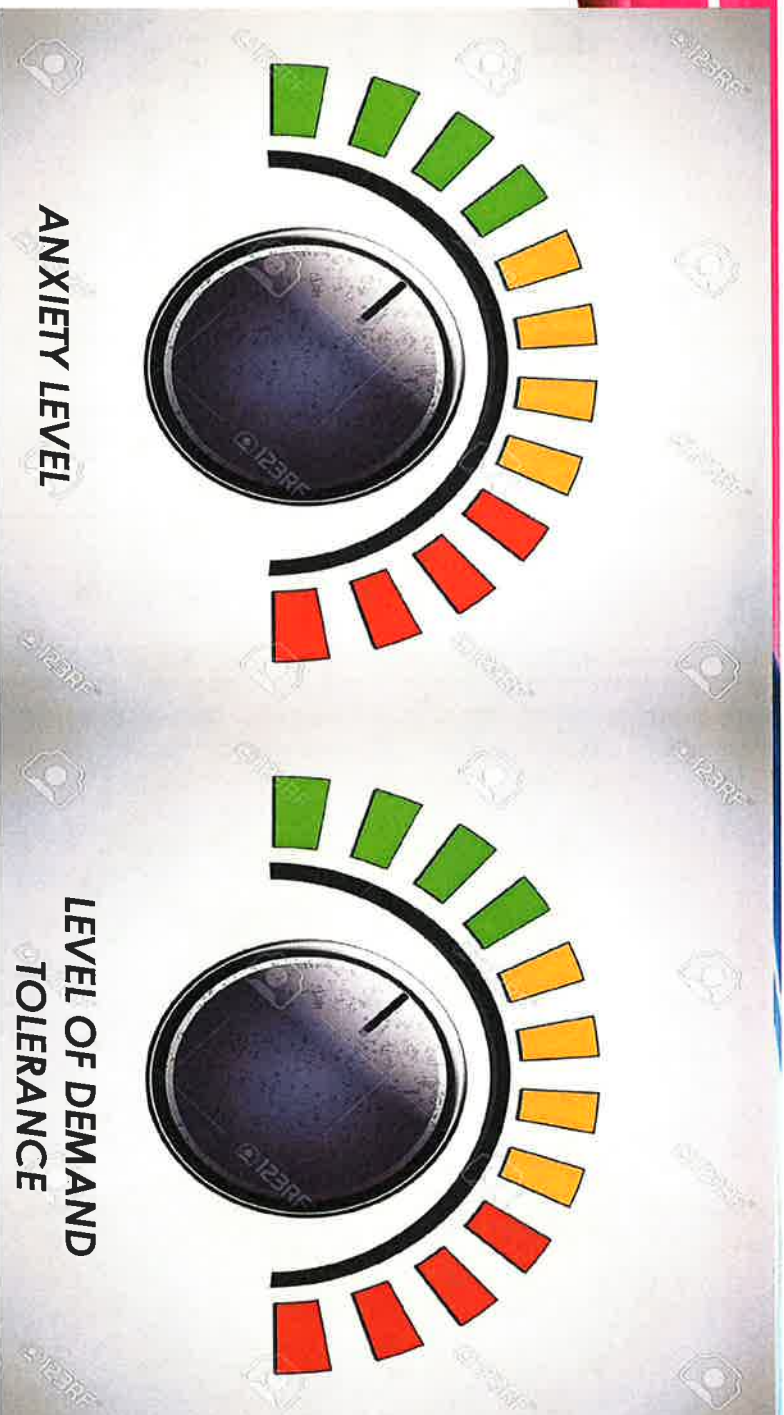
Keep in mind:

- Every interaction is a two-way process
- Having clear and agreed priorities set in terms of behaviour
- Adjust demands according to level of tolerance
- Build realistic goals and positive experiences gradually
- Low arousal approach

Backward chaining

It's never a direct route from A to B, so be prepared with strategies and resources to gently lead the child to where you want them.





It is important to be flexible, insightful and recognise when demands can be increased, and when they should be reduced.

As a person with PDA's anxiety levels increase, the level of demands expected of them should decrease – the supporter's dial should always be working in the opposite direction to that of the person with EDA.



SENSORY NEEDS

Individuals with demand avoidant profiles often have sensory differences as expected in Autistic people.

They may appear very 'hyper' as if 'driven by a motor' with an intense need to 'check' the sensory environment.

The intense anxiety they are experiencing increases this hypervigilance and sensitivity to sensory information to overwhelming levels

"Idleness is a demand – it's intolerable. I have to be doing SOMETHING"

Sally Cat

knows according.

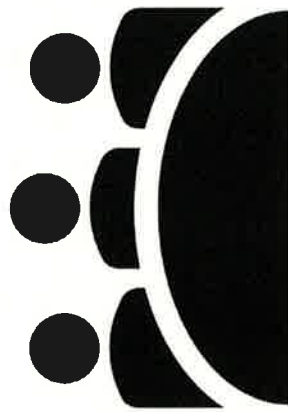
Spoon theory. { iPad theory.

A CREATIVE APPROACH

- Humour can be a very effective strategy at diffusing situations
- Use areas of interest to engage
- Building on strengths
- Use imagination and role play
- Novelty and spontaneity can work very well



“Clinical accounts highlight the need for a range of strategies, such that the child does not come to ‘see through’ a particular method”*



ACTIVITY



<i>Try:</i>	<i>Instead of:</i>
<i>"Shall we see if we can beat the clock..."</i>	<i>Hurry Up, times running out</i>



COMMUNICATION TECHNIQUES

- How we successfully use communication/language can be quite different for those with an EDA profile
- Being spontaneous, silly, inventive and 'mixing up' our communication can prove effective in engaging those with an EDA profile
- Remember those with EDA profiles often use language effectively but may have lower receptive language ability so check understanding/allow processing time as in traditional Autism management
- Use collaboration/collusion techniques "what our mission today" – be an ally rather than an 'enemy' or a 'boss'
- Use the person's interests - using characters or toys can depersonalise demands and appeal to the sense of novelty in EDA
- Humour can distract/lower anxiety – be prepared to make fun of yourself
- Use of indirect communication methods like post it notes, recorded messages, text messages can prove useful – be prepared to switch methods to keep it interesting!

✓

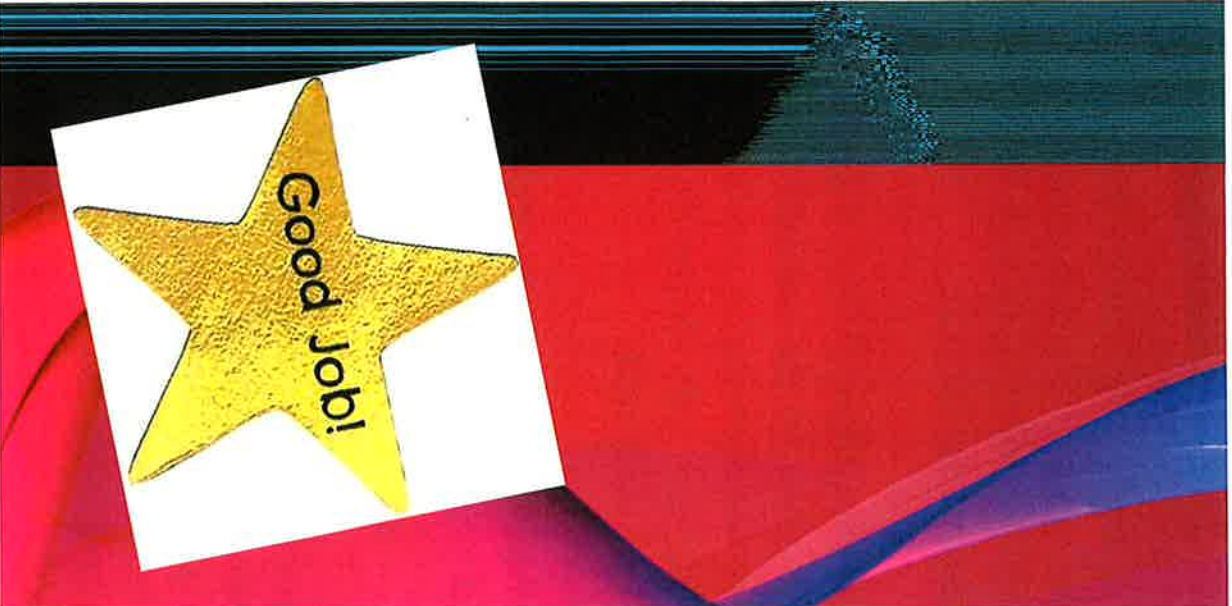
Keep switching it up

ILLUSION OF CHOICE

- This offers a sense of control and choice thus reducing the extreme demand avoidant reaction, whilst still achieving the necessary goal
- Offering a choice of two options where both options are suitable
- i.e. this jumper or this cardigan today?



Boost sense of agency by giving choices



AFFIRMATION INSTEAD OF PRAISE

- Remember that direct praise can be perceived as demand
- Indirect praise can be successful (e.g. 'I like how those two colours go together', rather than 'wow you're great at art David')
- However regular affirmation is important
- This can be achieved by taking an interest in what the person with EDA is doing, or listening to them talking
- Showing them value with your time and your actions

INDIRECT DEMANDS

- Posing demands/questions indirectly may be beneficial when interacting with/supporting/teaching those with a EDA profile
- Use of a toy or puppet to engage with the individual
- Use of technology including video modelling or AAC devices etc
- Talking out loud i.e. I wish someone knew how to do this

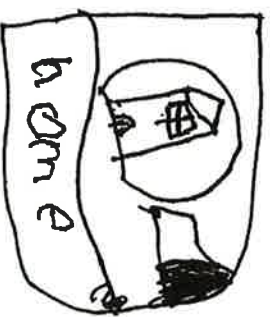
Video gaming/online forums may provide indirect engagement with peers

I know the way people say things to me makes a big difference – it's the way my brain responds to requests not a behavioural problem.

If I am asked in an indirect way I am more likely to be able to do something (e.g. dinner is ready might work whereas 'please can you come for dinner' will not.

Changing approaches regularly helps too – you could try texting one day?!

"If a direct request is part of a normal conversation, it's easier for me to co-operate with. If it feels a gentle question mixed in with a friendly chat it is much easier than having an instruction."



VISUAL SUPPORTS

Visual Supports are often extremely effective interventions in the management of Autism as you will likely already know – but they often need adaptation in EDA.

In EDA empowerment is the of utmost importance – involving the person in creating daily visual routines, use of contingency maps instead of traditional visual schedules, multiple choice feelings boards.

It is essential that visuals are used in a flexible and non confrontational way, that the person feels they do not add a demand, but rather they are a collaboration between the supporter and the individual.

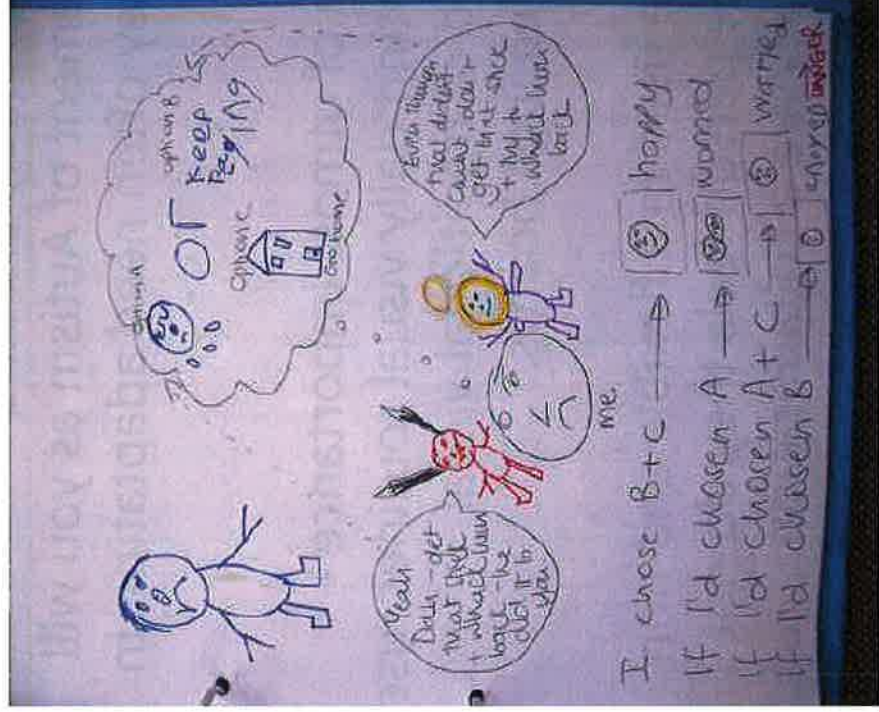
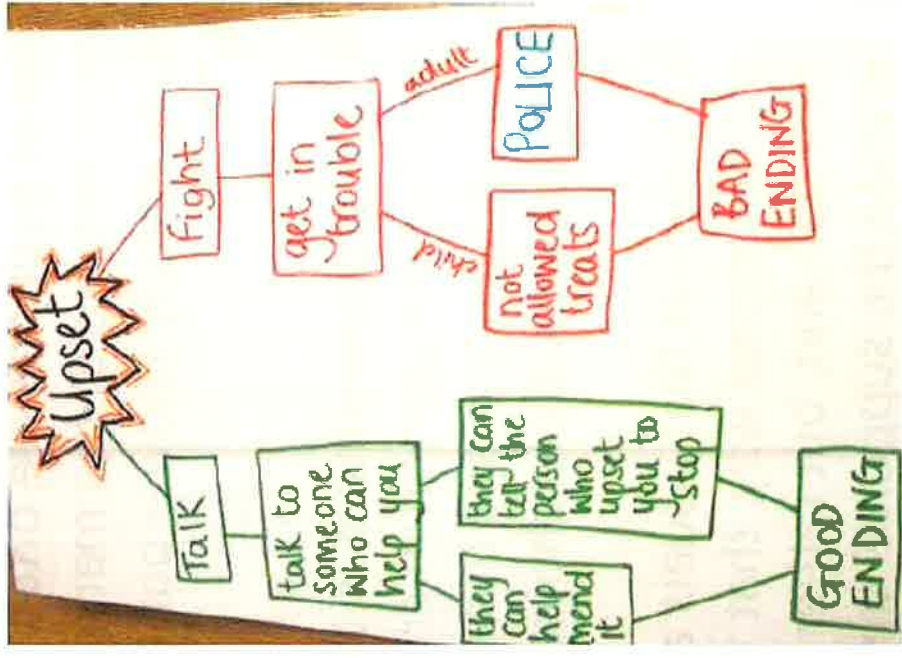


Instead of social story.



CONTINGENCY MAPS

- Indirect
- Visual
- Shows consequences
- Offers options



ADMT. → app.

People with EDA and their supporters say....

If people encourage me it gets worse, but with time and space and others around me doing the same things, I think it will get easier.

When things are depersonalised it is so much easier, so timetables it looks like everyone is following together might be ok for me.

Making things fun is helpful too – I sometimes use apps to develop good habits

I like to know plans in advance but I also hate 'routines'.
I find variety, flexibility, and being able to control things are important to me.

Living with a child on the autism spectrum will always be challenging, but having an understanding of what motivates her behaviour is invaluable, we will no longer try to apply traditional strategies for autism which were making her behaviour worse.

By Flexible



Thank-you for coming



Contact details are on the handouts



Please complete an evaluation of the
day



Have a safe journey home



AutSide

Education and Training

