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Management of children with severe self-injurious behaviour: Lessons from research

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Self-injurious Behaviour and Severe Intellectual Disability

- Prevalence: 10% - 35% (c. 50% in ASD)
- Can be chronic and resistant to intervention (c. 80% persistence over 18 years; ASD?)
- Human and economic costs: pain and discomfort, family and carer stress, relationship breakdown, medication effects, compromised quality of life and accomplishment, placement breakdown. (ASD?)
- Economic costs are likely to be significantly underestimated (ASD?)
- Lack of appropriate 'clinical' intervention. (SIB, 1987, psychological 2%, medication 40%; ASD?)

A robust and sustained operant learning theory literature

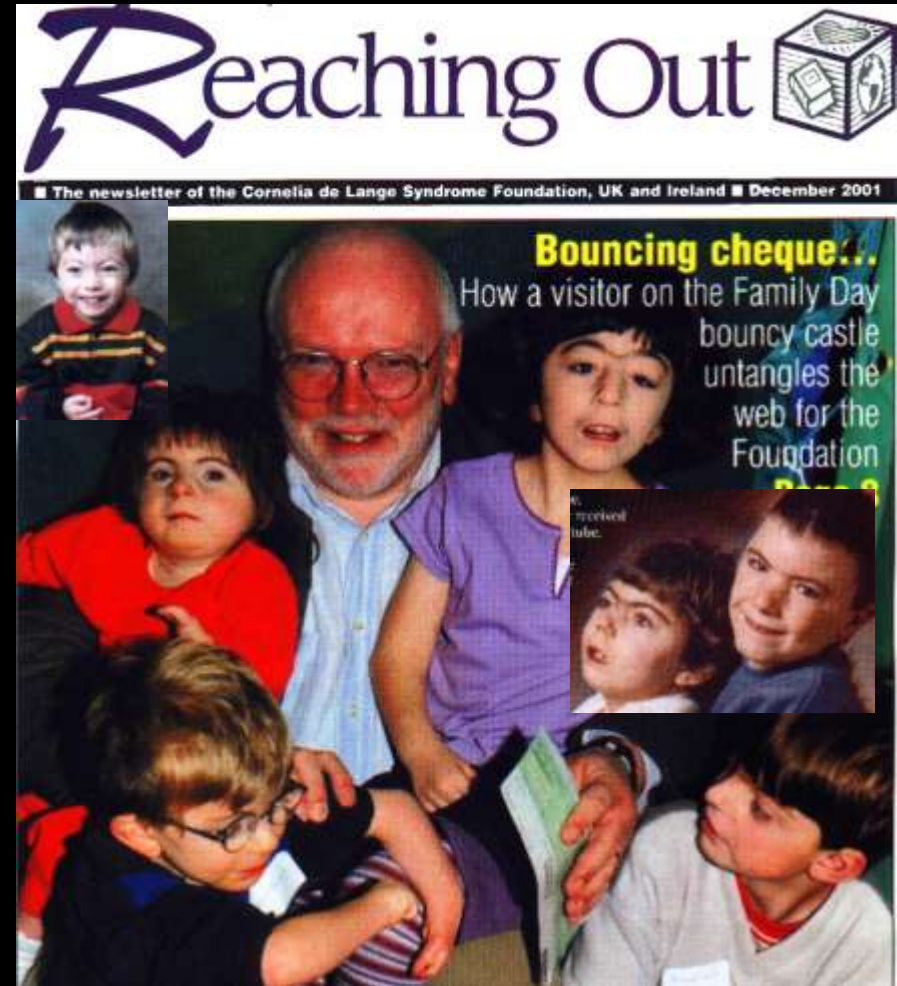
- c. 6,000 to 7,000 published papers
- The rise of functional analysis
- Translation into Positive Behavioural Support (e.g. FCT)
- Emerging evidence from RCT's
- An incomplete account

Pain?

Cornelia de Lange syndrome



- Prevalence: 1 in 10,000 to 40,000
- Deletions on chromosomes 5, 10 and X
- Main features: mild/moderate to severe ID, small stature, upper limb abnormalities, distinctive facial features, gastroesophageal reflux, limited speech, hirsute, SIB.

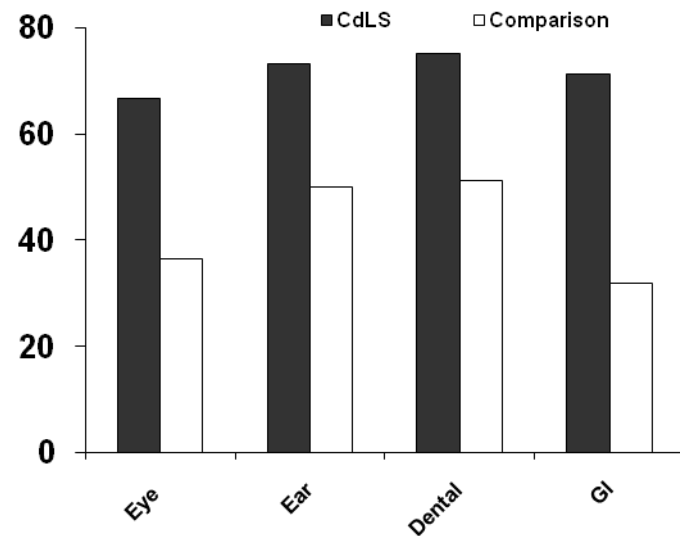
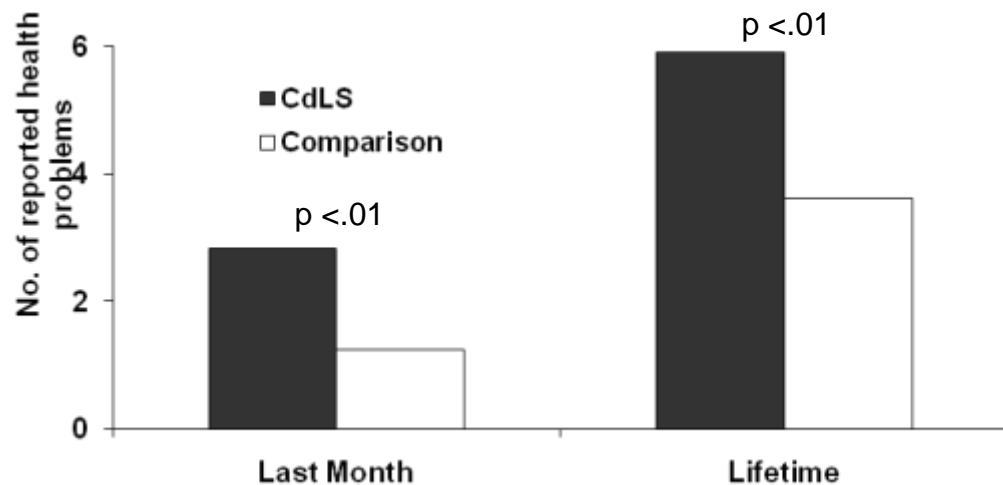


de Lange, C. (1933). Sur un Type nouvea de degeneration (typus amstelodamensis) Arch.med. enf. 36. 713 - 719.

Brachmann,W. (1916). Ein Fall von symmetrischer Monodaktylie durch Ulnadefekt, mit symmetrischer Flughautbildung in den Ellenbeugen, sowie anderen Abnormalitäten (Zwerghaftigkeit, Halsrippen, Behaarung). Jb. Kinderheilk., 84, 225-35.

Table 1 Percentage of individuals with Cornelia de Lange Syndrome (CdLS) showing specific health problems in published studies

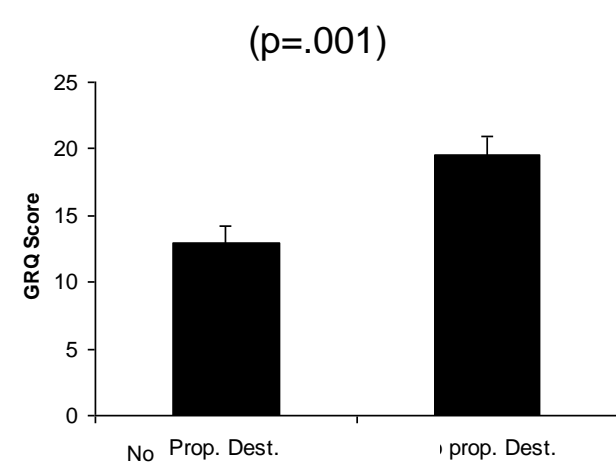
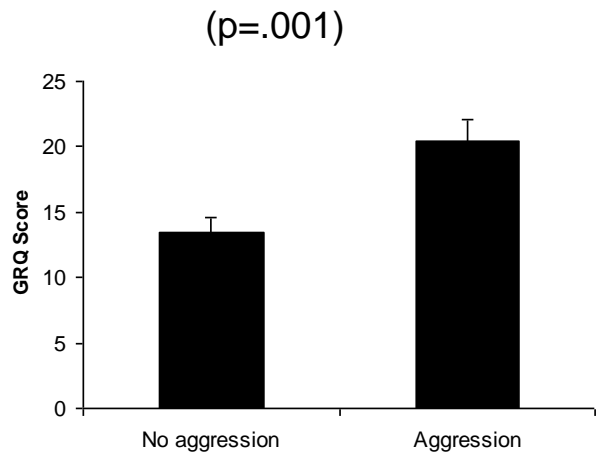
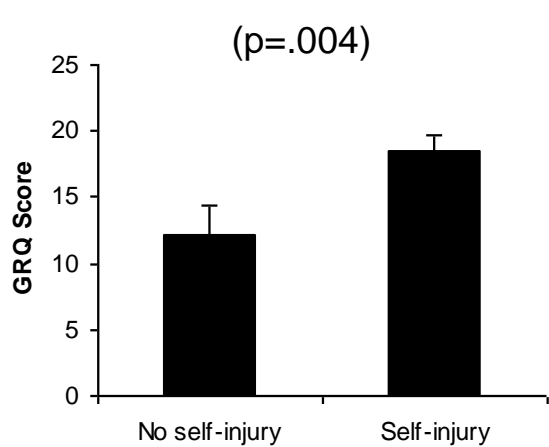
CdLS Studies	n	% of individuals experiencing health problems											
		Limb abnormalities	Gastrointestinal	Heart	Dental	Genitalia	Genito-urinary	Eye	Ear	Respiratory	Epilepsy	Skin	Cleft palate
Hawley et al. 1985	64	33	71	28	93	94 (males)	-	-	-	-	14	-	-
Gualtieri 1990	138	-	41	15	-	-	8	-	-	18	25	-	-
Sataloff et al. 1990	45	-	-	-	-	-	-	-	-	-	-	-	59
Ireland et al. 1993	20	80	10	15	-	-	-	-	-	-	5	-	10
Jackson et al. 1993	310	-	48	25	-	73 (males)	12	50	60	25	23	16	-
Sommer, 1993	17	-	76	-	-	-	-	-	-	-	-	-	-
Kousseff et al. 1994	37	56	49	14	-	-	33	38	-	-	38	-	21
Berney et al. 1999	49	-	67	-	-	-	-	-	-	-	29	-	-
Tsukahara et al. 1998	50	-	-	26	-	-	-	-	-	-	-	-	-
Luzzani et al. 2003	43	-	65	-	-	-	-	-	-	-	-	-	-



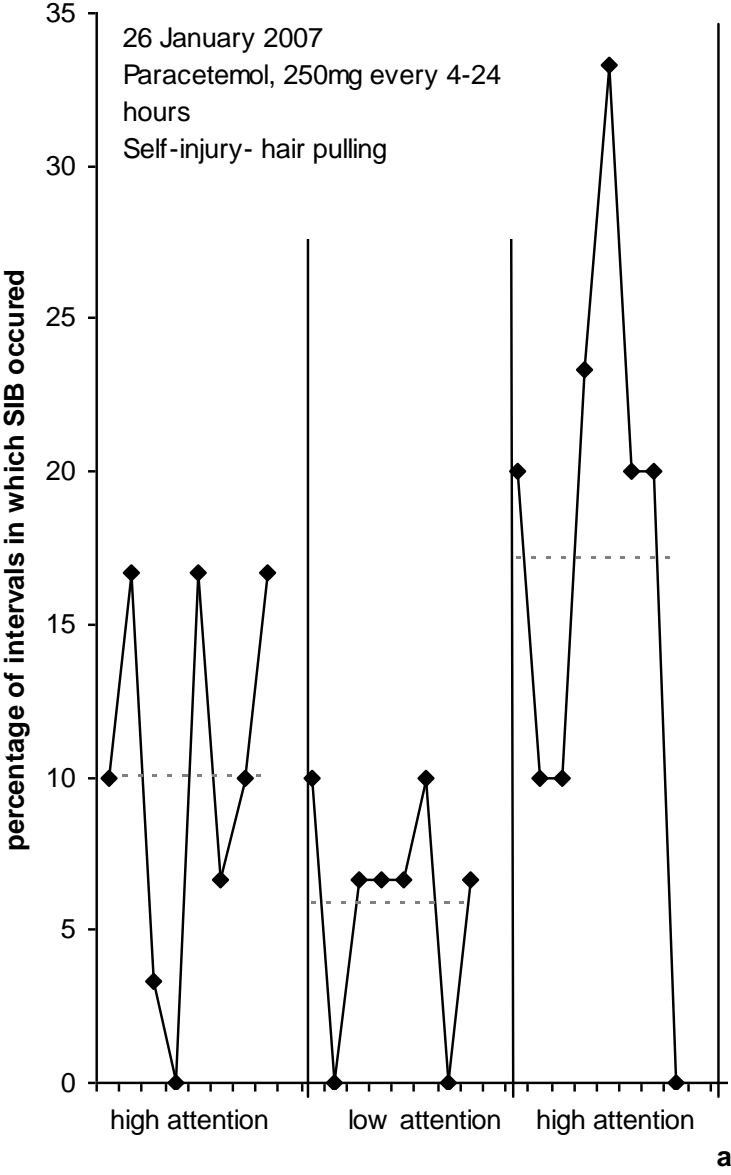
Hall, S., Arron, K., Sloneem, J. and Oliver, C. (2008). Health and sleep problems in Cornelia de Lange Syndrome: A case control study. *Journal of Intellectual Disability Research*, **52**, 458-468.

Arch his/her back
 Lie over object on stomach
 Salivate excessively
 Fidget/wriggle
 Fingers in mouth
 Chew clothes
 Grind teeth
 Scratch/rub chest/throat
 Drink excessively

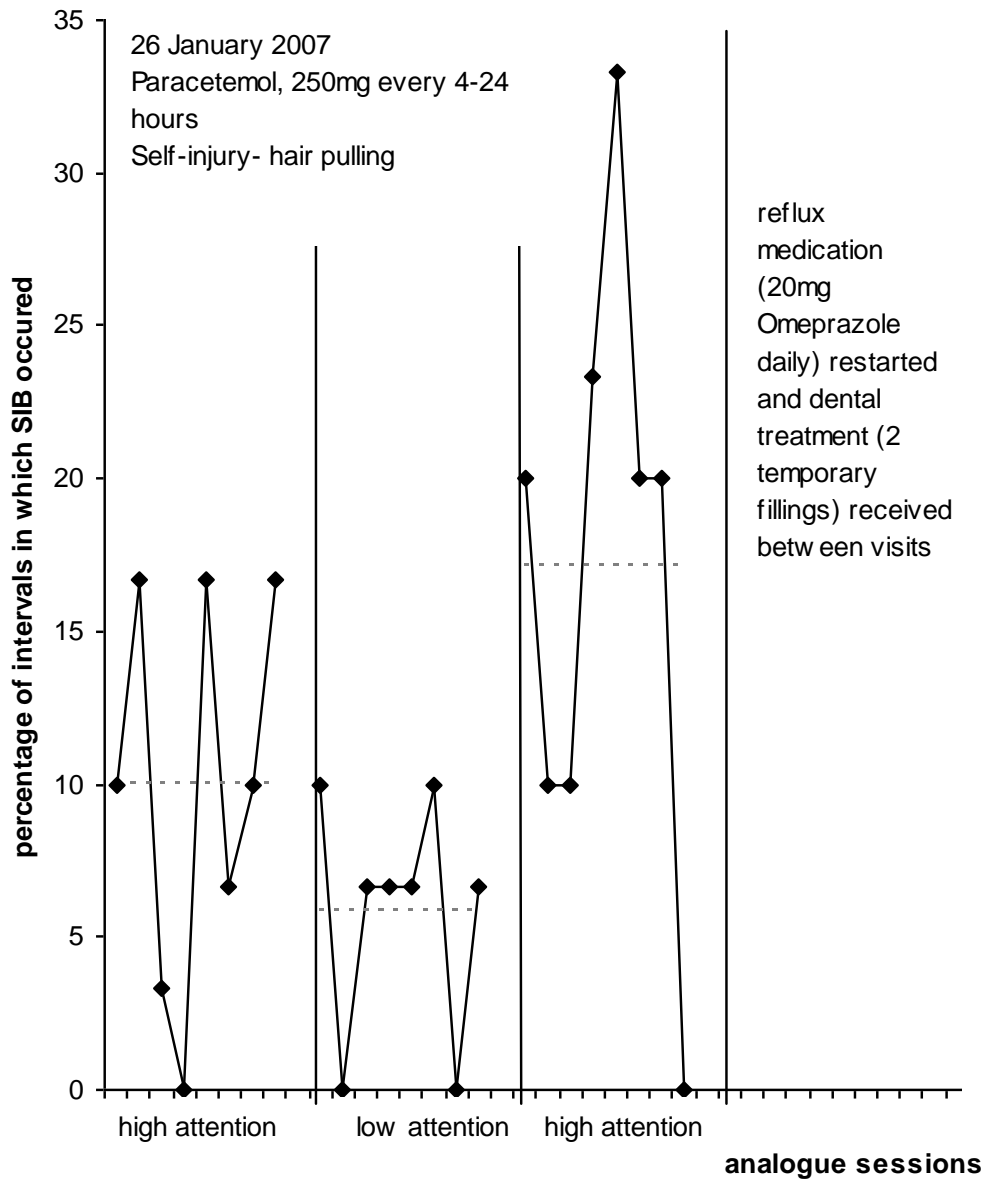
Cough/gag/regurgitate
 Discomfort
 Refuse food
 Indecisive about food
 Wake during the night
 Sleep sitting or propped up
 Bad Breath
 Respiratory tract infections



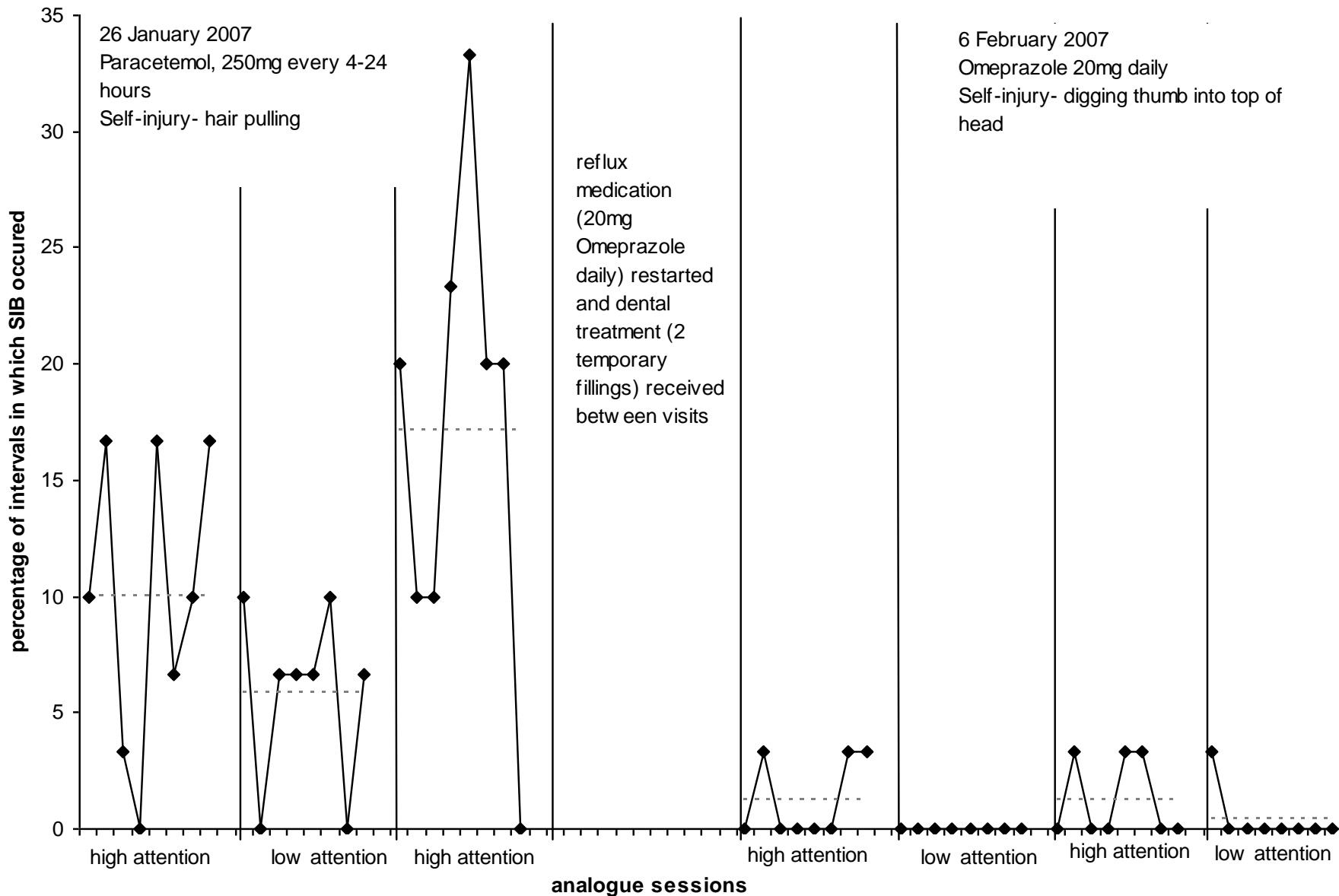
With: Richard Hastings, Gemma Griffiths, Pat Howlin, Jo Moss, Jane Petty and Penny Tunnicliffe

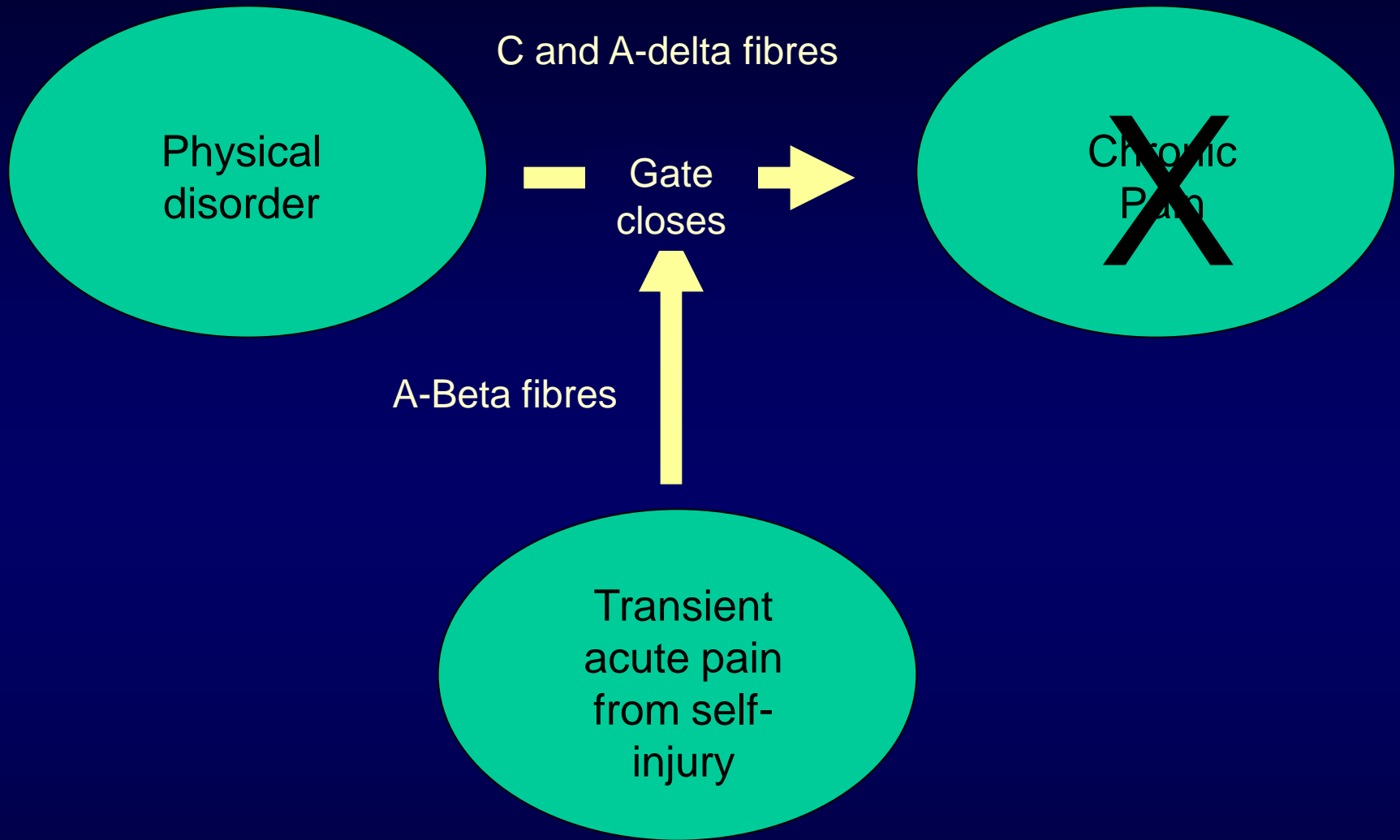


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With: Richard Hastings, Gemma Griffiths, Pat Howlin, Jo Moss, Jane Petty and Penny Tunnicliffe

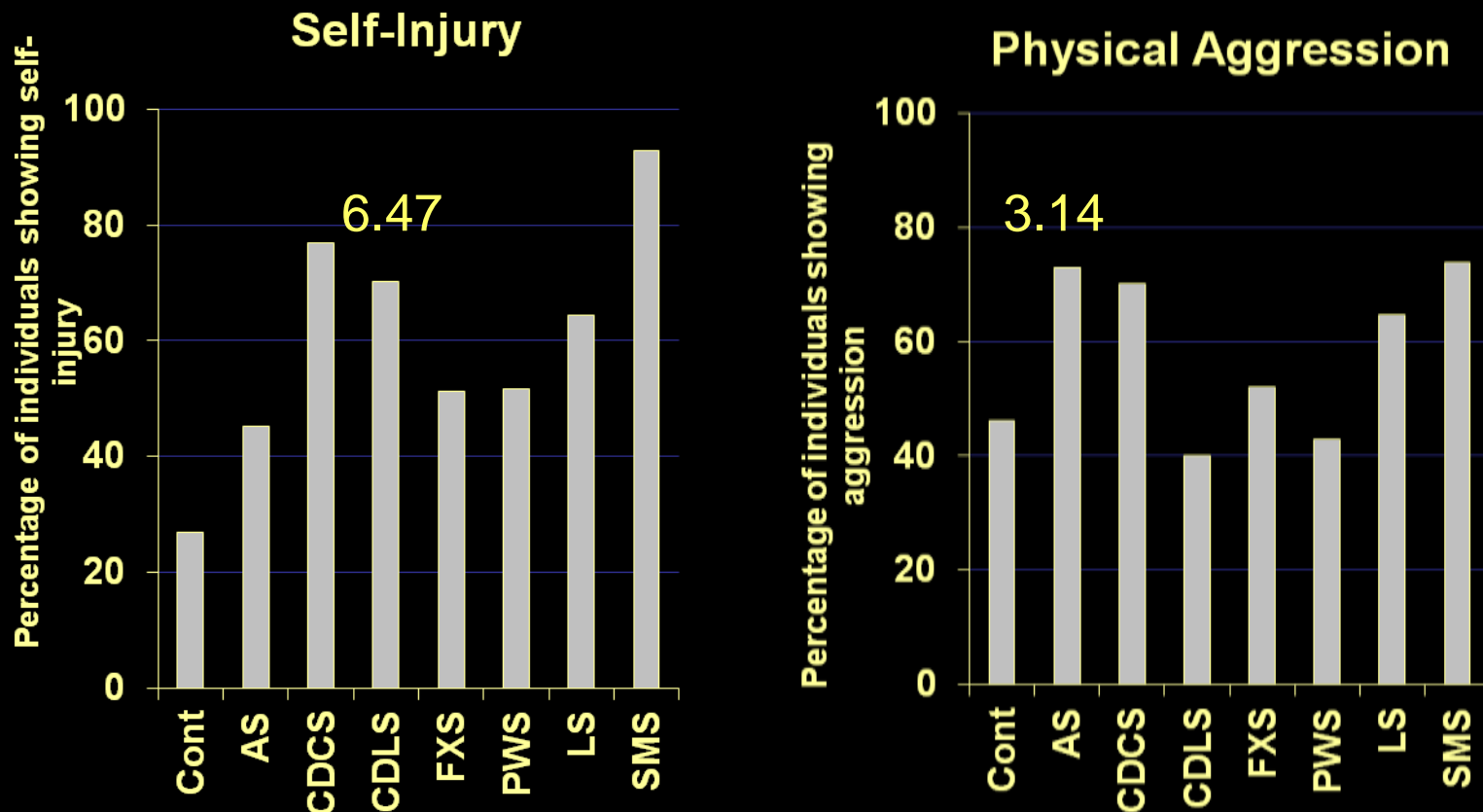




Pain gate theory and learning to self-injure

Risk and very
severe SIB?

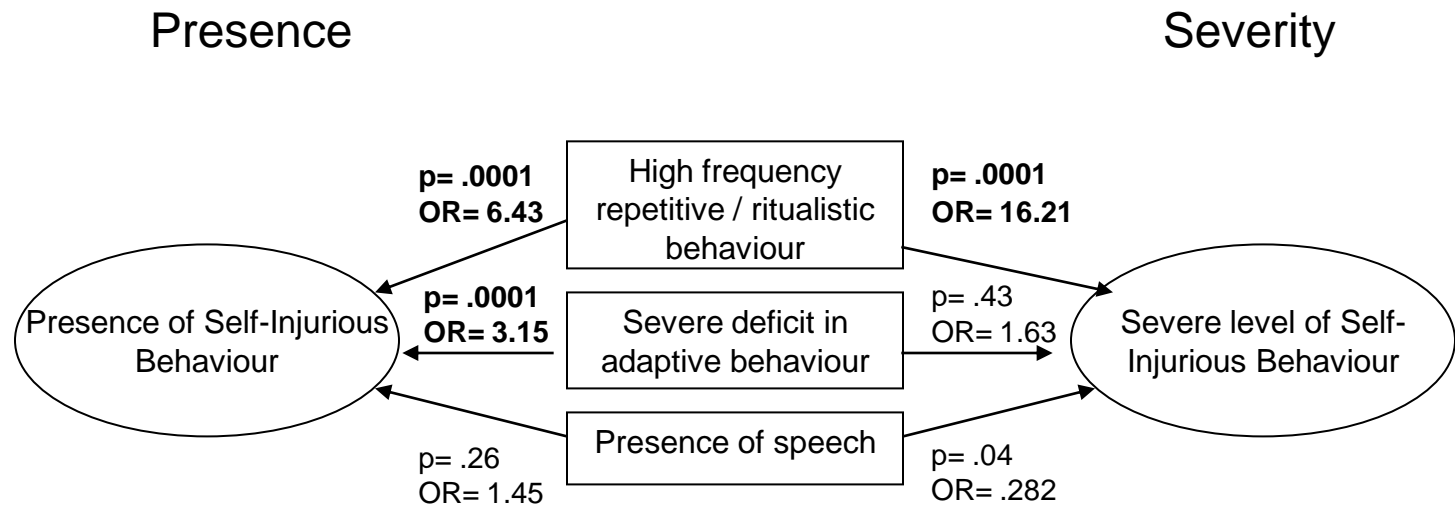
Does the prevalence of self-injury and aggression vary across syndromes?



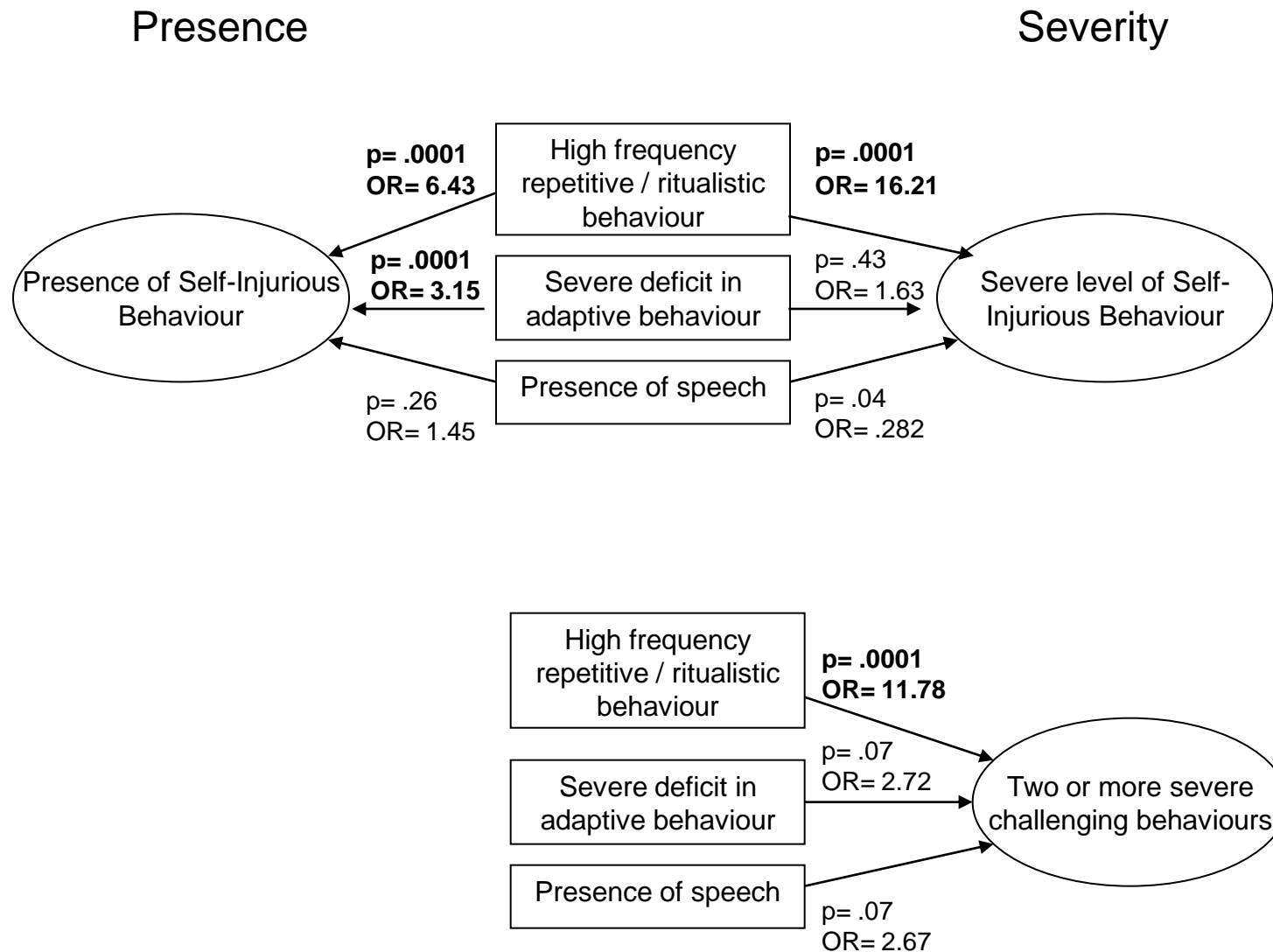
Arron, K., Oliver, C., Berg, K., Moss, J. and Burbidge, C. (2011). Prevalence and phenomenology of self-injurious and aggressive behaviour in genetic syndromes. *Journal of Intellectual Disability Research*

Risk markers

- P\SLD (vs. Mod\Mild LD) [x 4.1]
- Specific genetic syndromes [x 6.0 to 40.0]
- Autism Spectrum Disorder [x 2.9 to 6.4]
- Behavioural markers [x 2.5 to 3.5]



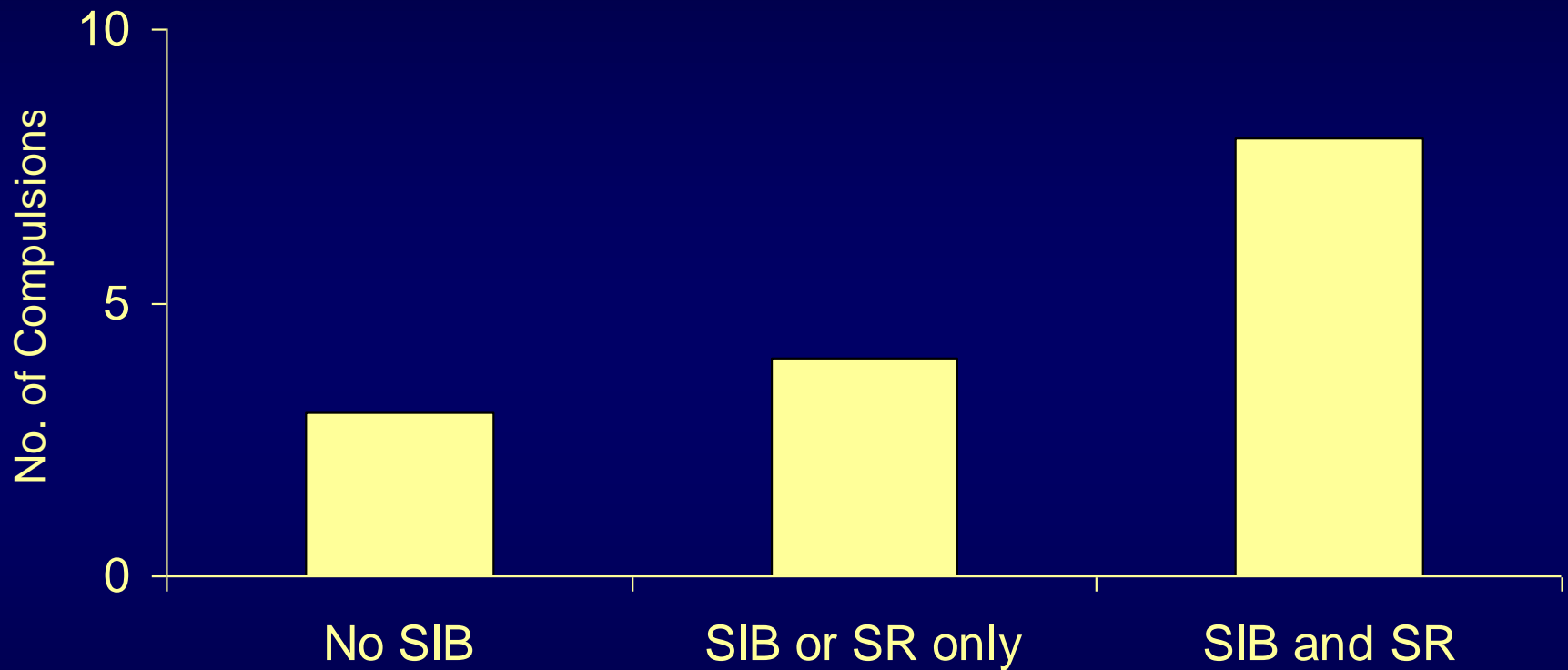
Oliver et al., (2011) Journal of Autism and Developmental Disorders



Oliver et al., (2011) Journal of Autism and Developmental Disorders



SIB, self-restraint and compulsive behaviours in Cornelia de Lange syndrome ($p < .0001$)



Hyman, P., Oliver, C. & Hall, S. (2002). Self-injurious behavior, self-restraint and compulsive behaviors in Cornelia de Lange syndrome. *American Journal on Mental Retardation*, **107**, 146-154.

So.....

- Persistence?
- Characteristics associated with SIB and SR (and hence 'risk')
 - Pain?
 - Behavioural correlates and person characteristics?
- Operant learning?

What do we know about self-injury in ASD?

- 1 • Prevalence of self-injury
- 2 • Persistence of self-injury
- 3 • Factors that increase prevalence
- 4 • Function of self-injury

What do we know about self-injury in ASD?

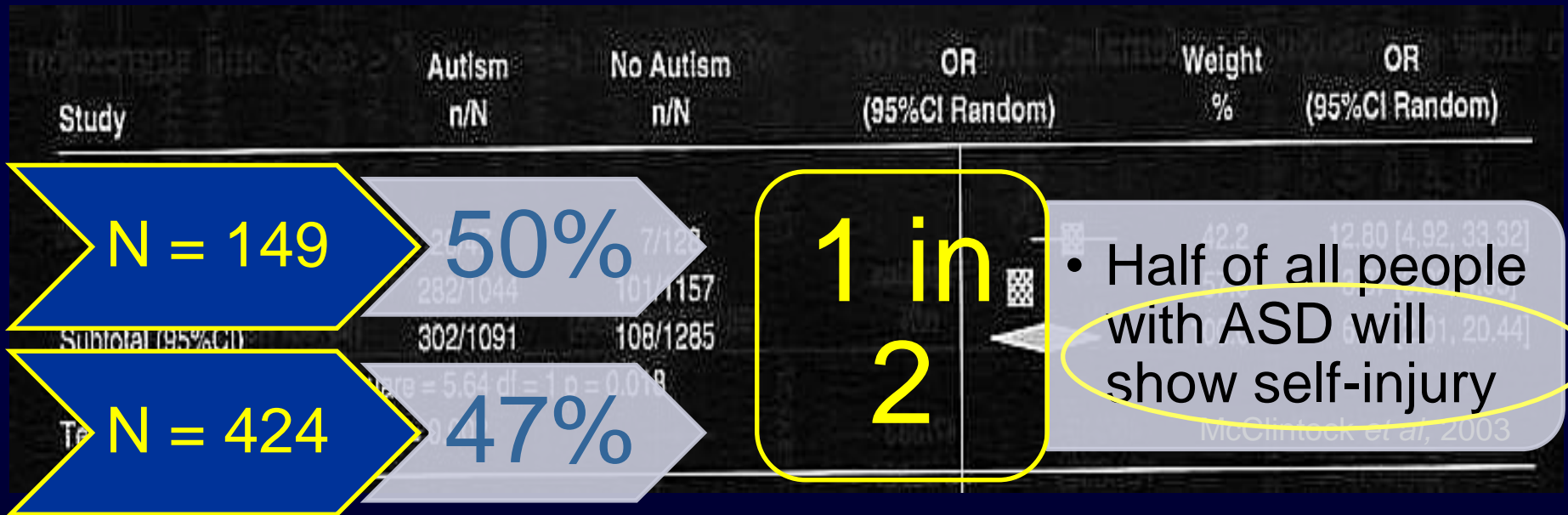
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1

• Prevalence of self-injury

Prevalence of self-injurious behaviour in ID = 4-12%

(Cohen *et al.*, 2010; Cooper *et al.*, 2009; Emerson *et al.*, 1997; Holden & Gitlesen, 2006; Lowe *et al.*, 2007; Oliver, Murphy & Corbett, 1987)



What do we know about self-injury in ASD?

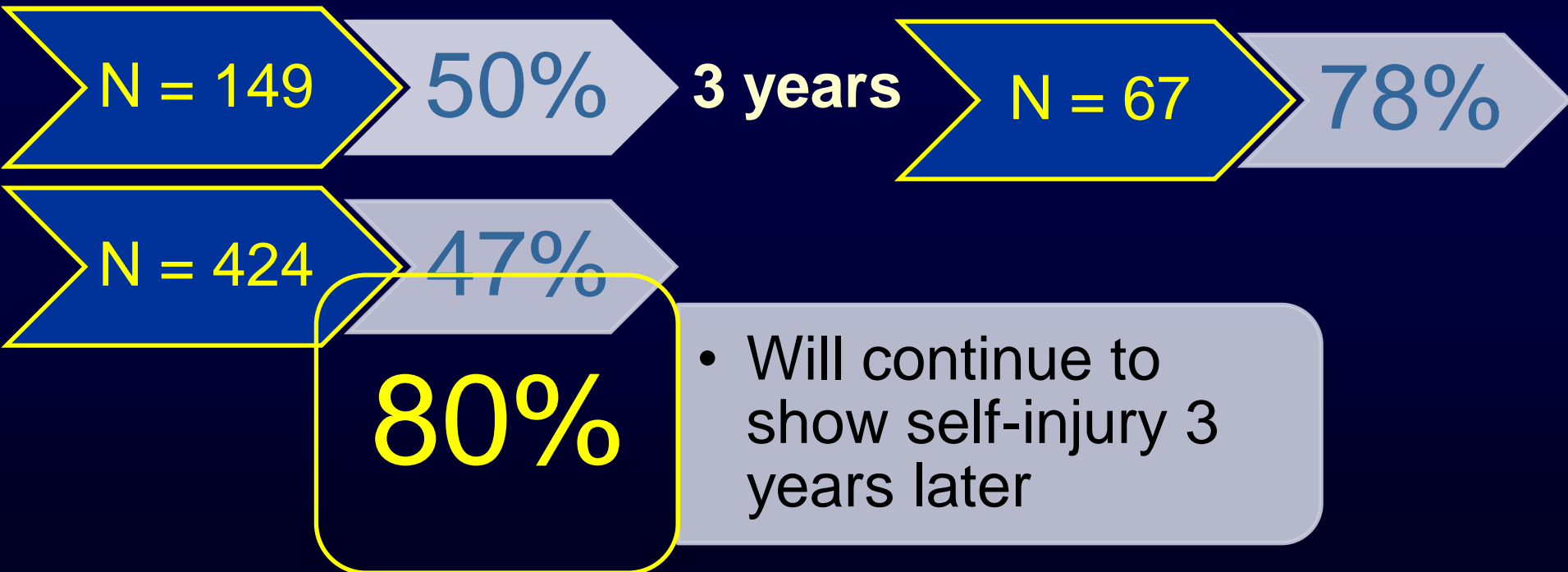
- 1 • Prevalence of self-injury
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2

- Persistence of self-injury

Persistence of self-injurious behaviour in ID = 70-80%

(Emerson *et al.*, 2001; Taylor, Oliver & Murphy, 2011)



What do we know about self-injury in ASD?

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- 4 • Function of self-injury

3

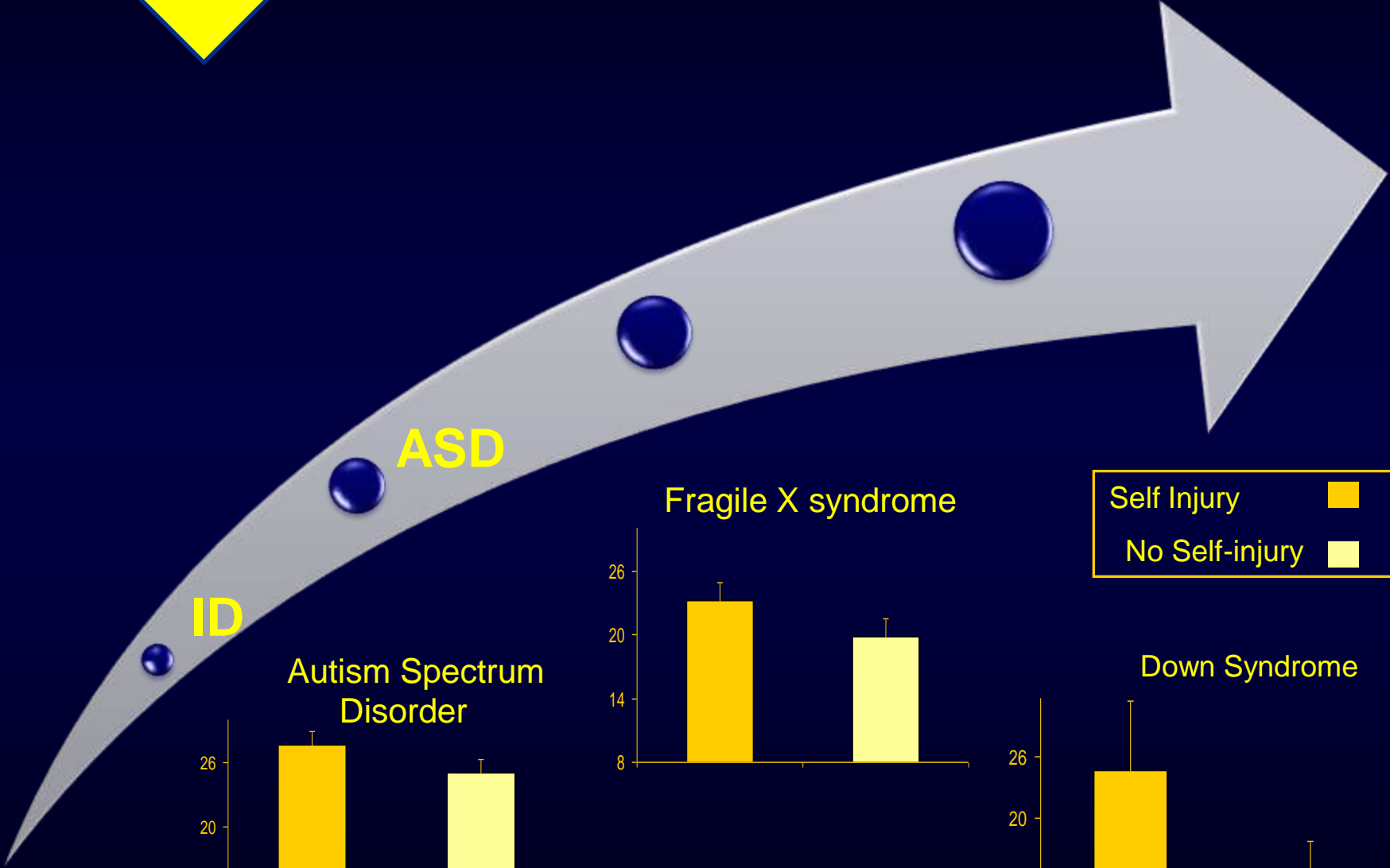
- Factors that increase prevalence

ID

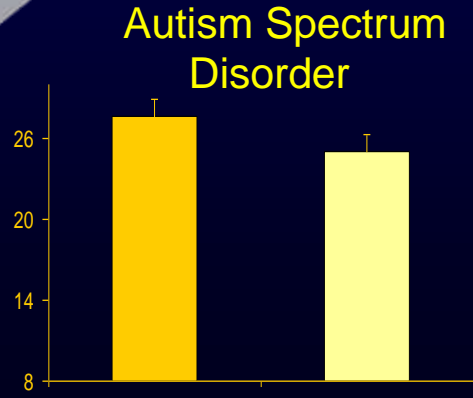


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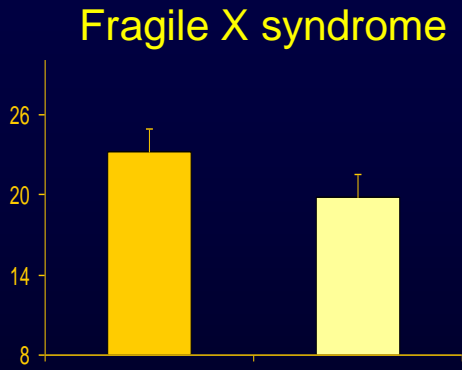
• Factors that increase prevalence



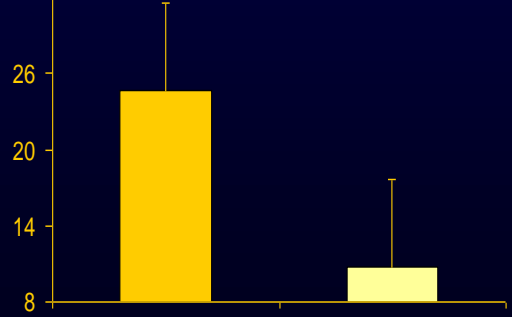
ID



ASD

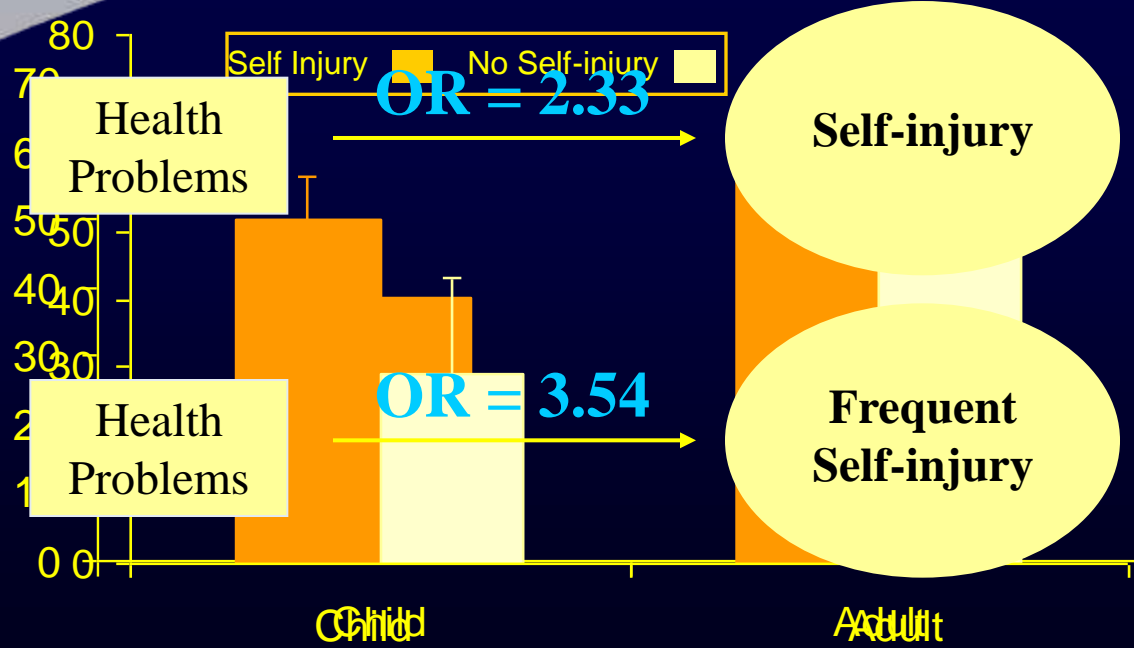


Down Syndrome



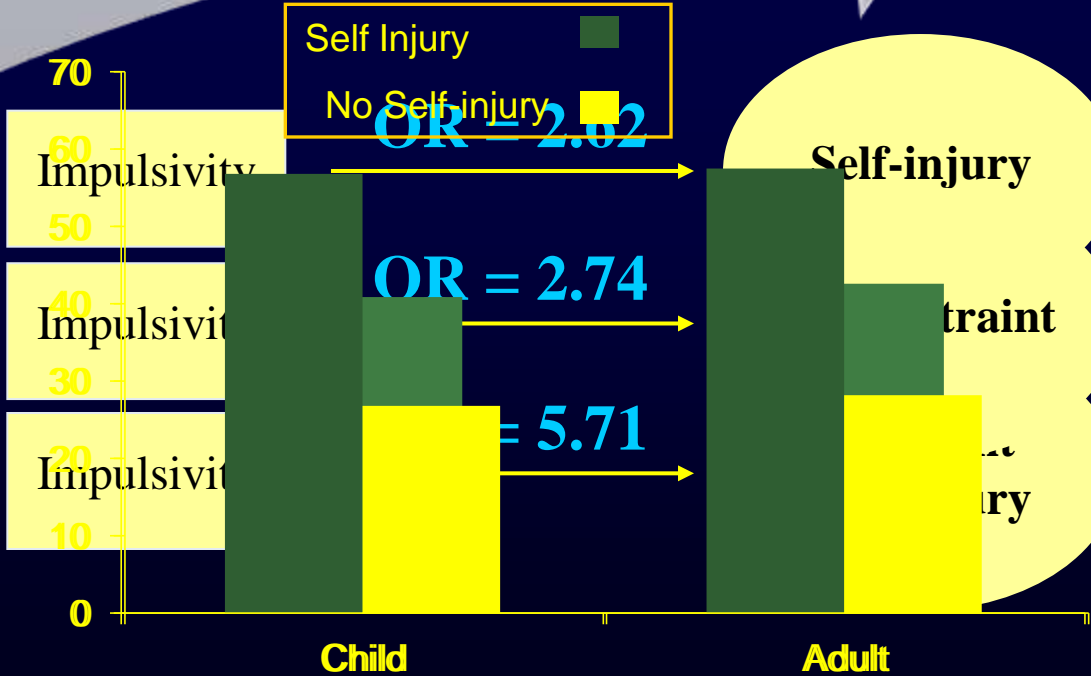
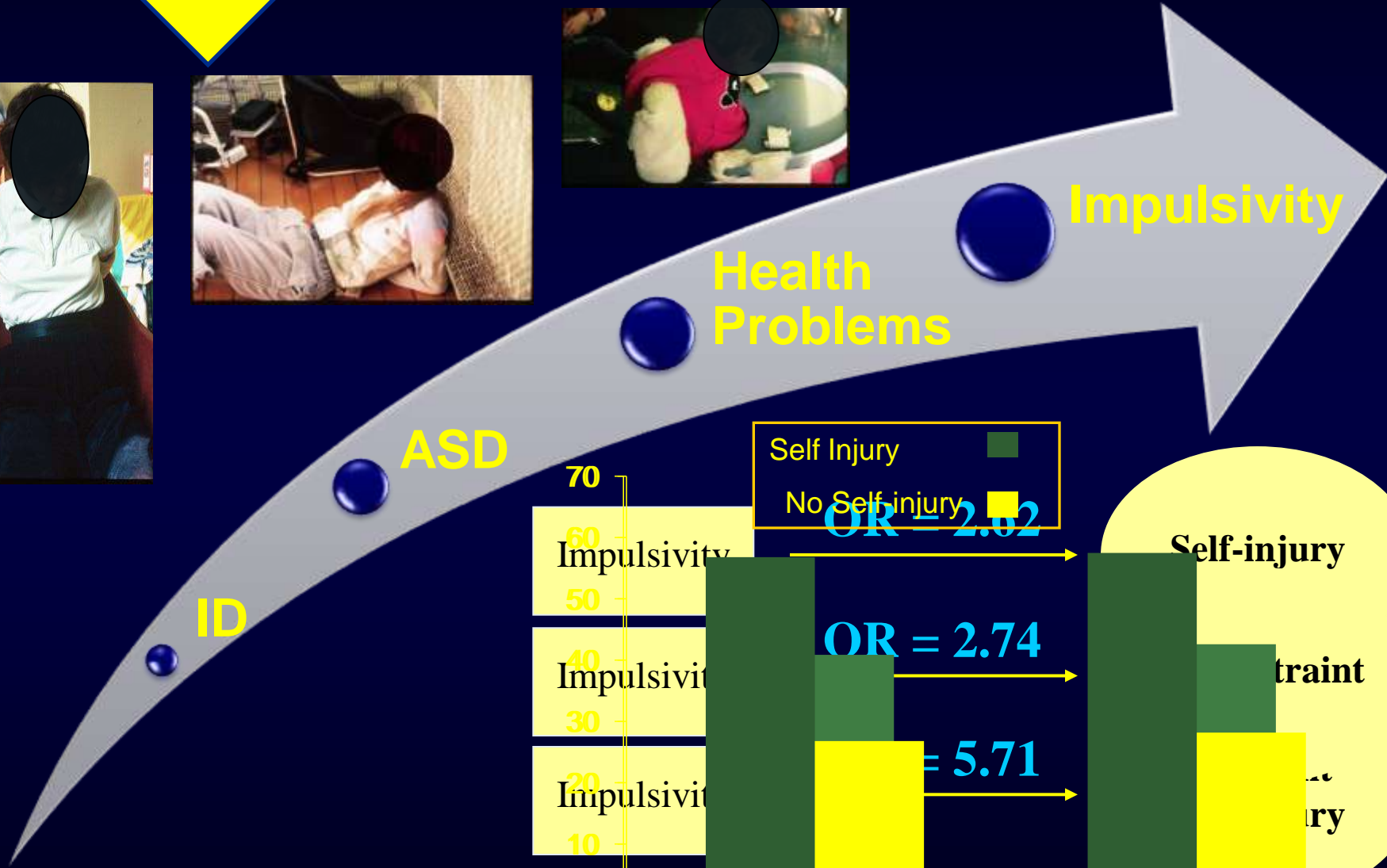
3

• Factors that increase prevalence



3

• Factors that increase prevalence



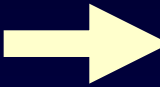
What do we know about self-injury in ASD?

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• Function of self-injury

Need for something to start or stop



AVERSIVE!

- Concern
- Frustration
- Anxiety
- Confusion
- Distress



ACTION



ENGAGE



REWARD



Increase in chance of SIB

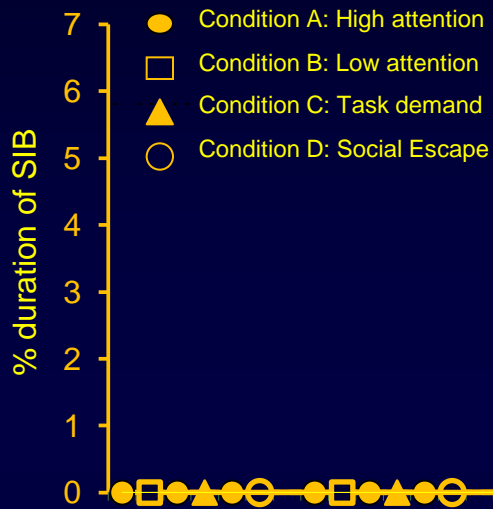


Positive/negative
Reinforcement

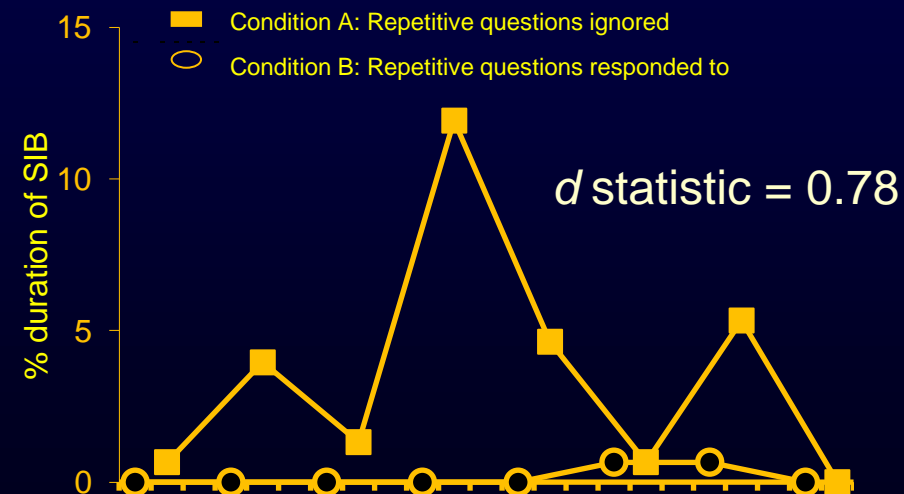
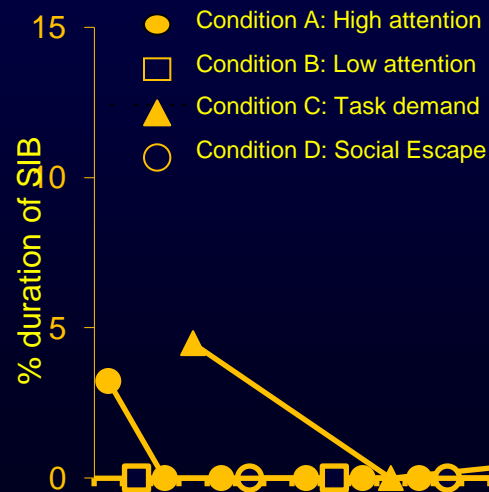
- Comfort
- Reprimand
- Offer
- Restrain
- Occupy
- Distract

Function of self-injury

Participant One



Participant Six



10 children with ASD and reported SIB

'Standard' experimental functional analyses

No Function

10 participants

Function

0 participants

ASD 'Modified' experimental functional analyses

No Function

4 participants

Function

6 participants

Other

1 participants

Sensory Escape

2 participants

Access to Repetitive Behaviour

3 participants

6 in 10

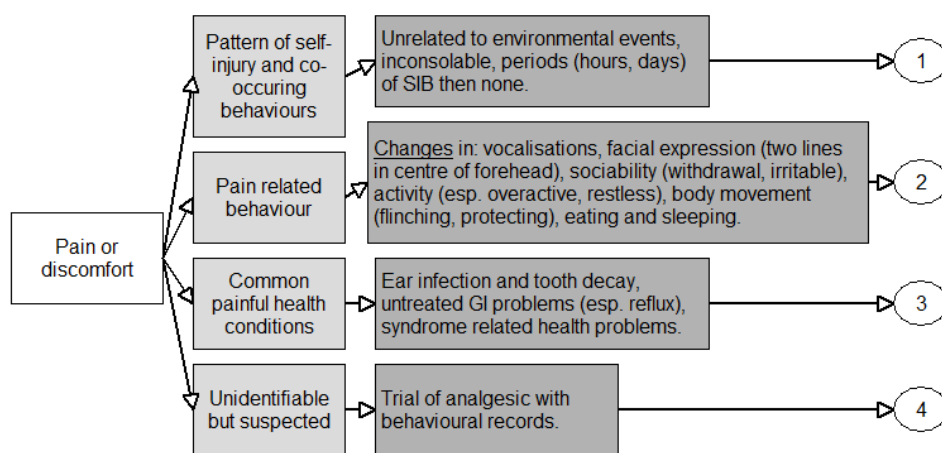
• Function for self-injury

What do we know about self-injury in ASD?

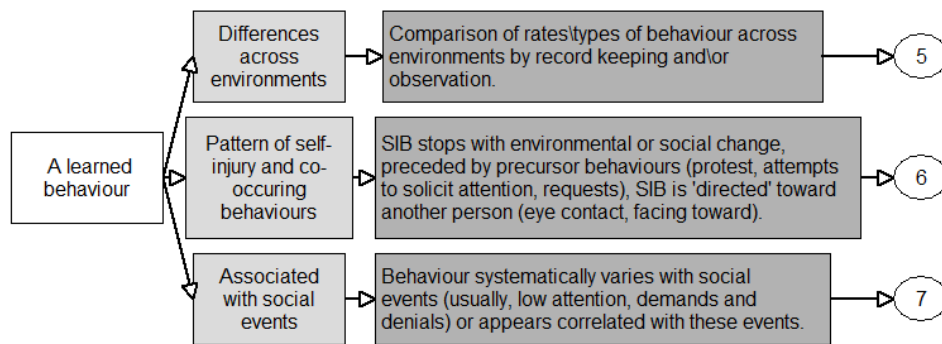
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Unfinished business

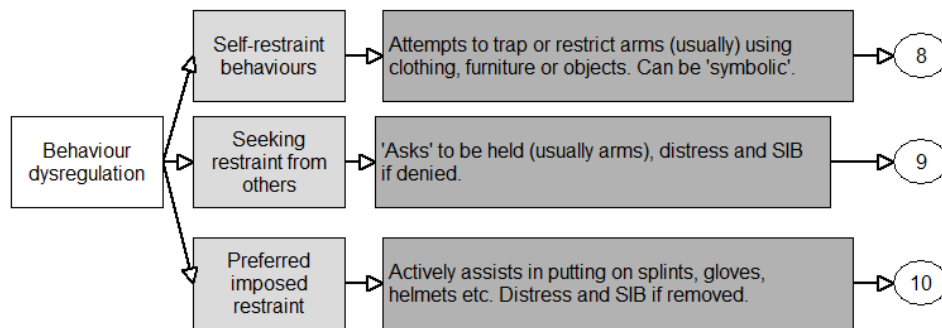
- Service access and intervention availability (not how but when)



Identifying and resolving health problems

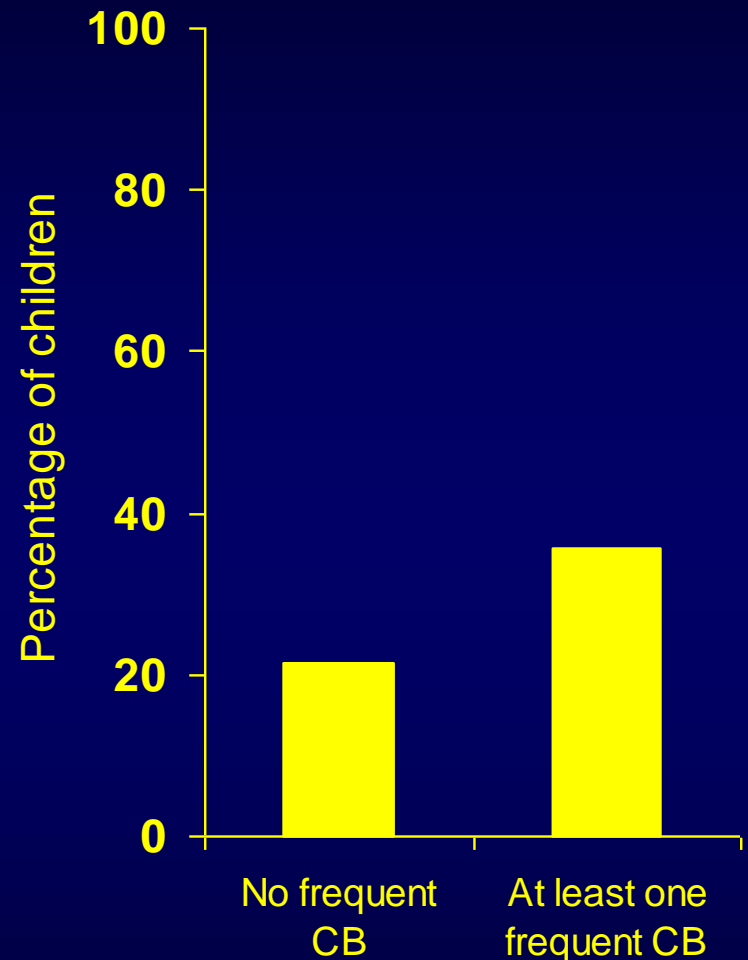


Effective behavioural management based on functional assessment



The most common influences on self-injurious behaviour are shown on the left. The boxes in the centre list the signs that each influence might be relevant. The boxes on the right show either behavioural indicators of each influence or the assessments that might be undertaken to identify indicators. Further information on each indicator or assessment is given in the numbered sections on the following pages.

Of those children showing frequent and severe challenging behaviour, what percentage have had at least one contact with a relevant professional in the last month?



Allocation of new and substantial funds to the NHS, ringfenced for people with autism spectrum disorder, to enable the implementation of a large scale, effective intervention strategy for self-injury.

Six lives: the provision of public services to people with learning disabilities

Part one: overview and summary investigation reports

Before : MR JUSTICE RYDER

This is the judgement handed down regarding the 'treatment' of challenging behaviour shown by a man with severe intellectual disability and autism spectrum disorder.

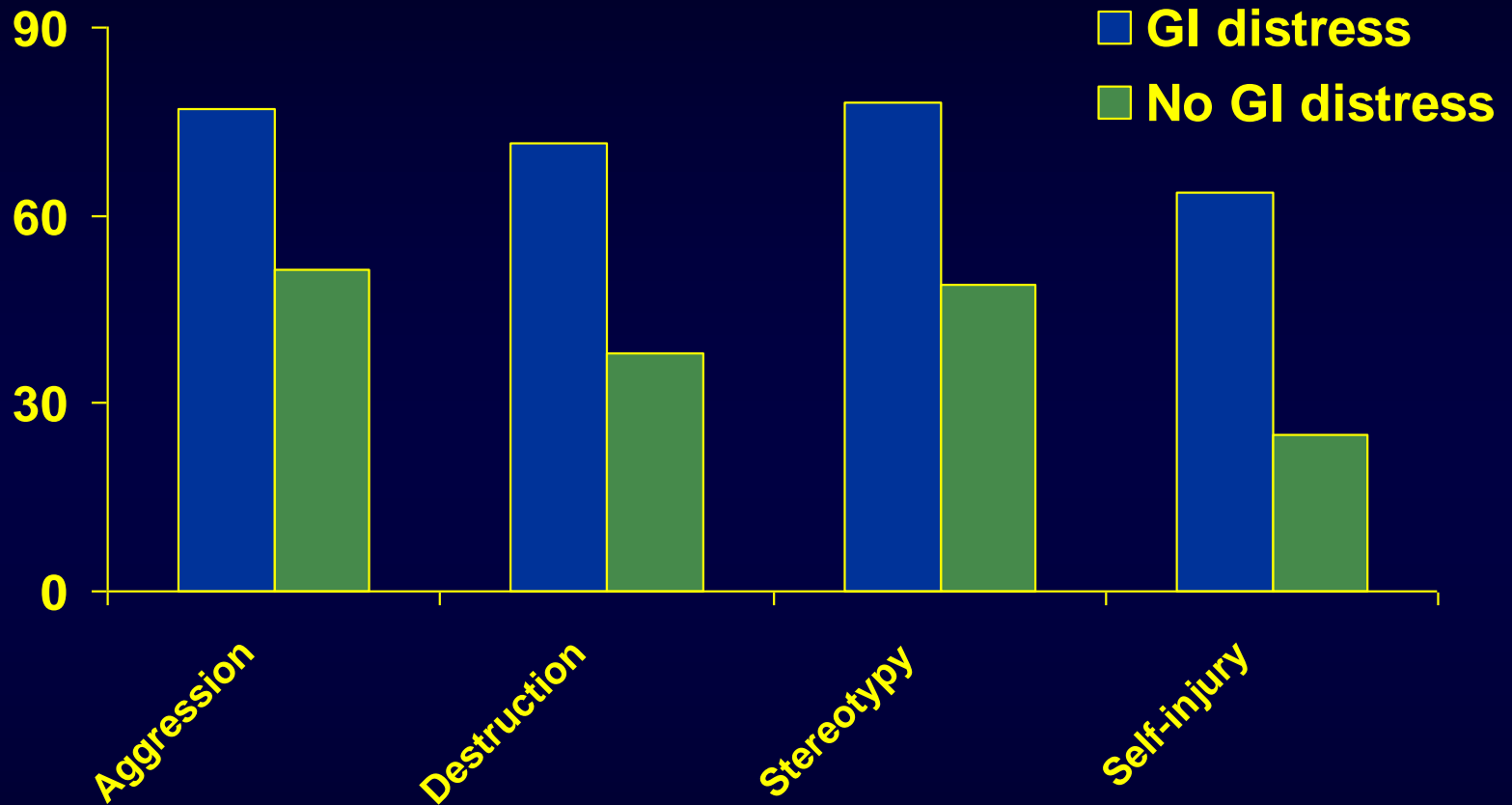
"..... despite the plethora of Government guidance and regulation urban myth and so called 'common sense' rather than expert advice and multi-disciplinary working practices continues to be influential in some residential settings. Inquiries long ago established the need for specialist, qualified care and treatment for pupils and patients with special needsUntil this court's intervention, that multi-disciplinary environment with access to high quality inter-disciplinary advice did not exist for C. That was unacceptable. "

Between: 'C' (by his litigation friend the Official Solicitor) Claimant
- and -
A Local Authority Defendant

Unfinished business

- Service access and intervention availability (not how but when)
- Research questions (how)
 - Most severe self-injury (usually when self restraint is evident)
 - Pain and discomfort
 - Risk driven early intervention strategy
- Distribution of research funding

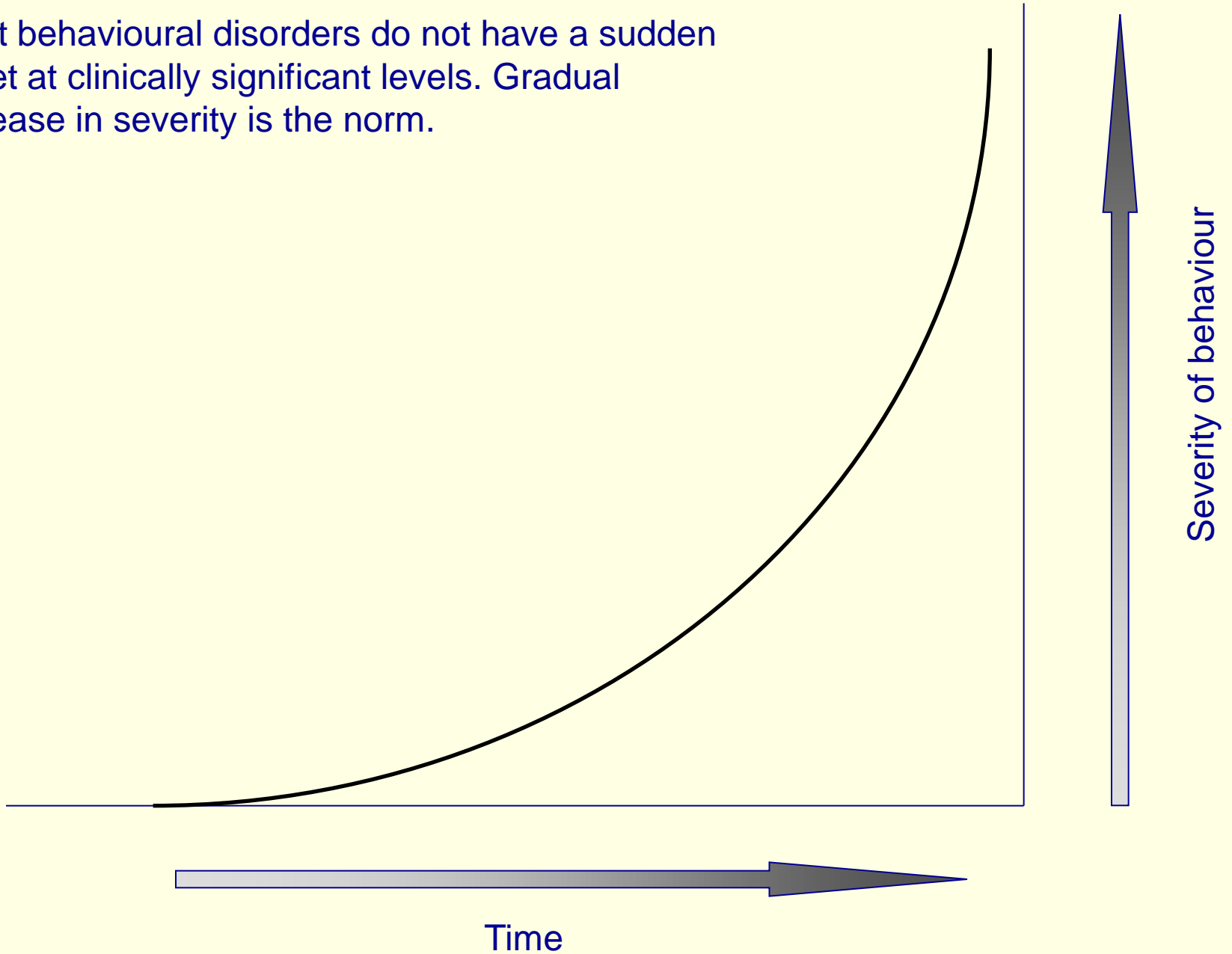
GI distress and SIB in ASD



Two recent JADD papers of interest:

1. GI disorders
2. Sensory sensitivity

Most behavioural disorders do not have a sudden onset at clinically significant levels. Gradual increase in severity is the norm.



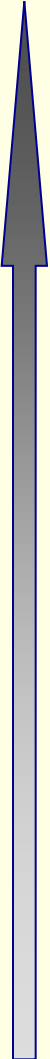
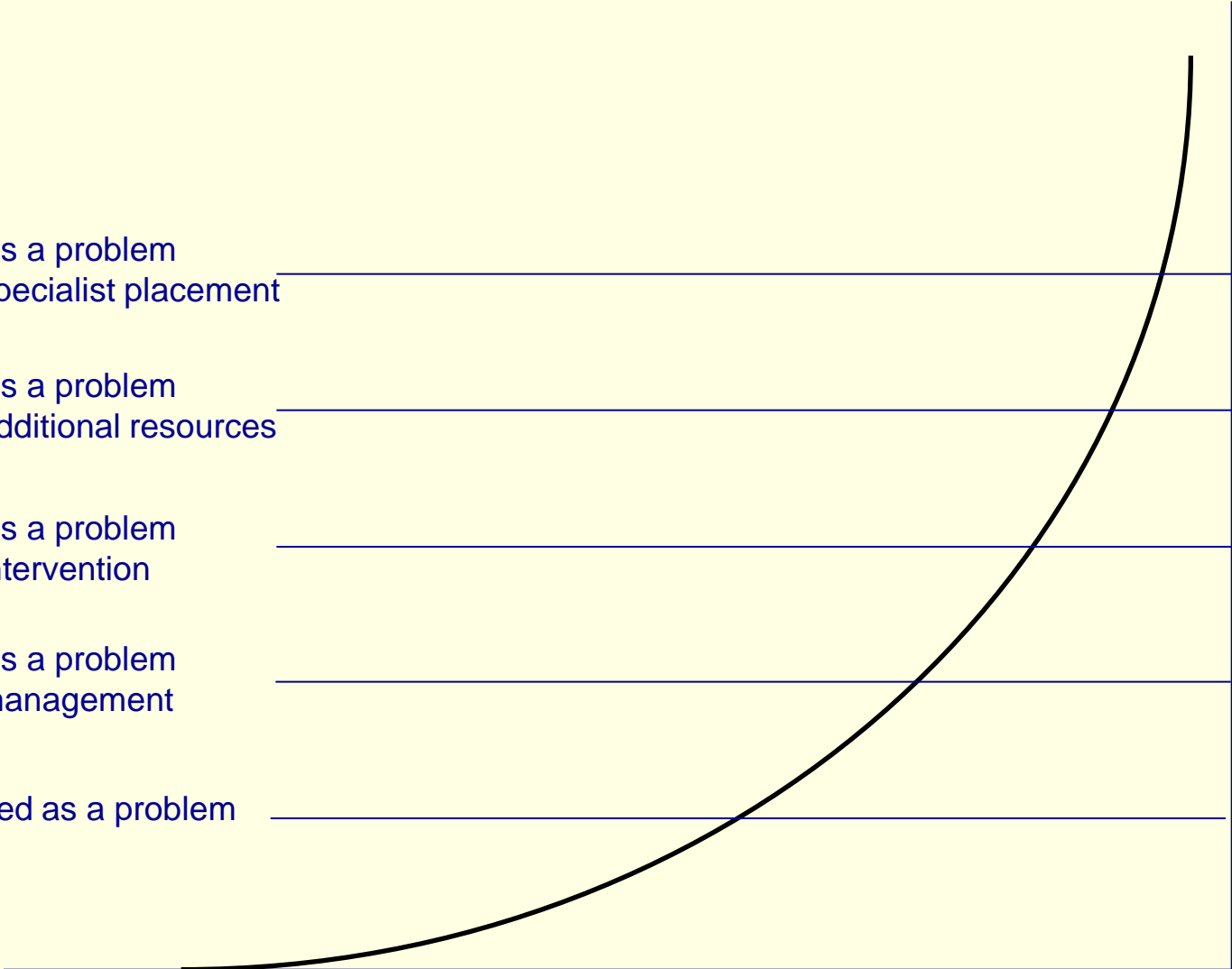
Identified as a problem
requiring specialist placement

Identified as a problem
requiring additional resources

Identified as a problem
requiring intervention

Identified as a problem
requiring management

Not identified as a problem



Severity of behaviour

Time

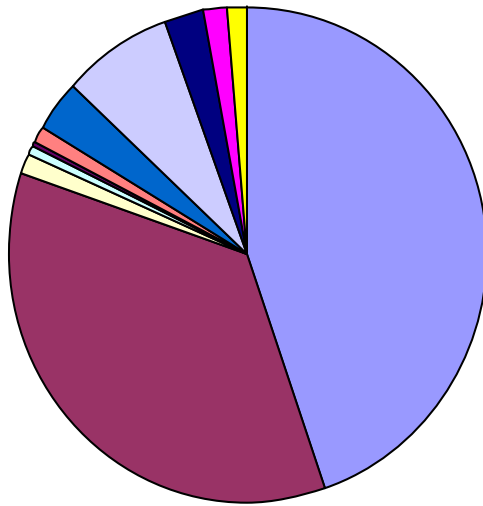


'Helping hands' volunteer team

EPoCH

Unfinished business

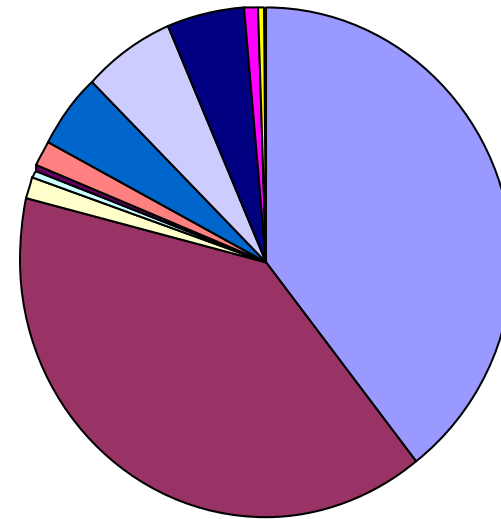
- Service access and intervention availability (not how but when)
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2001 - 2005

5,271 publications

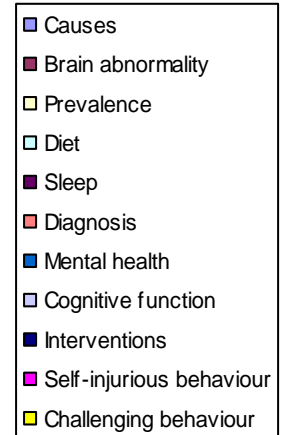
(Self-injury 1.25%)



2006 - to date

13,222 publications

(Self-injury 0.086%)





Core Funding

Cerebra

Grant Support

Medical Research Council
The Big Lottery
Baily Thomas Foundation
Cornelia de Lange Syndrome Foundation
Research Autism
NE Essex PCT
Birmingham Children's Hospital
Angelman Syndrome Foundation (USA)
Newlife
National Autistic Society
ESRC
Tuberous Sclerosis Alliance

www.birmingham.ac.uk/cnnd

C.Oliver@Bham.ac.uk

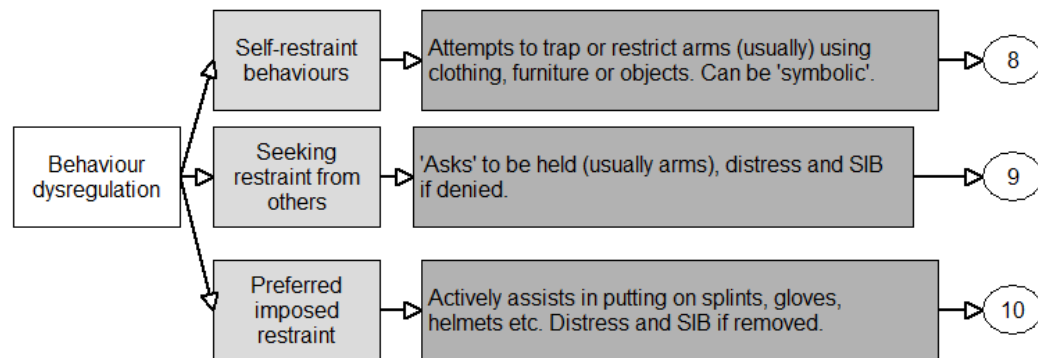
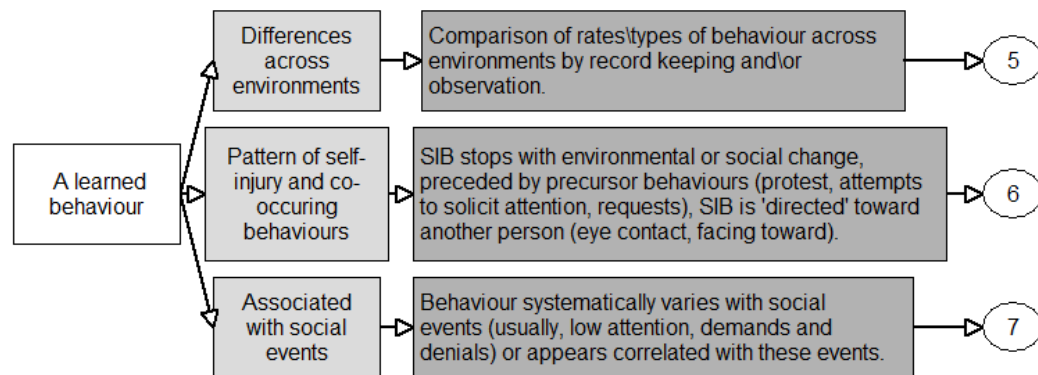
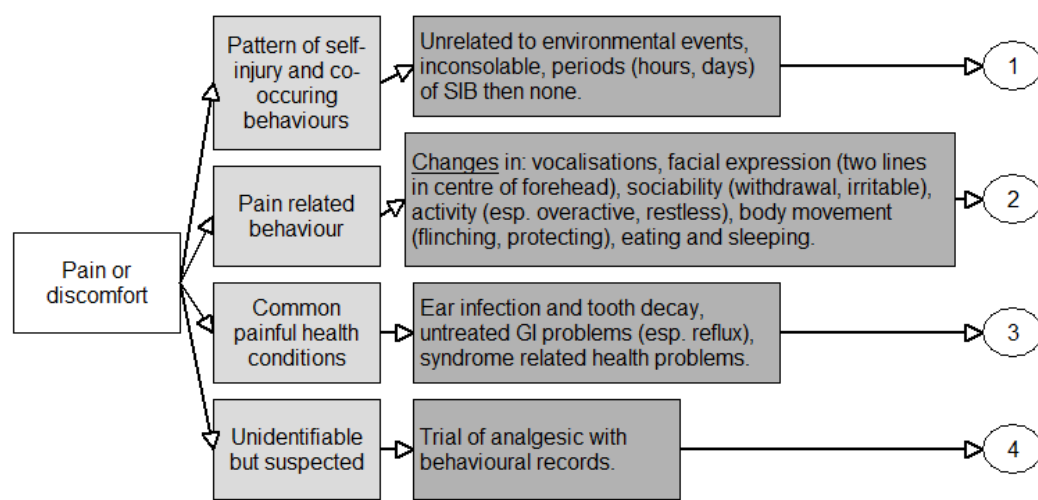
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Where to now?

- Making the case
 - Health economics
 - Parental concerns
 - Current service delivery
- Pain and discomfort, sensory difference
- Proof of principle of assessment process (both early and responsive intervention)
 - Pre-RCT
 - EPoCH (proactive and risk related)
- Delivery of service
 - Web based expert systems



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- Delivery of service
 - Web based expert systems
 - Remote consultation
 - Advocacy
 - “We do not have any money so we will have to think”

“(.....) only has challenging behaviours when in pain. This results in a complete change in personality, ripping lumps of hair out so massive patches are missing. screaming like a banshee.

But we are not believed at hospital and just get sent home as they see no fever, no infections, ears, eyes, teeth, skin, joints. And refuse to do anything even basic bloods or x-rays. We then have to go to our community consultant who found that acid reflux had burned her severely and finally got meds needed. The hospital telling us that she had nothing wrong and it was behavioural or neurological.

Is this pain tool going to be any use to use if no one listens?”

Parent of a child with Angelman Syndrome

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Is the ability to inhibit a previously learned behaviour compromised?

