The Cerebra Centre for Neurodevelopmental Disorders

UNIVERSITY OF BIRMINGHAM

RESEARCH AUTISM
IMPROVING THE QUALITY OF LIFE

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

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# Self-injurious Behaviour and Severe Intellectual Disability

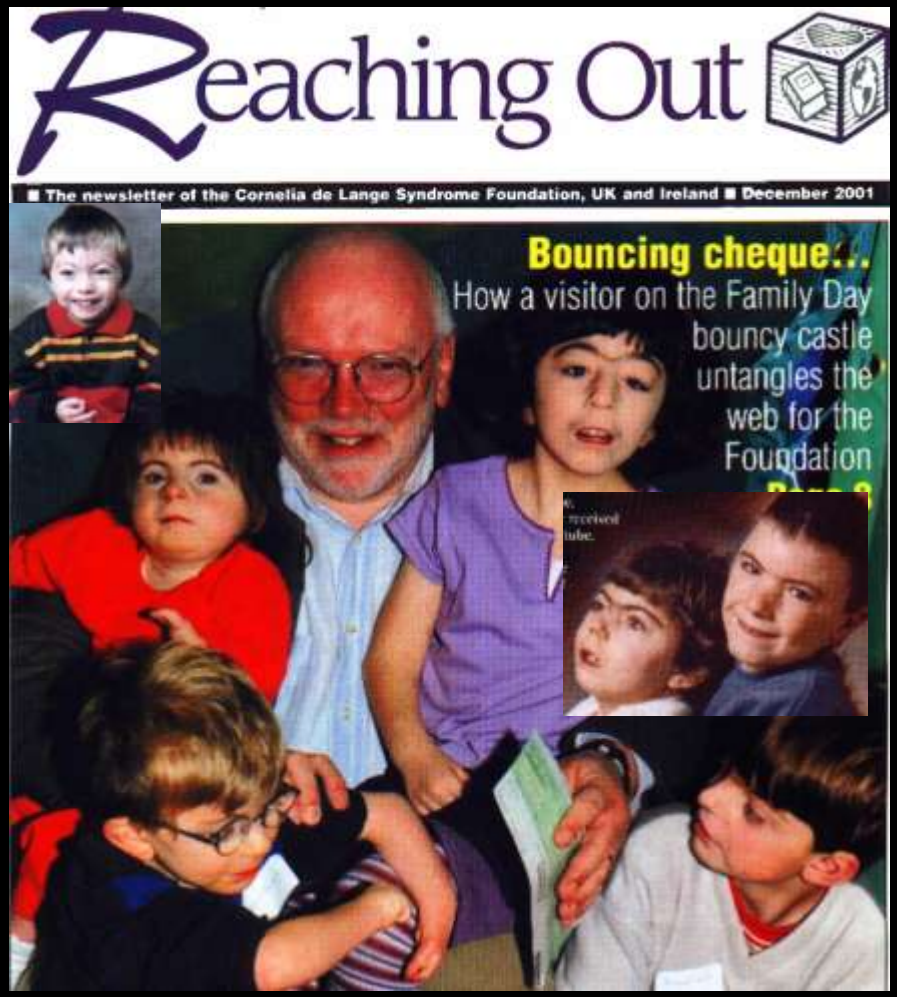
- Prevalence: 10% - 35% (c. 50% in ASD)
- Can be chronic and resistant to intervention (c. 80% persistence over 18 years; ASD?)
- Human and economic costs: pain and discomfort, family and carer stress, relationship breakdown, medication effects, compromised quality of life and accomplishment, placement 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

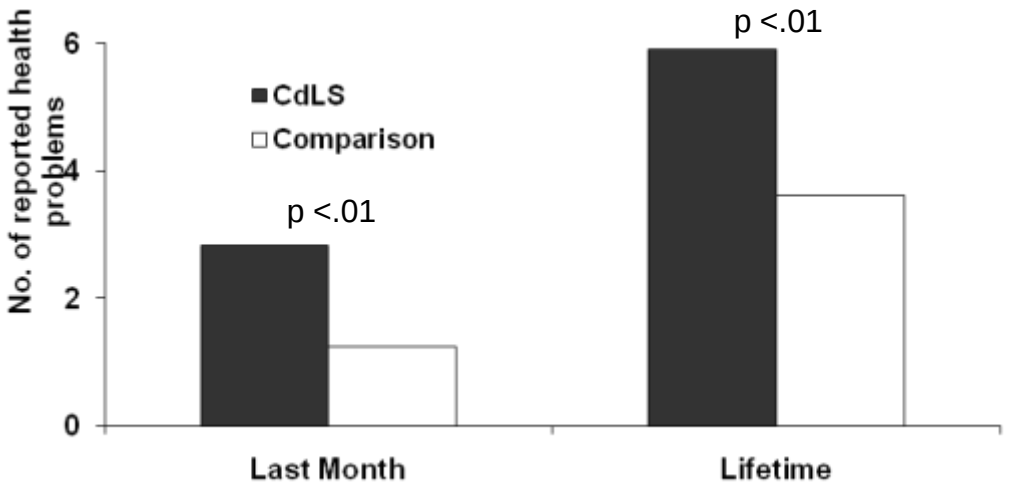

- Prevalence: 1 in 10,000 to 40,000
- Deletions on chromosomes 5, 10 and X
- Main features: mild\moderate to severe ID, small stature, upper limb abnormalities, distinctive facial features, gastroesophageal reflux, limited speech, hirsute, SIB.

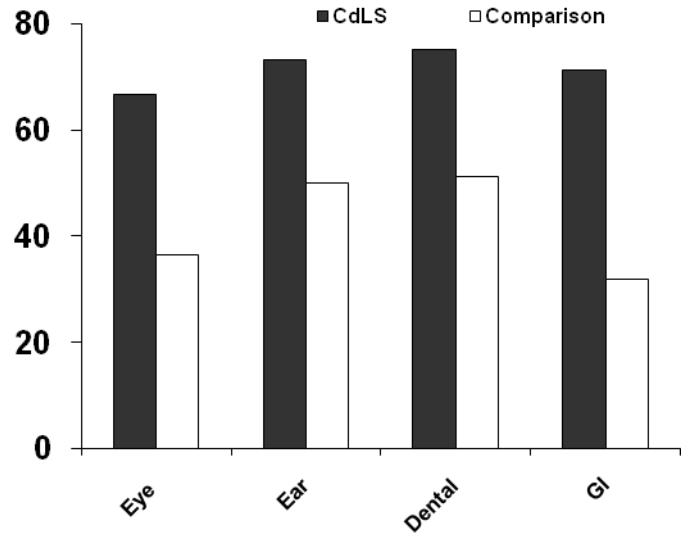
de Lange, C. (1933). Sur un Type nouvea de degeneration (typus amstelodamensis) Arch.med. enf. 36. 713 - 719.

Brachmann,W. (1916). Ein Fall von symmetrischer Monodaktylie durch Ulnadefedkt, mit symmetrischer Flughautbildung in den Ellenbeugen, sowie anderen Abnormalitaten (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

| | | % of individuals experiencing health problems | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| CdLS Studies | *n* | 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 | – | – | – | – | – | – | – | – | – | – |



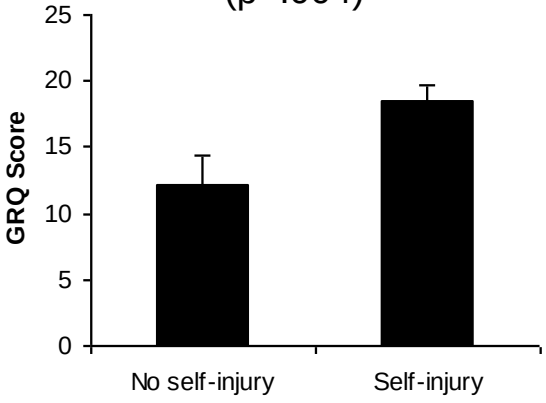




Hall, S., Arron, K., Sloneem, J. and Oliver, C. (2008). Health and sleep problems in Cornelia de Lange Syndrome: A case control study. *Journal of Intellectual Disability Research,* **52**, 458-468.

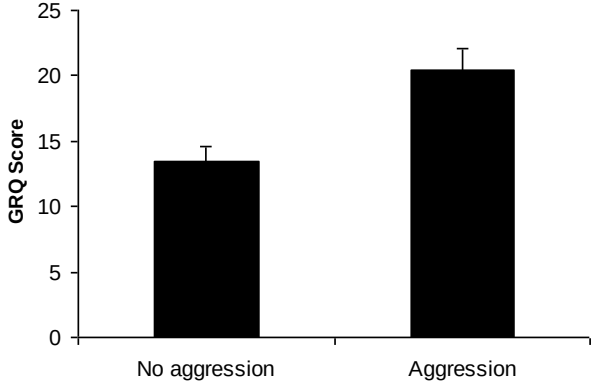
Arch his/her back
Lie over object on stomach
Salivate excessively
Fidget/wriggle
Fingers in mouth
Chew clothes
Grind teeth
Scratch/rub chest/throat
Drink excessively

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

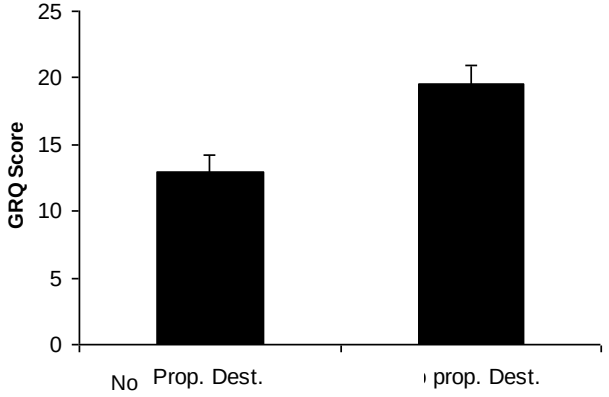
(p=.004)



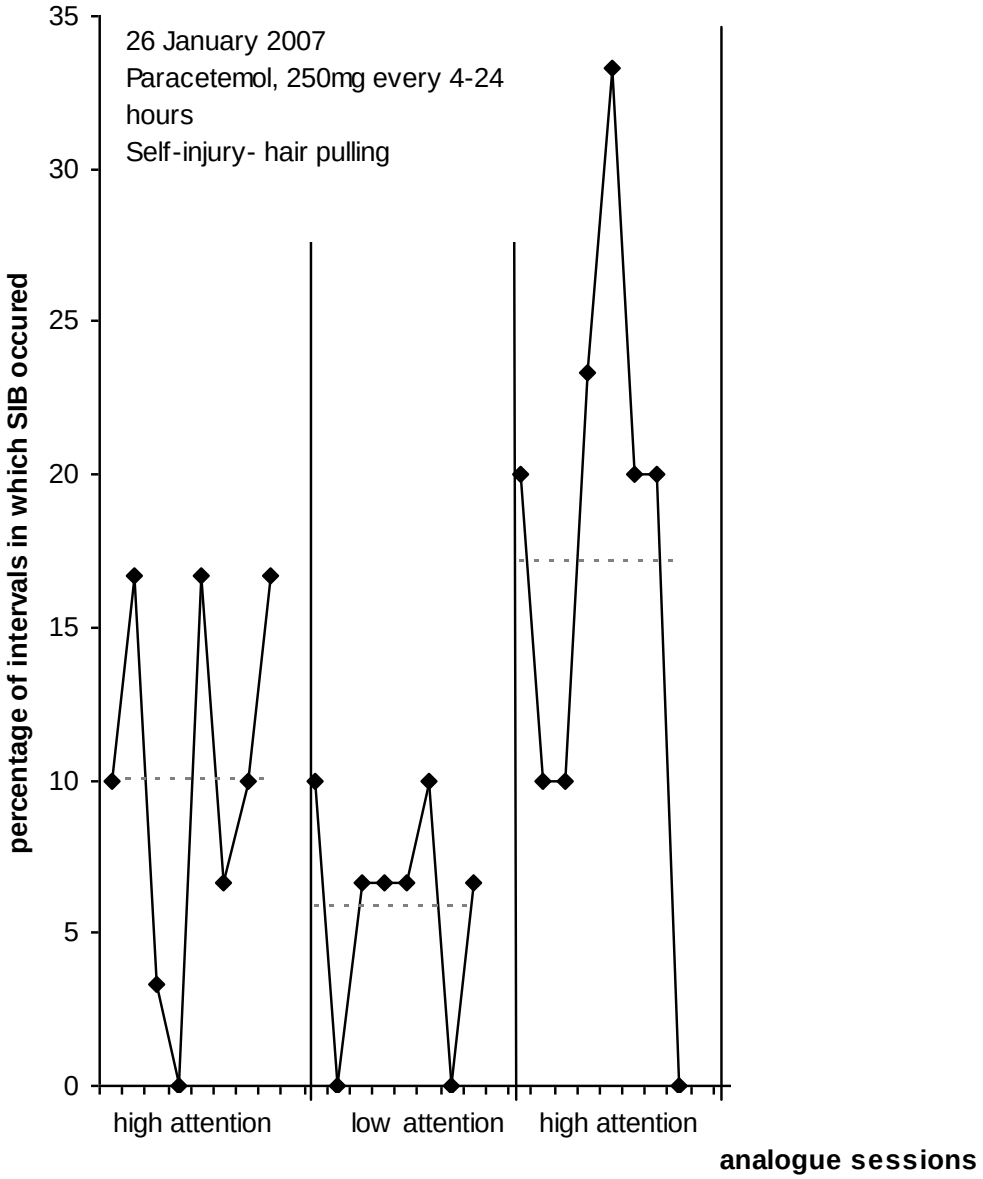

(p=.001)




(p=.001)



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



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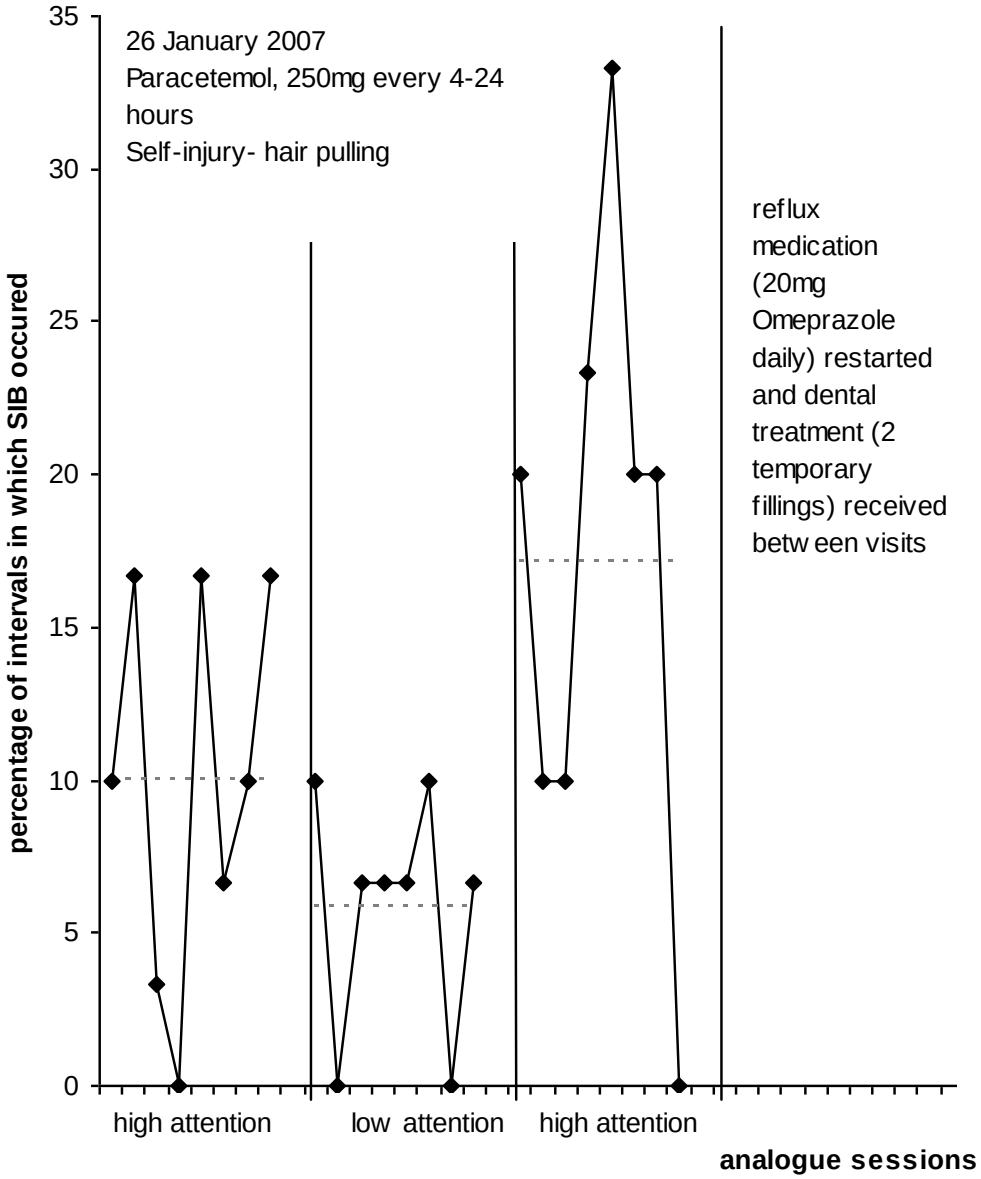

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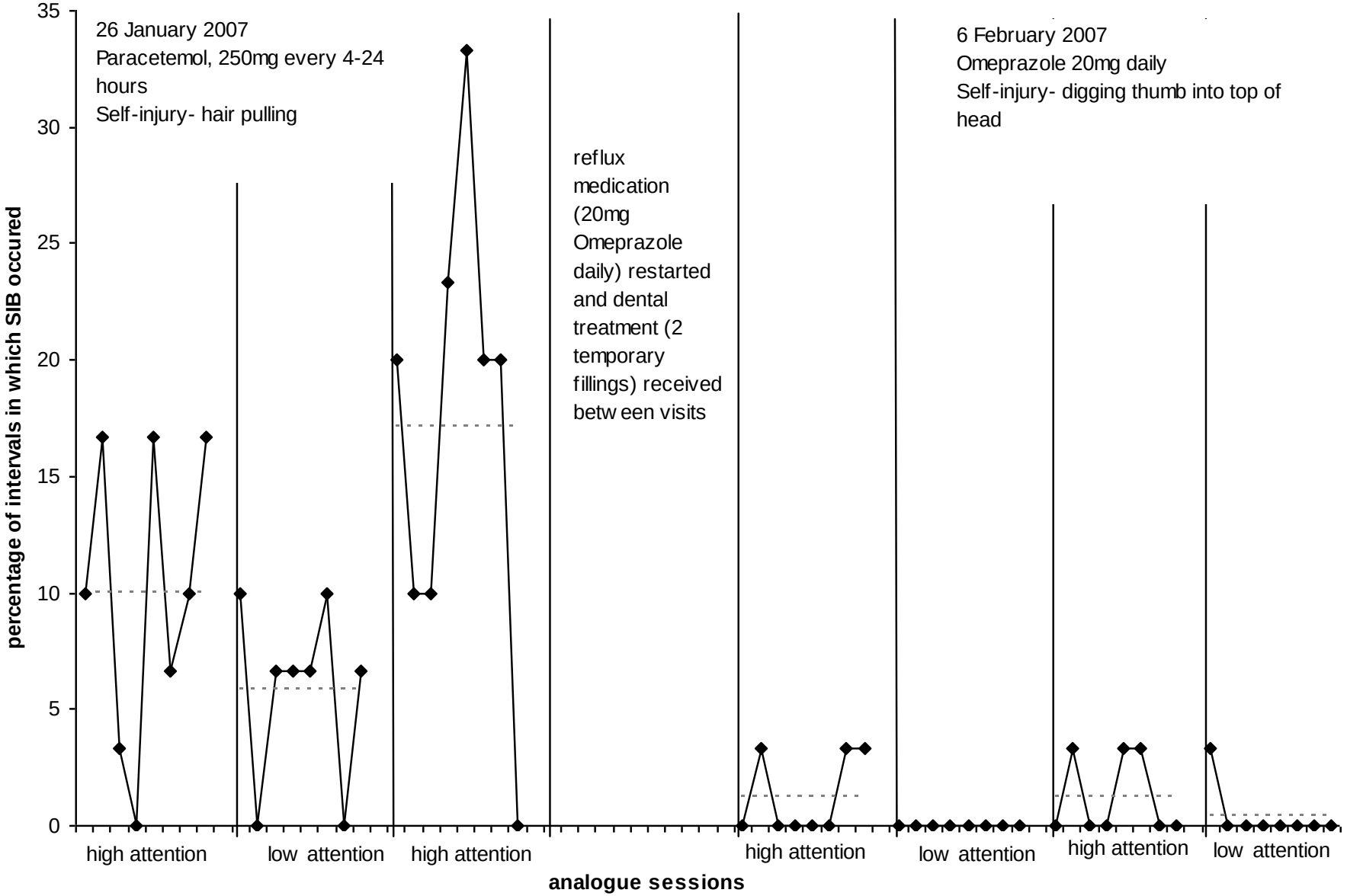
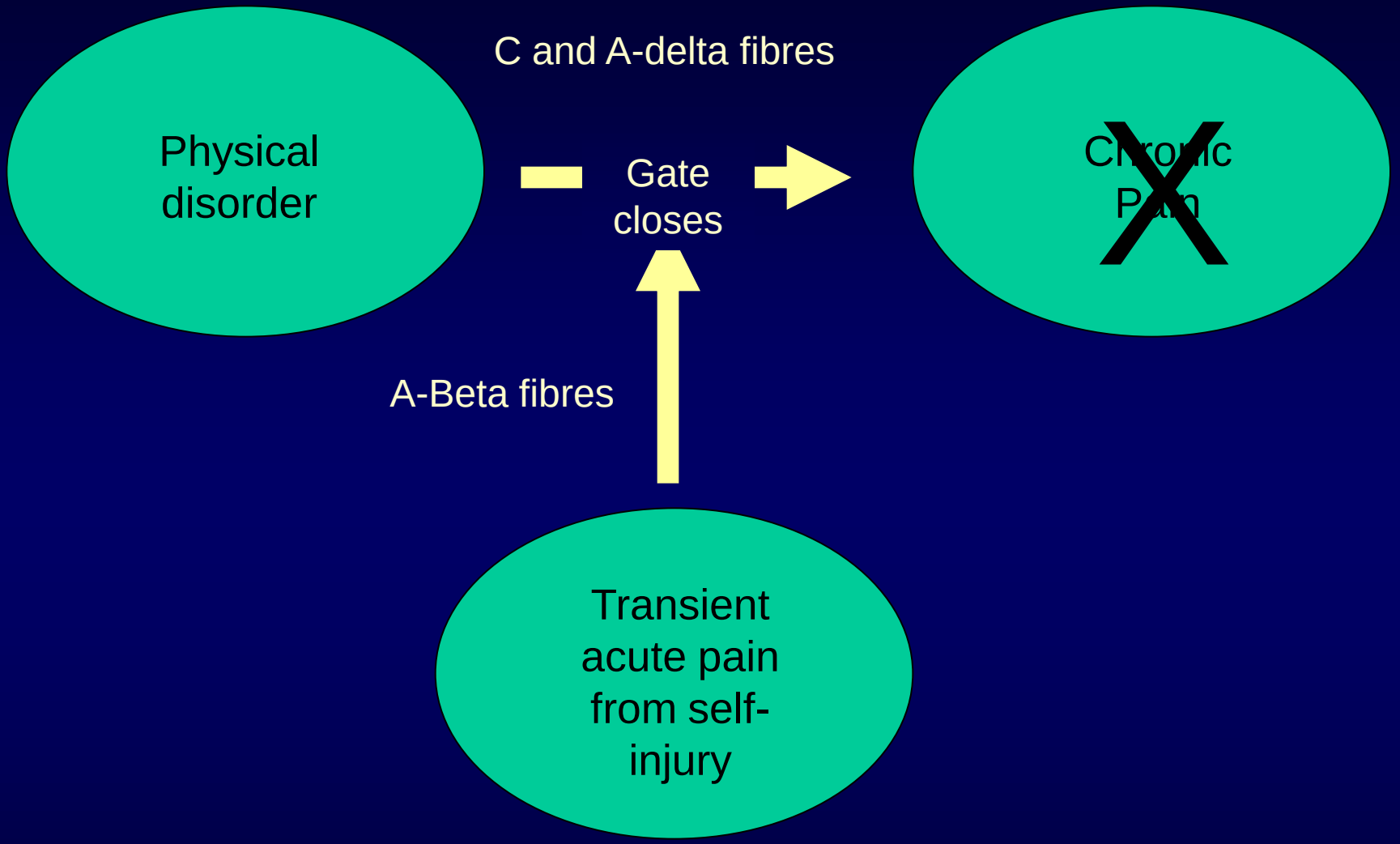
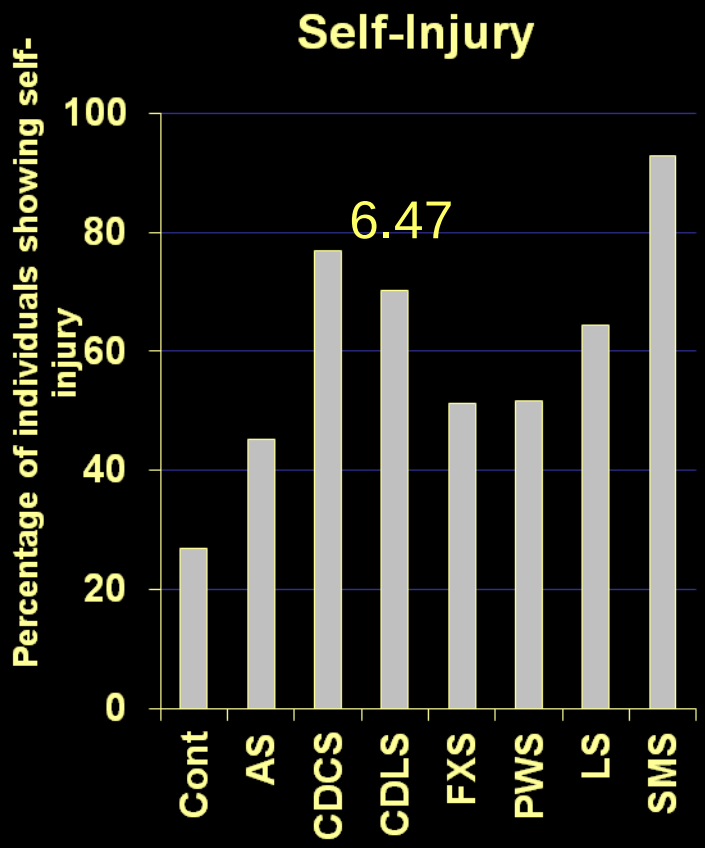


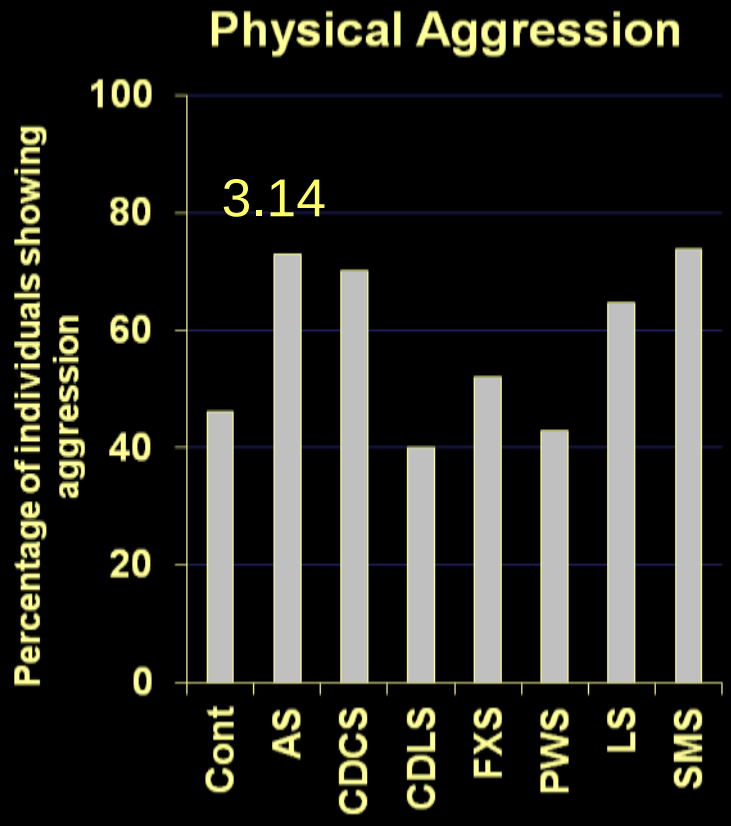



Pain gate theory and learning to self-injure

# Risk and very severe SIB?

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



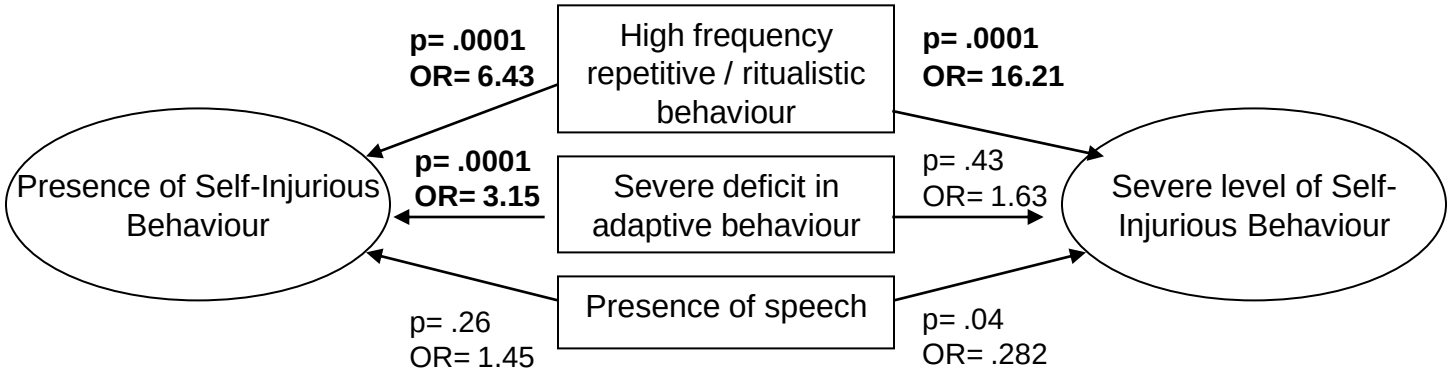

Arron, K., Oliver, C., Berg, K., Moss, J. and Burbidge, C. (2011). Prevalence and phenomenology of self-injurious and aggressive behaviour in genetic syndromes. *Journal of Intellectual Disability Research*

# Risk markers

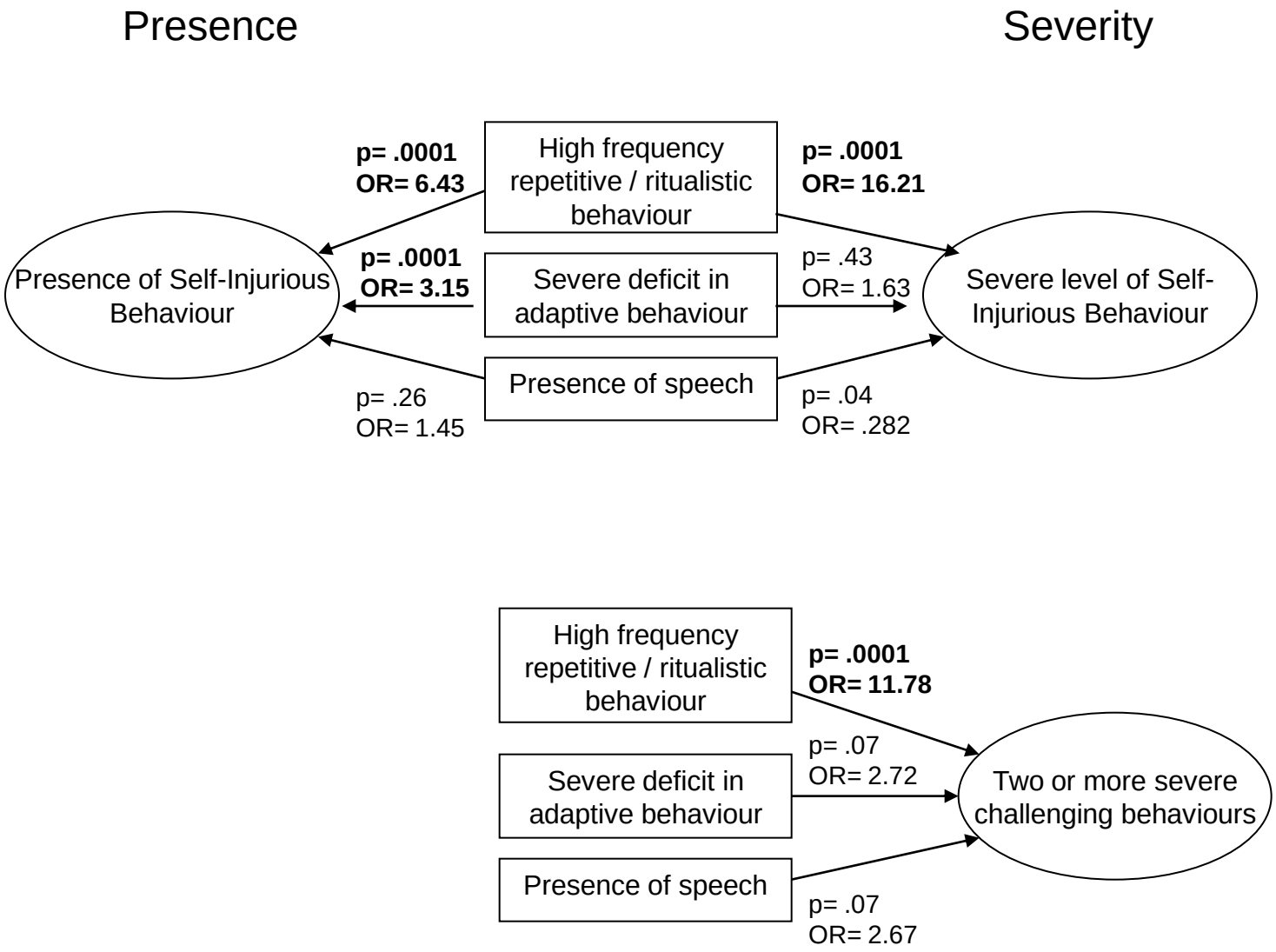
- P\SLD (vs. Mod\Mild LD) [x 4.1]
- Specific genetic syndromes [x 6.0 to 40.0]
- Autism Spectrum Disorder [x 2.9 to 6.4]
- Behavioural markers [x 2.5 to 3.5]

Presence

Severity

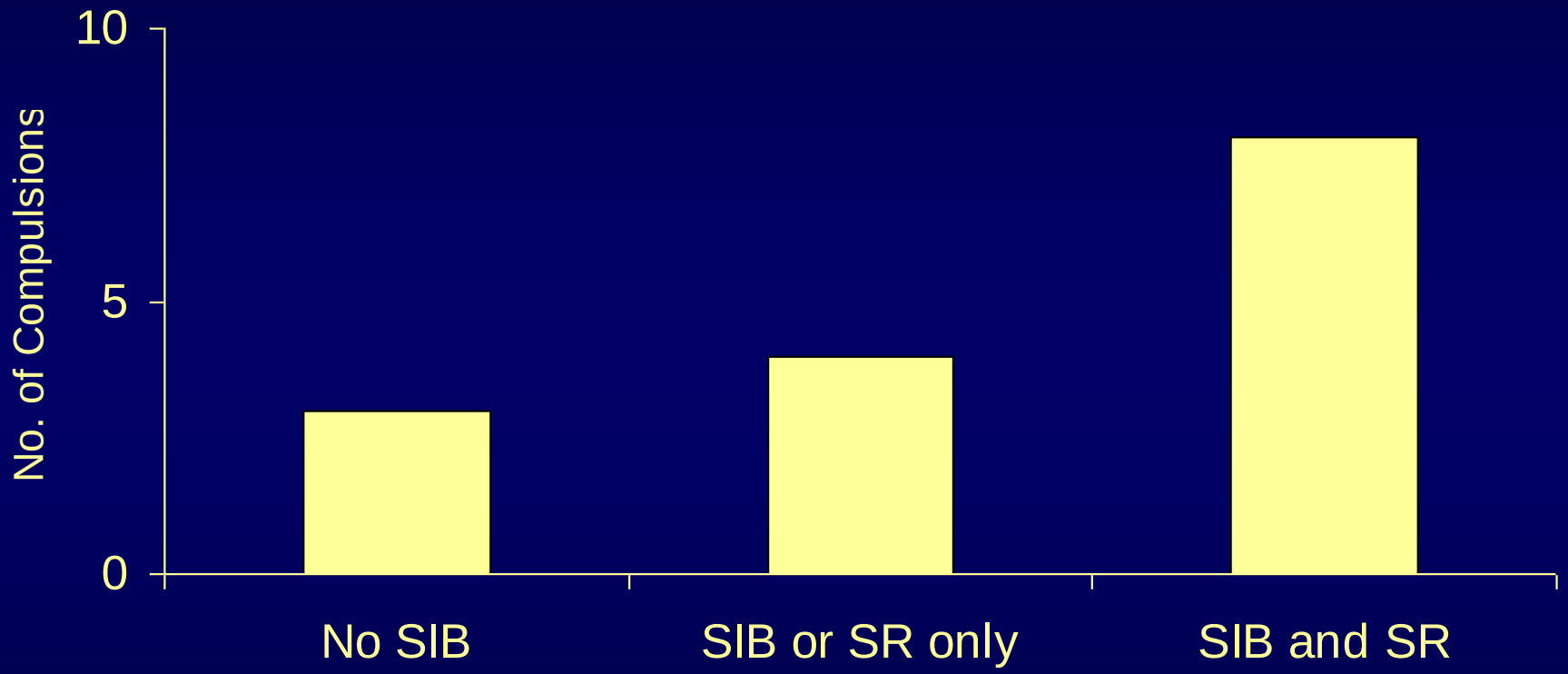



Oliver et al., (2011) Journal of Autism and Developmental Disorders




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?

1. Prevalence of self-injury
2. Persistence of self-injury
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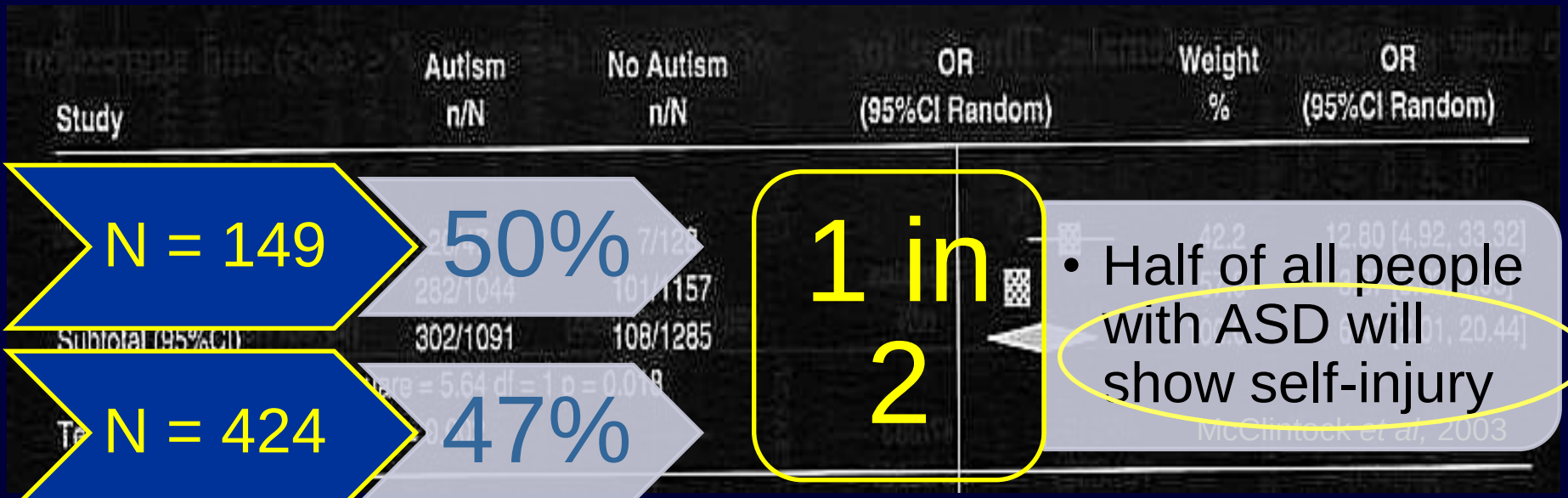
1

# • 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
2. Persistence 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)

N = 149 50% **3 years** N = 67 78%

N = 424 47%

80%

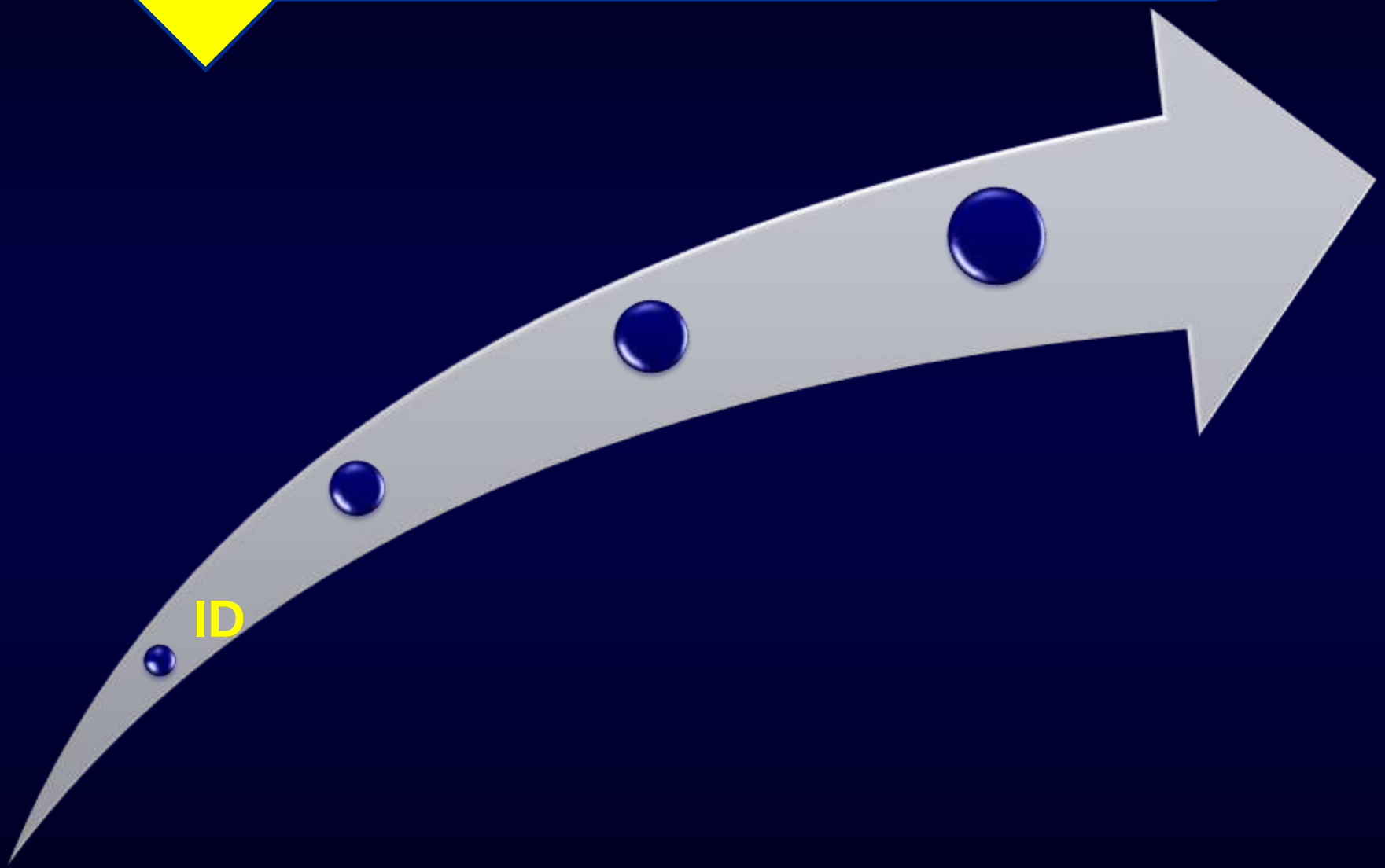
- Will continue to show self-injury 3 years later

# 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

3

- Factors that increase prevalence

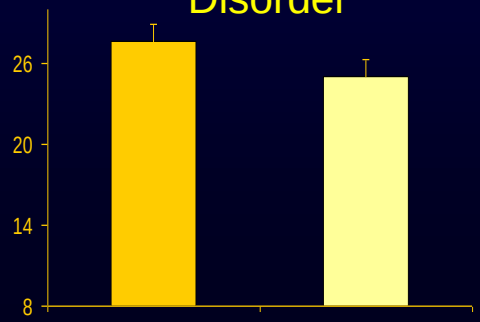


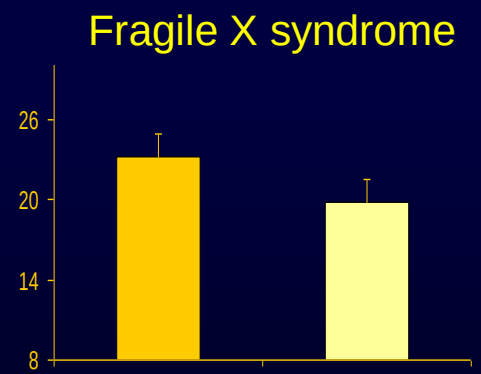
3

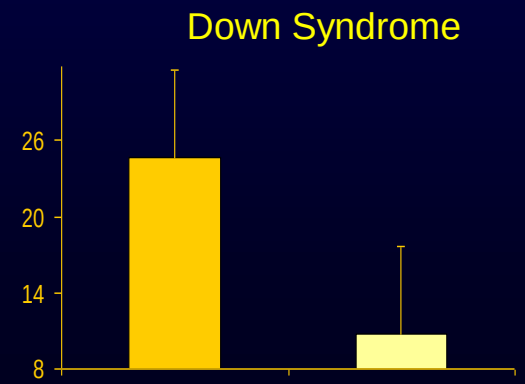
- Factors that increase prevalence

ID

ASD

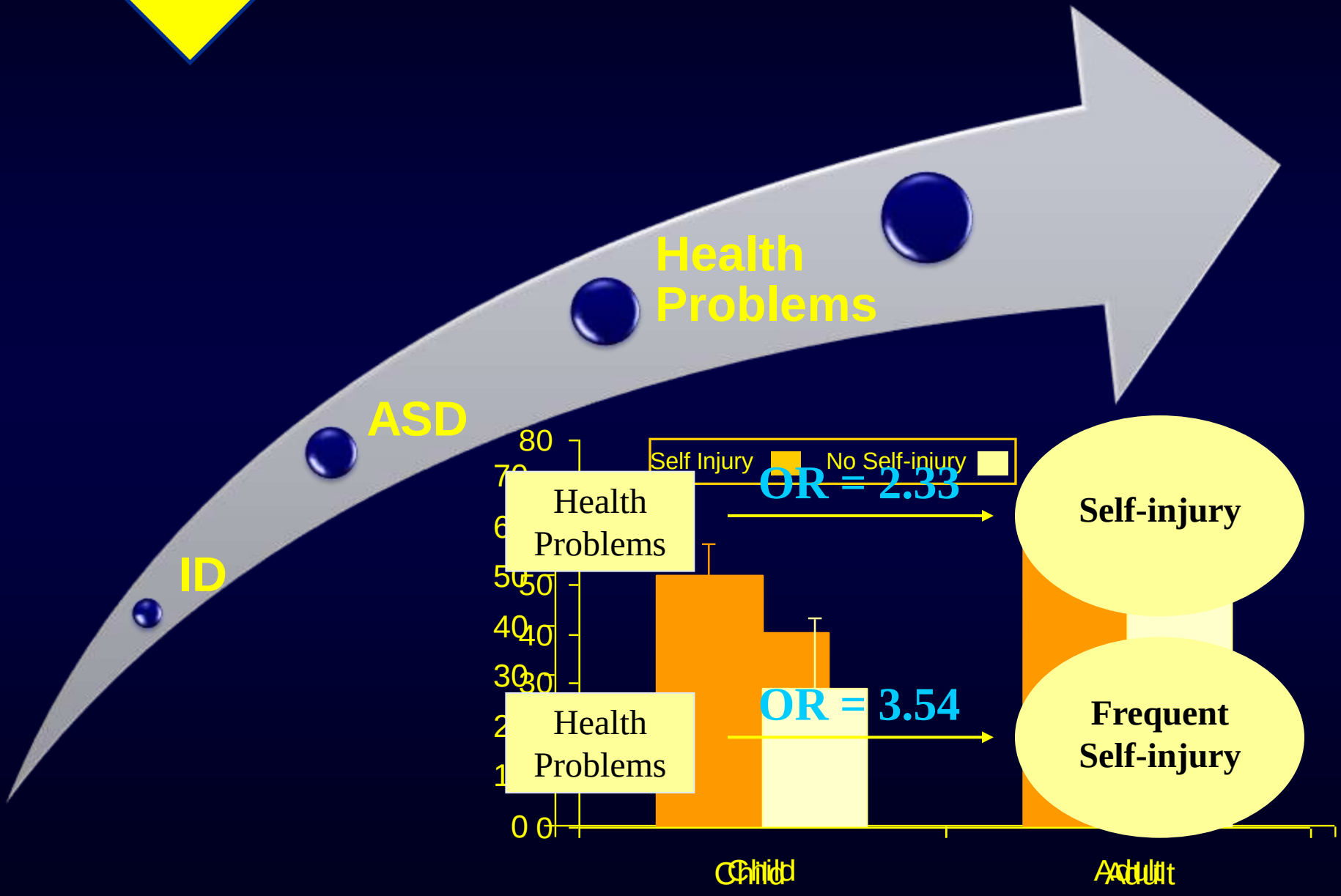



3

- Factors that increase prevalence



# 3

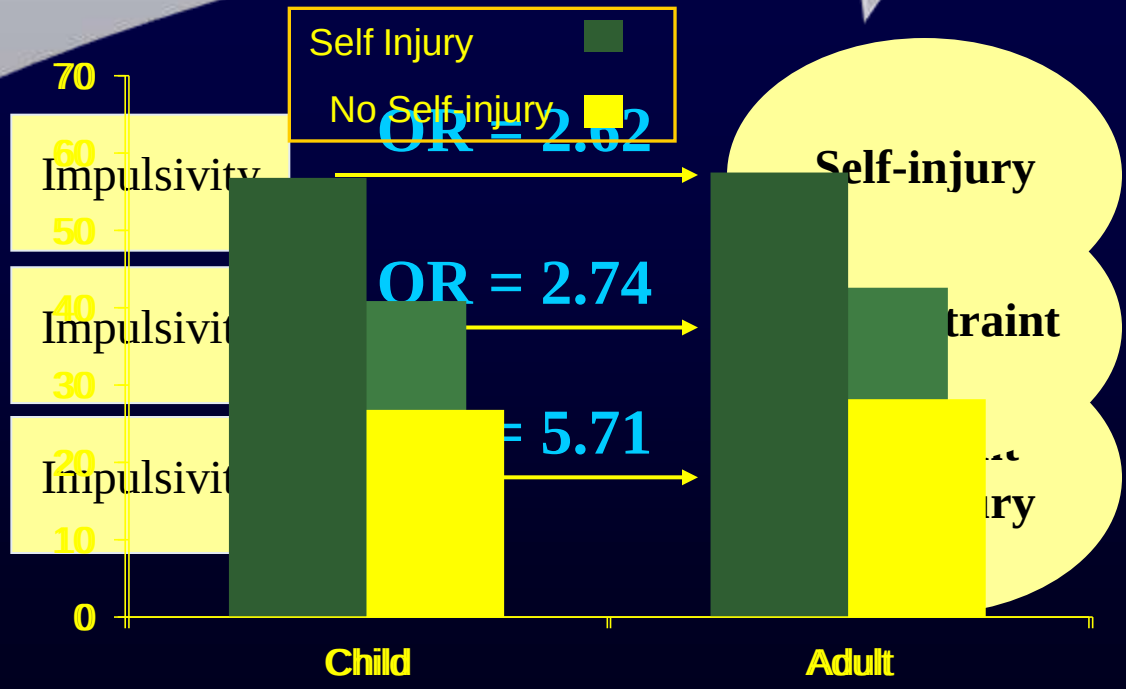
- Factors that increase prevalence

Impulsivity

Health Problems

ASD

ID

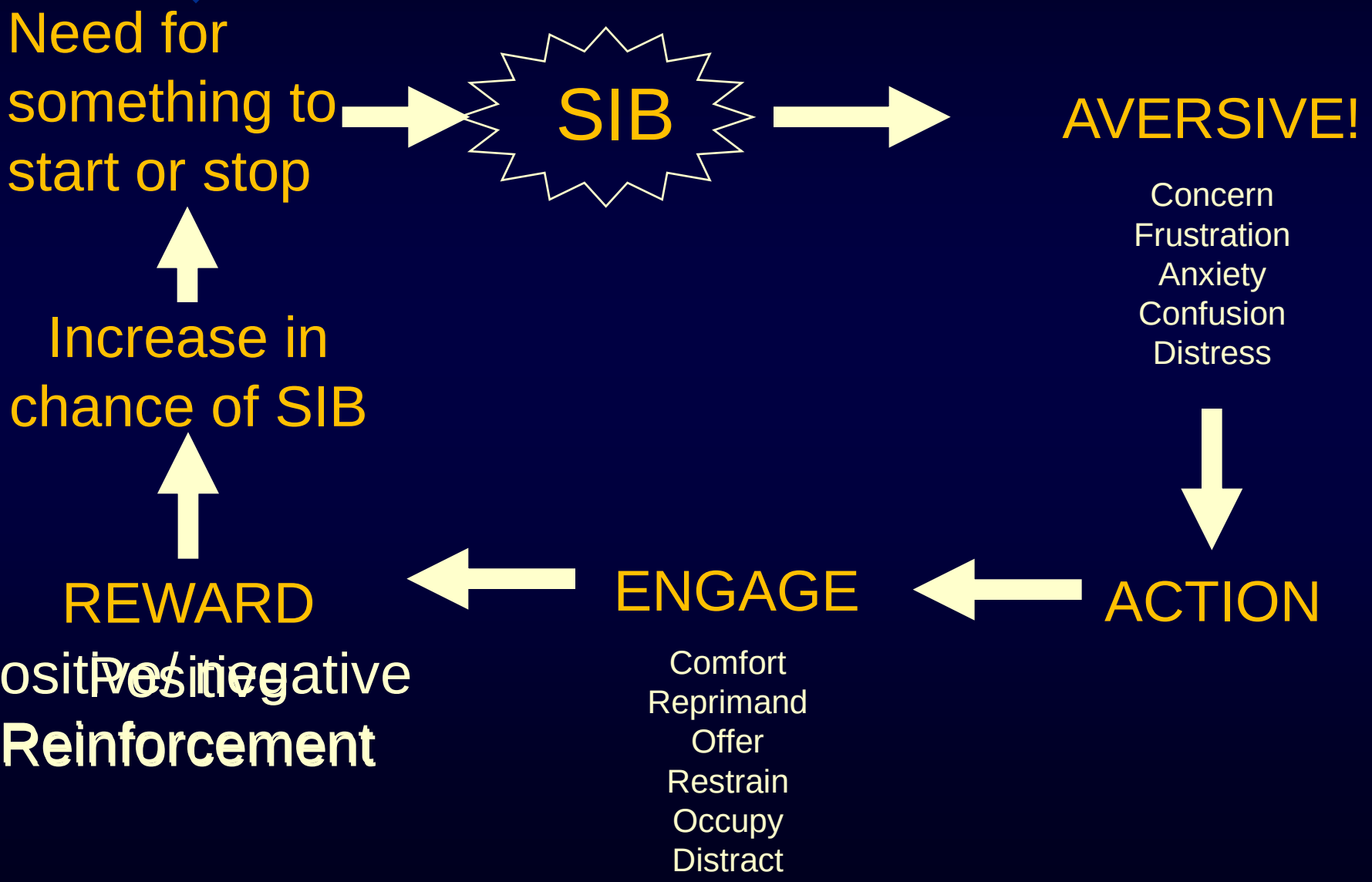


# What do we know about self-injury in ASD?

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

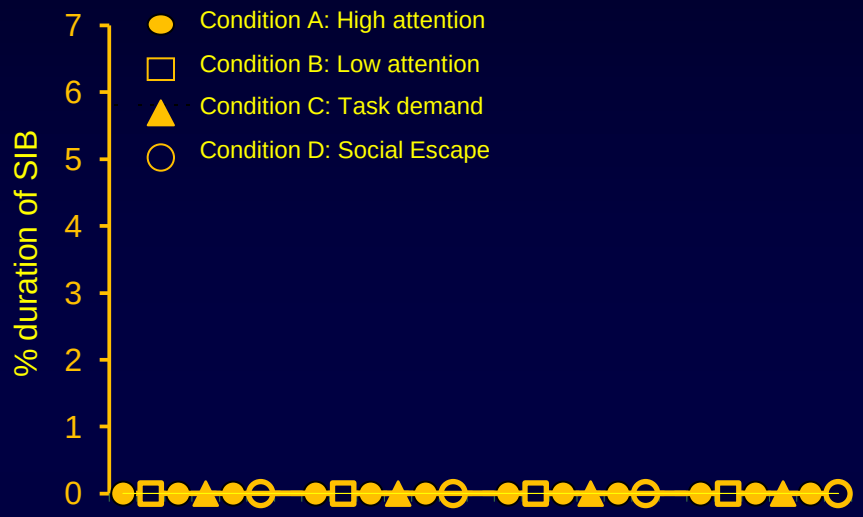
4

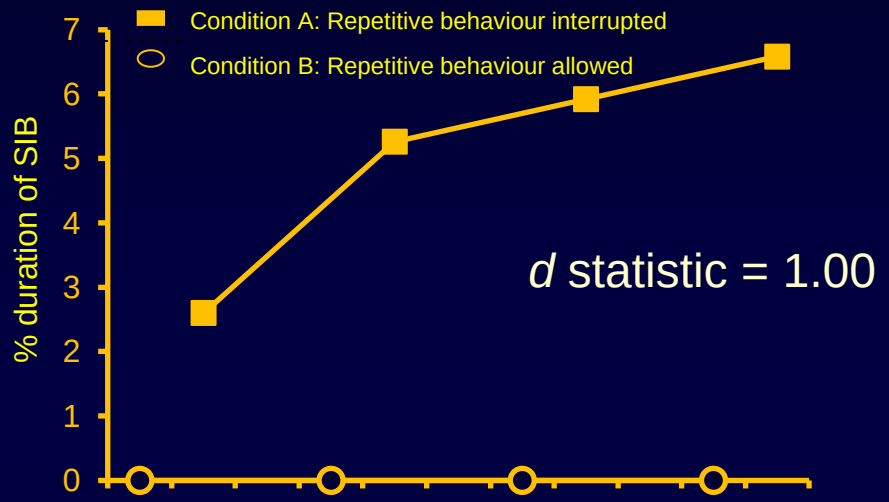
- Function of self-injury



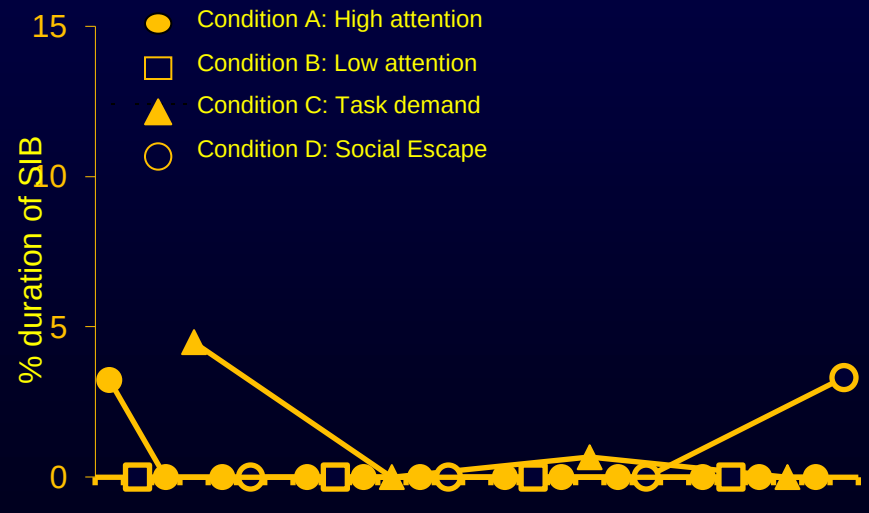
# 4 • Function of self-injury

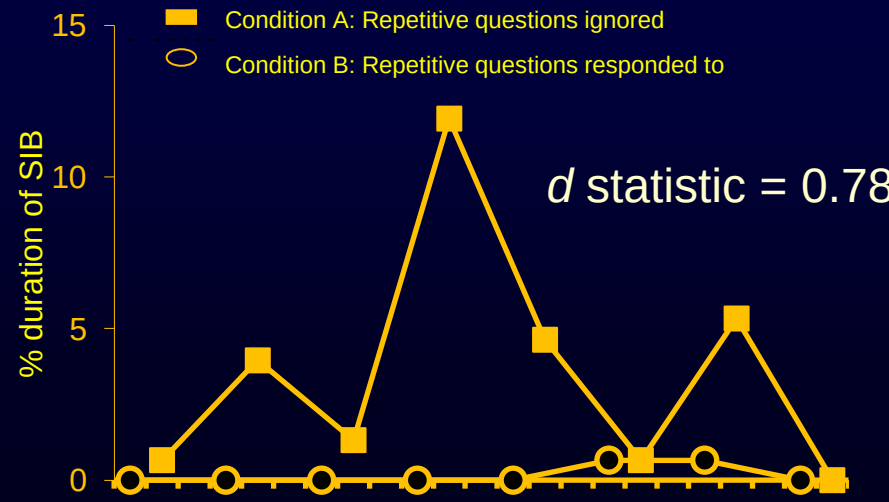
## Participant One

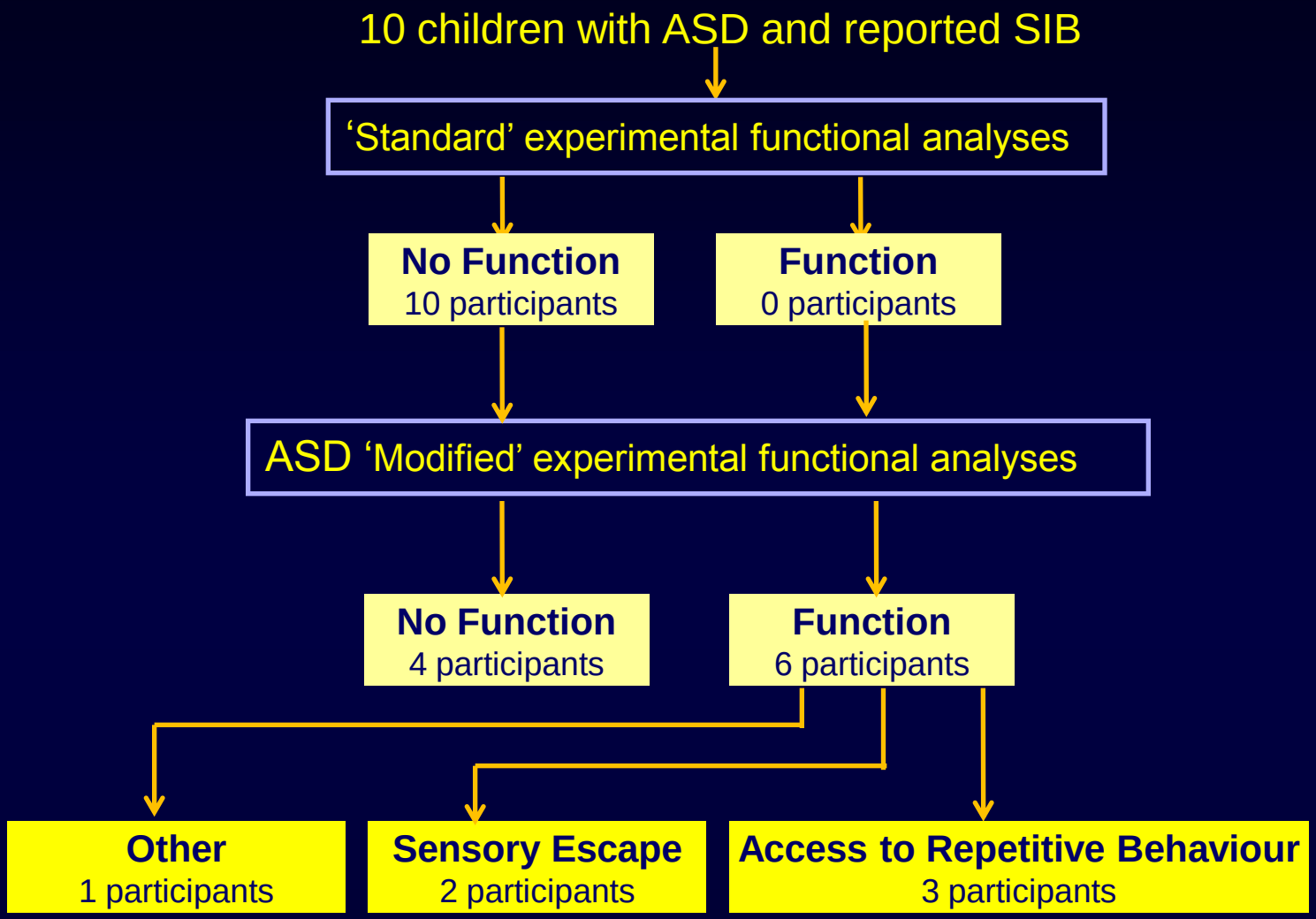



## Participant Six






**6 in 10**

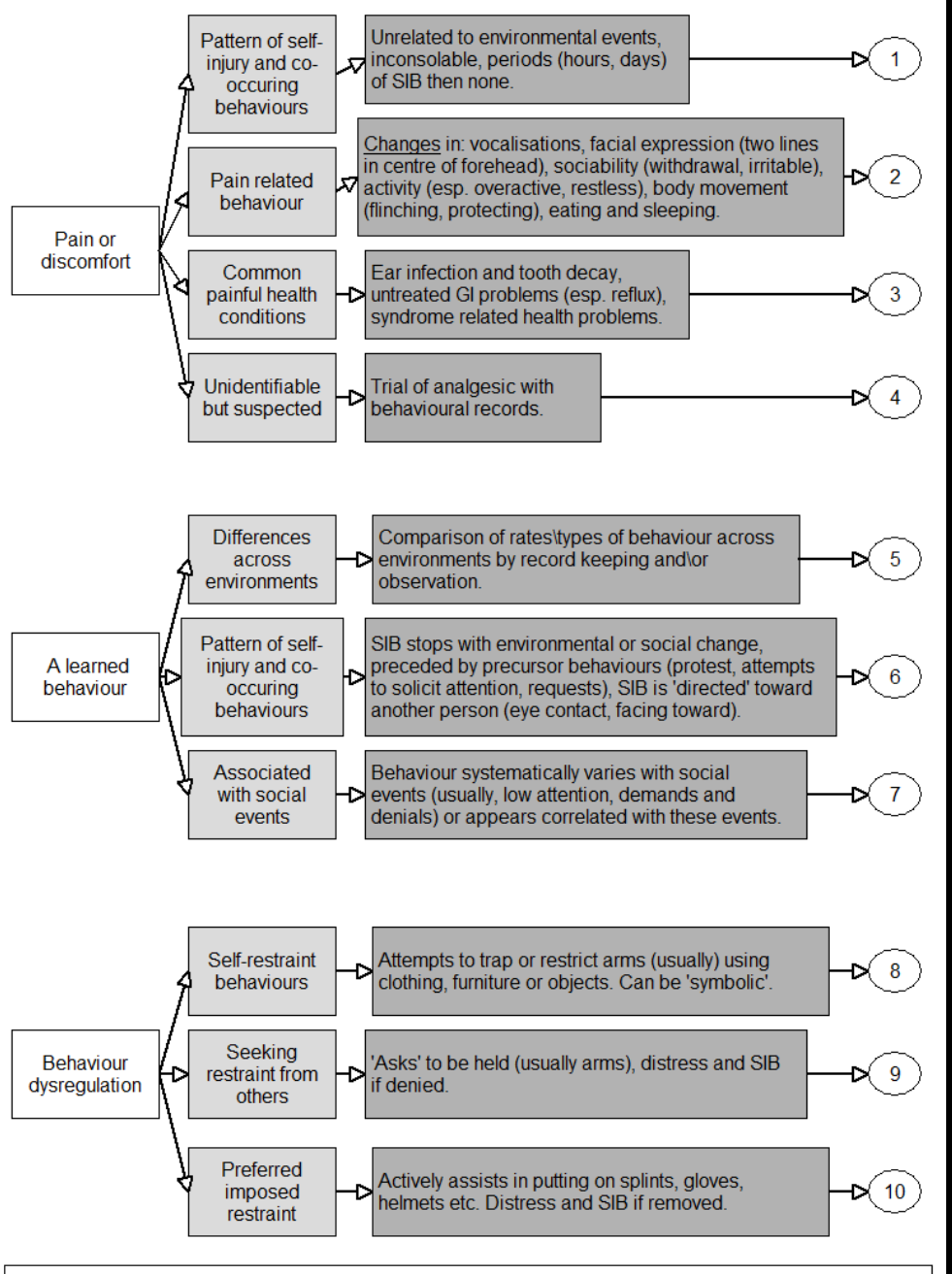
- Function for self-injury

# 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

# Unfinished business

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

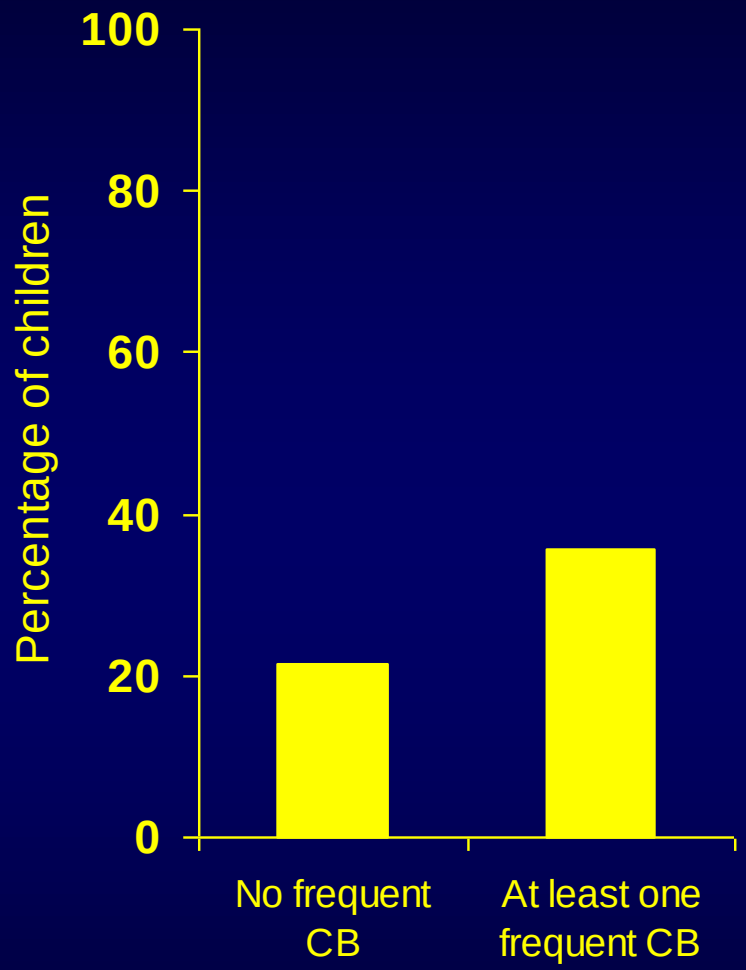



The most common influences on self-injurious behaviour are shown on the left. The boxes in the centre list the signs that each influence might be relevant. The boxes on the right show either behavioural indicators of each influence or the assessments that might be undertaken to identify indicators. Further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

Identifying and resolving health problems

Effective behavioural management based on functional assessment

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?




Oliver, C., Petty, J., Davies, L., Ruddick, L. and Bacarese-Hamilton, M. (2009). The children of Birmingham with Severe Intellectual Disability who show Challenging Behaviour. *Clinical Psychology and People with Learning Disabilities*, 7, 15-21.

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.

Local Government
OMBUDSMAN

Parliamentary
and Health Service
Ombudsman

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

## Part one: overview and summary investigation reports

B e f o r e : 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 needs .....Until this court's intervention, that multi-disciplinary environment with access to high quality inter-disciplinary advice did not exist for C. That was unacceptable. "

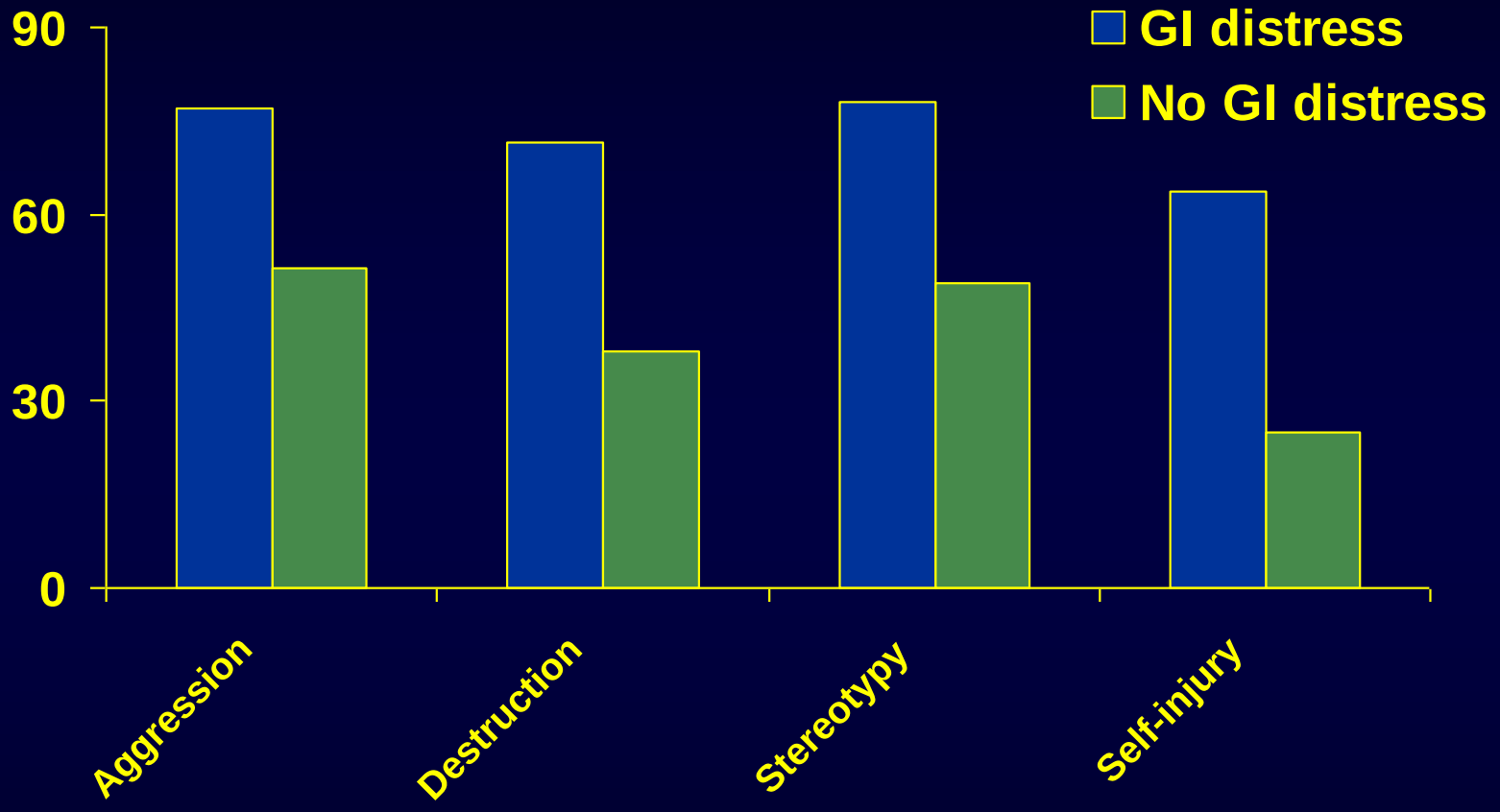
---

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

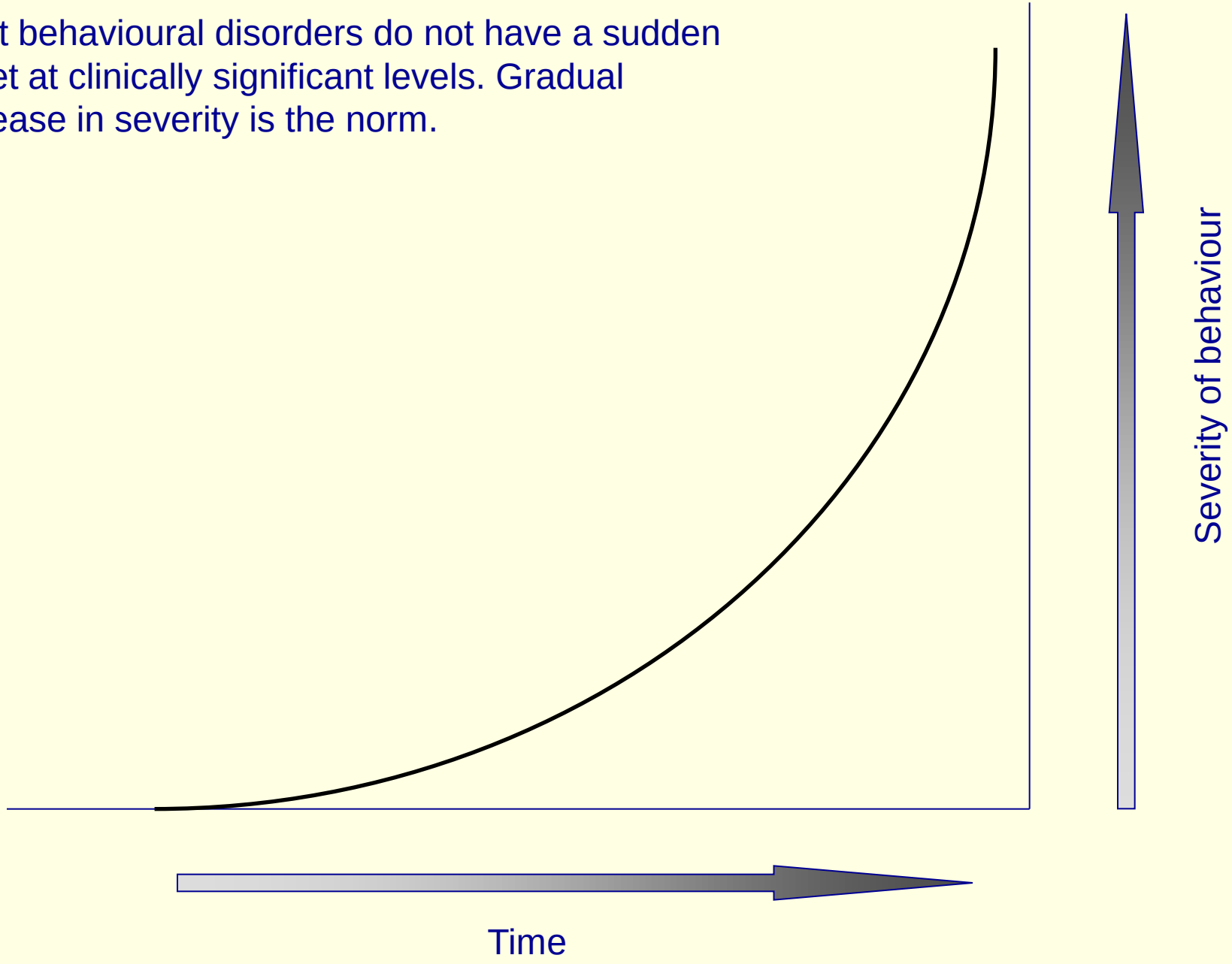
# GI distress and SIB in ASD

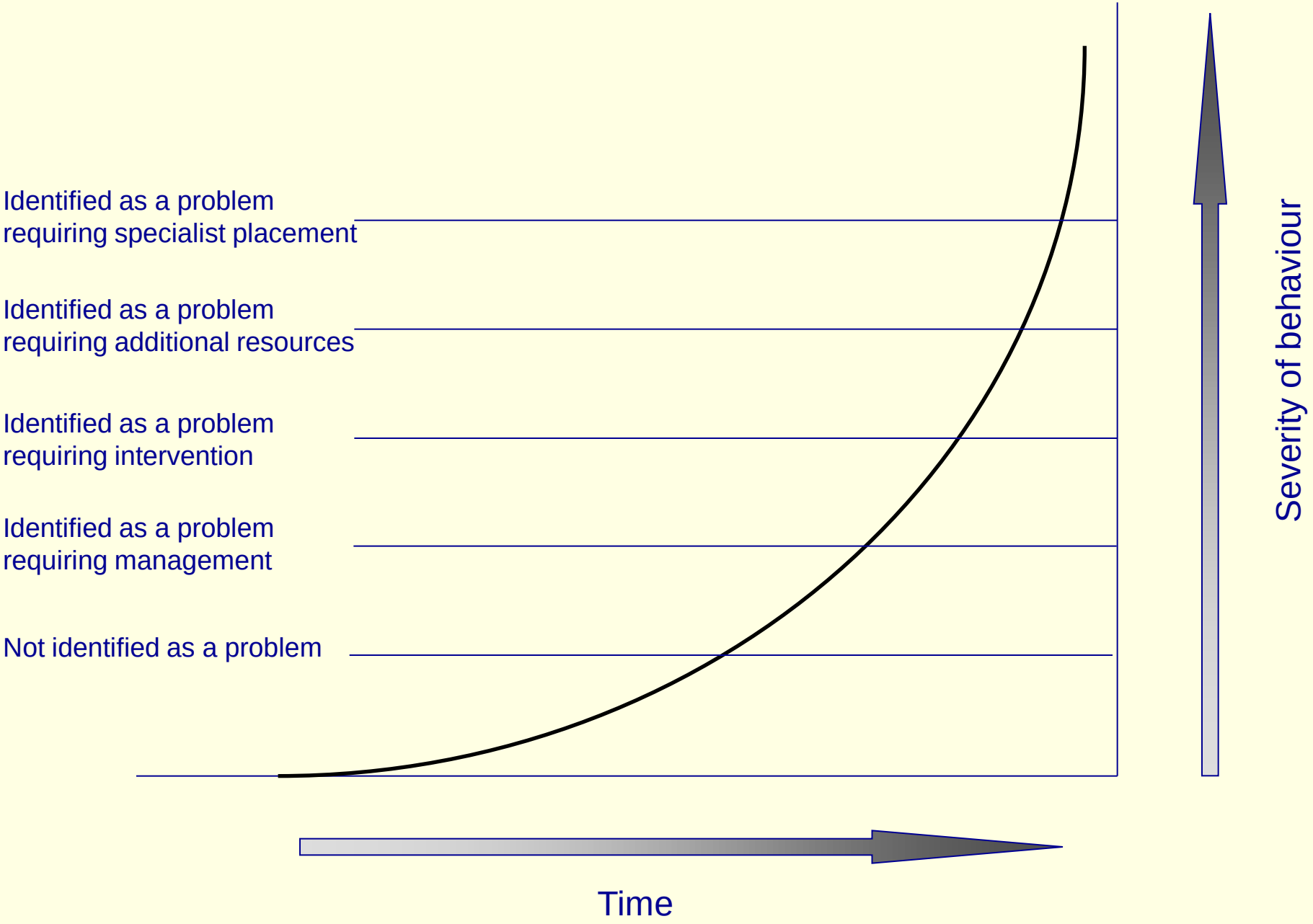



Two recent JADD papers of interest:

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

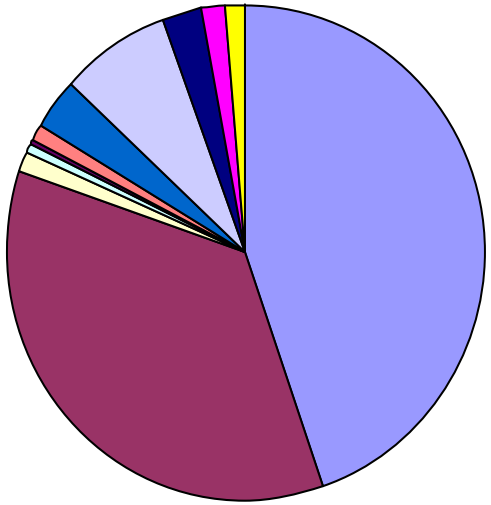
The Cerebra Centre for Neurodevelopmental Disorders

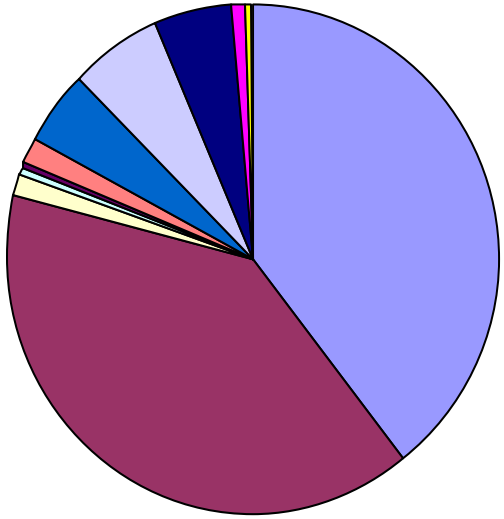
‘Helping hands’ volunteer team

# EPoCH

# 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






2001 - 2005

5,271 publications

(Self-injury 1.25%)

2006 - to date

13,222 publications

(Self-injury 0.086%)

The Cerebra Centre for Neurodevelopmental Disorders

Cerebra
Positively Different

## 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/cndd

C.Oliver@Bham.ac.uk

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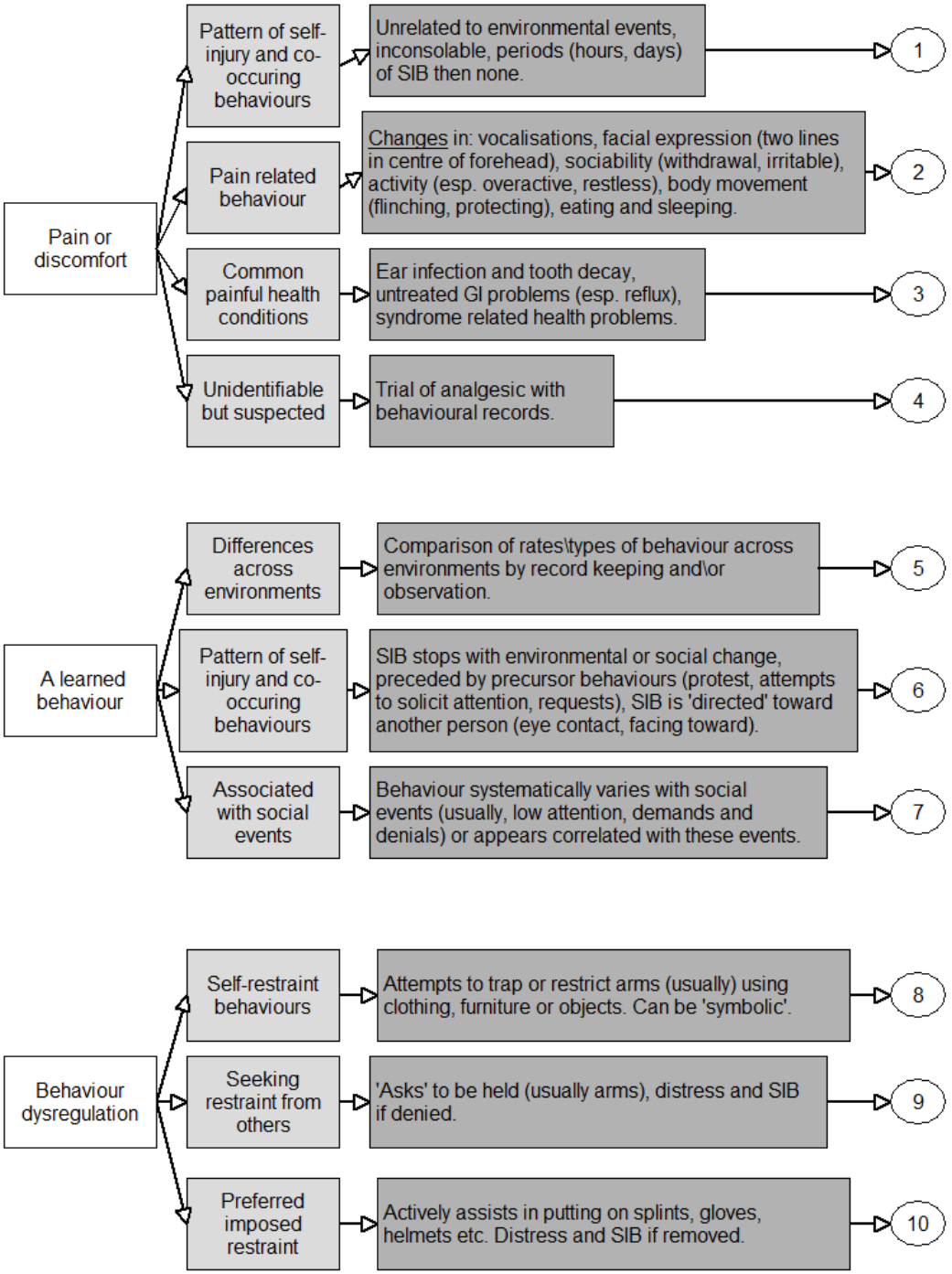
# Where to now?

- 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
  - Remote consultation
  - We do not have any money so we will have to think


Pain or discomfort
Pattern of self-injury and co-occuring behaviours
Unrelated to environmental events, inconsolable, periods (hours, days) of SIB then none.
1
Pain related behaviour
Changes in: vocalisations, facial expression (two lines in centre of forehead), sociability (withdrawal, irritable), activity (esp. overactive, restless), body movement (flinching, protecting), eating and sleeping.
2
Common painful health conditions
Ear infection and tooth decay, untreated GI problems (esp. reflux), syndrome related health problems.
3
Unidentifiable but suspected
Trial of analgesic with behavioural records.
4
A learned behaviour
Differences across environments
Comparison of rates\types of behaviour across environments by record keeping and\or observation.
5
Pattern of self-injury and co-occuring behaviours
SIB stops with environmental or social change, preceded by precursor behaviours (protest, attempts to solicit attention, requests), SIB is 'directed' toward another person (eye contact, facing toward).
6
Associated with social events
Behaviour systematically varies with social events (usually, low attention, demands and denials) or appears correlated with these events.
7
Behaviour dysregulation
Self-restraint behaviours
Attempts to trap or restrict arms (usually) using clothing, furniture or objects. Can be 'symbolic'.
8
Seeking restraint from others
'Asks' to be held (usually arms), distress and SIB if denied.
9
Preferred imposed restraint
Actively assists in putting on splints, gloves, helmets etc. Distress and SIB if removed.
10

# 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
  - 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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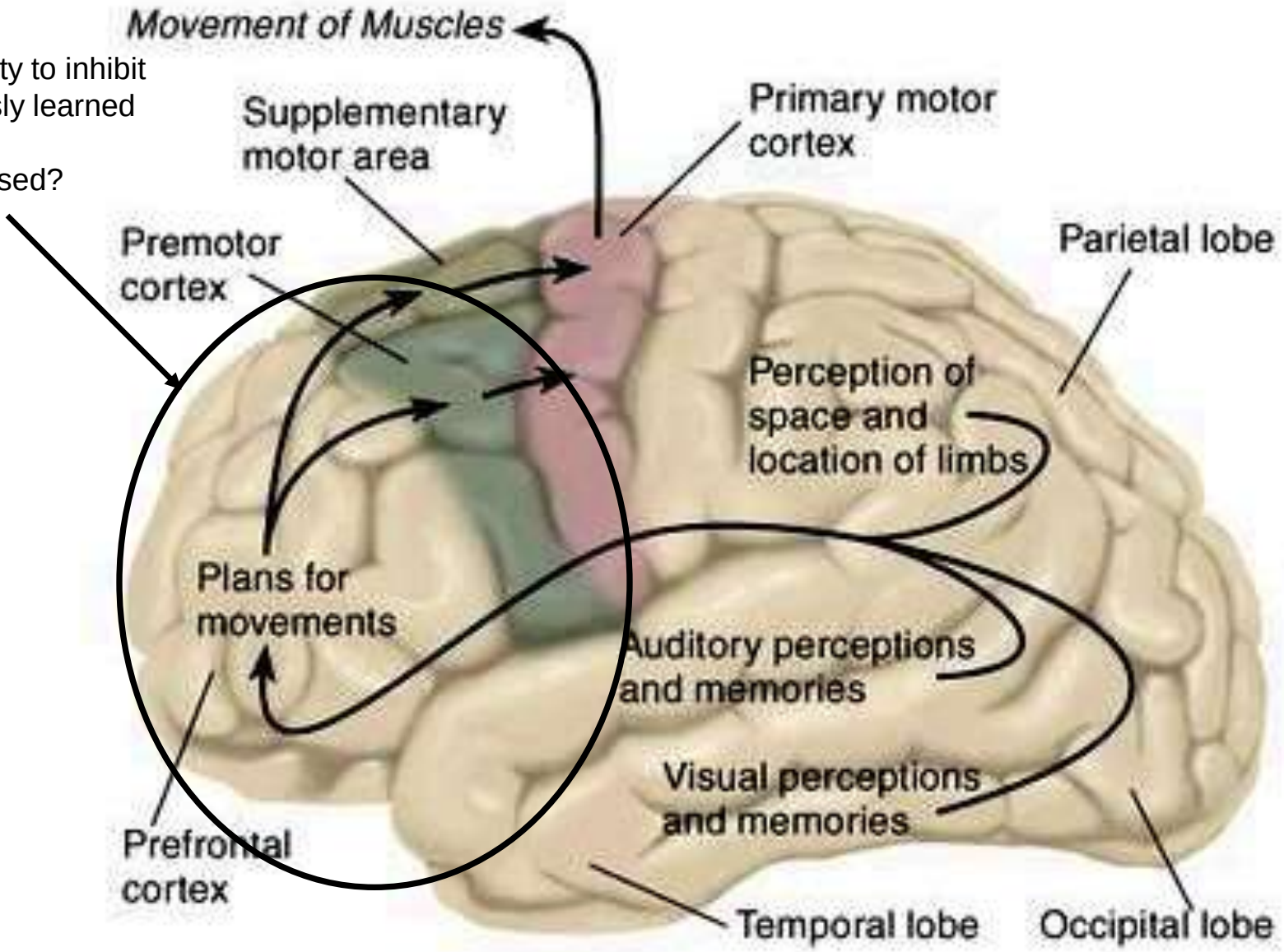
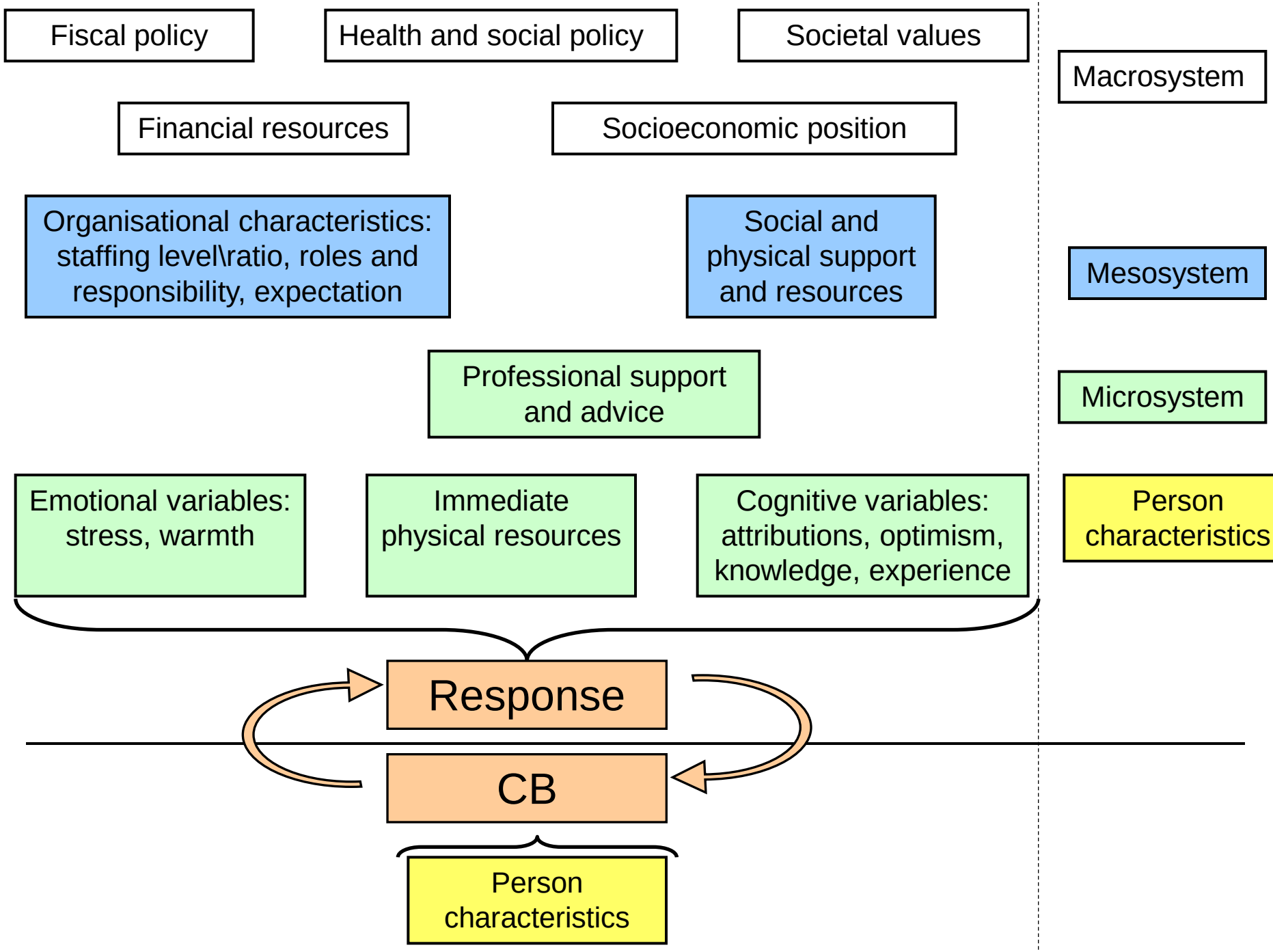
Is the ability to inhibit a previously learned behaviour compromised?




Fiscal policy
Health and social policy
Societal values
Macrosystem
Financial resources
Socioeconomic position
Organisational characteristics: staffing level\ratio, roles and responsibility, expectation
Social and physical support and resources
Mesosystem
Professional support and advice
Microsystem
Emotional variables: stress, warmth
Immediate physical resources
Cognitive variables: attributions, optimism, knowledge, experience
Person characteristics
Response
CB
Person characteristics