Understanding PDA

Part of the Autism Spectrum

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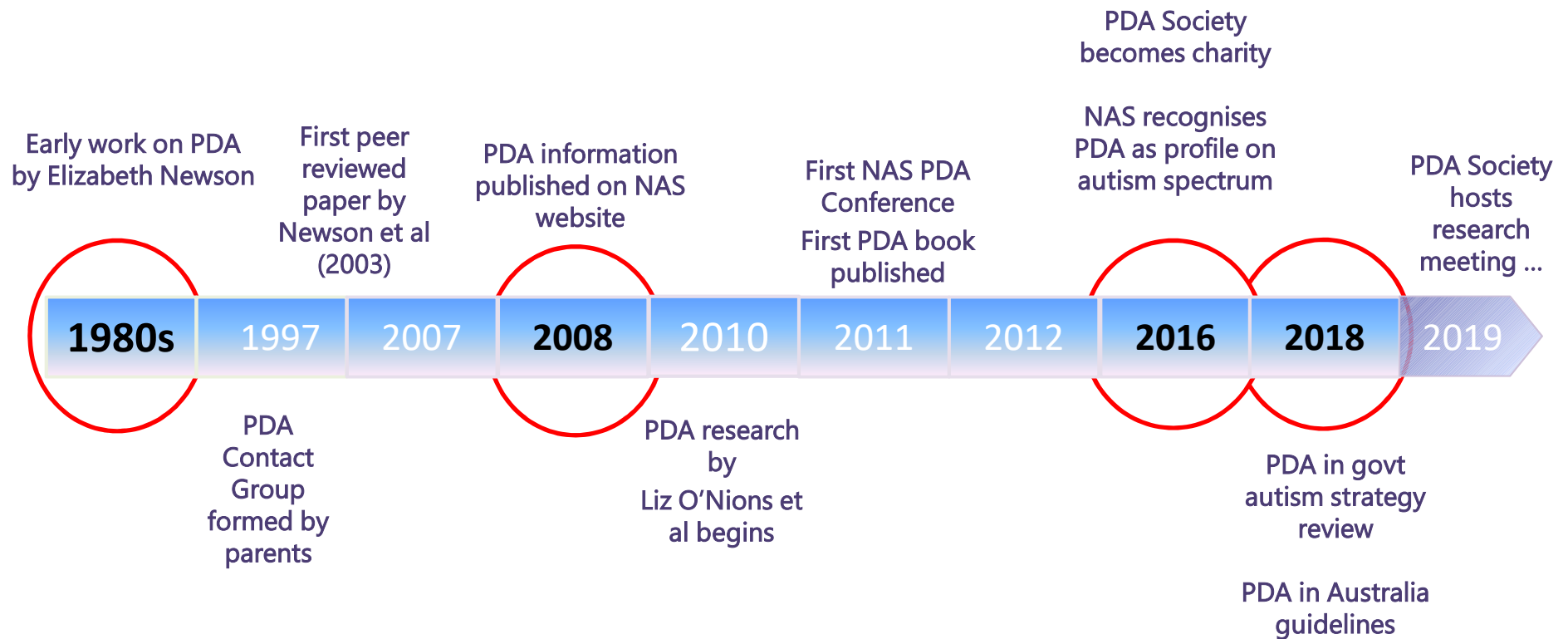© PDA Society 2019

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It doesn't exist

yes it does

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Syndromes

- Not diseases
- Symptoms that are correlated with each other: psychopathologies are also syndromes

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A **short** history lesson

PDA Society
becomes charity

NAS recognises
PDA as profile on
autism spectrum

Early work on PDA
by Elizabeth Newson

First peer
reviewed
paper by
Newson et al
(2003)

PDA information
published on NAS
website

First NAS PDA
Conference

First PDA book
published

PDA Society
hosts
research
meeting ...

| 1980s | 1997 | 2007 | 2008 | 2010 | 2011 | 2012 | 2016 | 2018 | 2019 |

PDA
Contact
Group
formed by
parents

PDA research
by
Liz O'Nions et
al begins

PDA in govt
autism strategy
review

PDA in Australia
guidelines

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What is PDA?

Research is ongoing – best described as a profile on the autism spectrum

Pathological   excessive, extreme, can't help it

Demand   request to act AND internal 'I ought to'

Avoidance   'giving in'= loss of control = extreme anxiety

aka… Permanent Demand Anxiety

(Margo Duncan)

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PDA profile key features

- resists and avoids the ordinary demands of life
- uses social strategies as part of avoidance
- appears sociable but lacks understanding
- experiences excessive mood swings and impulsivity
- appears comfortable in role play and pretence
- displays obsessive behaviour often focused on other people

https://www.autism.org.uk/about/what-is/pda.aspxv

National Autistic Society

It's a lifelong condition

Professional viewpoints

"PDA is already 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 and parents, teachers and clinicians may be driven half crazy by the child's stubborn refusal to cooperate and by avoidant...behaviours""

Professor Christopher Gillberg, University of Gothenburg, June 2015

"Diagnostically the **PDA sub-group is recognisable** and has **implications for management and support.**"

Dr Judith Gould, consultant clinical psychologist, Lead Consultant at the Lorna Wing Centre for Autism

Why distinguish?

The underlying causes of the behaviour are somewhat different and require **different strategies** when providing support.

DA vs PDA

- Demand Anxiety?
- Maybe nothing to do with psychiatric diagnostic structures
- But remains a clinical problem

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Our experience

- We set up activities that the person wanted to do and significant incidents followed.

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What helps?

1. Reduce demands (including expectations)
2. Change the *experience* of demands
3. Increase tolerance to demands when possible

This means helping someone to do what they can, doing some stuff for them and accepting that some things can't be done.

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In practice…

It's 3pm and Isaac is busy on a laptop & not yet had a drink…

What do you do or say?

You must be thirsty, would you like a drink?

Please would you have your drink now?

Here's a drink for you

I've brought you a drink

Are you OK to get yourself a drink?

It's getting late, you've not had a drink yet

In a minute

. . . . .

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Unusual Support Style

'Good parenting' is ineffective

What works can look like 'bad parenting'

✗ Clarity

✗ Firm boundaries

✗ Rewards & consequences

✗ Praise (positive reinforcement)

✓ Flexibility

✓ Few boundaries

✓ Negotiation

✓ Indirect affirmation

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relationships

- It is essential to adapt responses to reduce tensions
- Be aware that onlookers confuse cause and effect
- It isn't the same as doing everything for a PDA individual – it's about also making it possible to do more.
- Development of rapport with one person helps
- Needs to be built on shared interests, fairness and trust
- Staff need support and protection from burnout

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Helpful approaches (1)

- ## Understand the source of behaviour
  (develop individual's understanding too)

- ## Few rules, but predictability from others

- ## Take time and plan ahead (have Plan b & c)
  (give some information but not too much)

- ## Use more indirect communication, 'Sowing the seed'
  (Model behaviour, talk aloud to yourself, don't talk, use messages & notes)

And remember that people with a **PDA** profile need tailored support in order to thrive

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Helpful approaches (2)

- ## Non-directive language
  (avoid: must, now, no, can't, when you're ready…)

- ## De-personalisation
  avoid 'you', try visual cues

- ## Novelty & variety / use of humour

- ## Gentle affirming with less direct praise
  ('it's looking tidier in here' rather than 'well done for tidying up')

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Helpful approaches (3)

- Cut a deal, negotiate, enable control

- Reduce expectations and foster acceptance – progression based on 'sneaky treatment'

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- **Further info** at www.pdasociety.org.uk
- PDA Society **enquiry line** info@pdasociety.org.uk

- **Facebook**: thepdasociety
- **Twitter**: @PDASociety

- Remember the panda ☺
- Any other questions?

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