The Cerebra Network for Neurodevelopmental Disorders

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Working wonders for children with brain conditions

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Understanding behaviours that challenge

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Research to improve the lives of children with severe and complex needs and their families

Dr Caroline Richards

Dr Jane Waite

Dr Hayley Crawford

Dr Jo Moss

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www.findresources.co.uk

www.cerebra.org.uk

www.researchgate.net

1. What are behaviours that challenge and how common are they?
2. What causes these behaviours?
    a. Learnt behaviour
    b. Internal causes
3. How can we reduce them?
    a. Learnt behaviour
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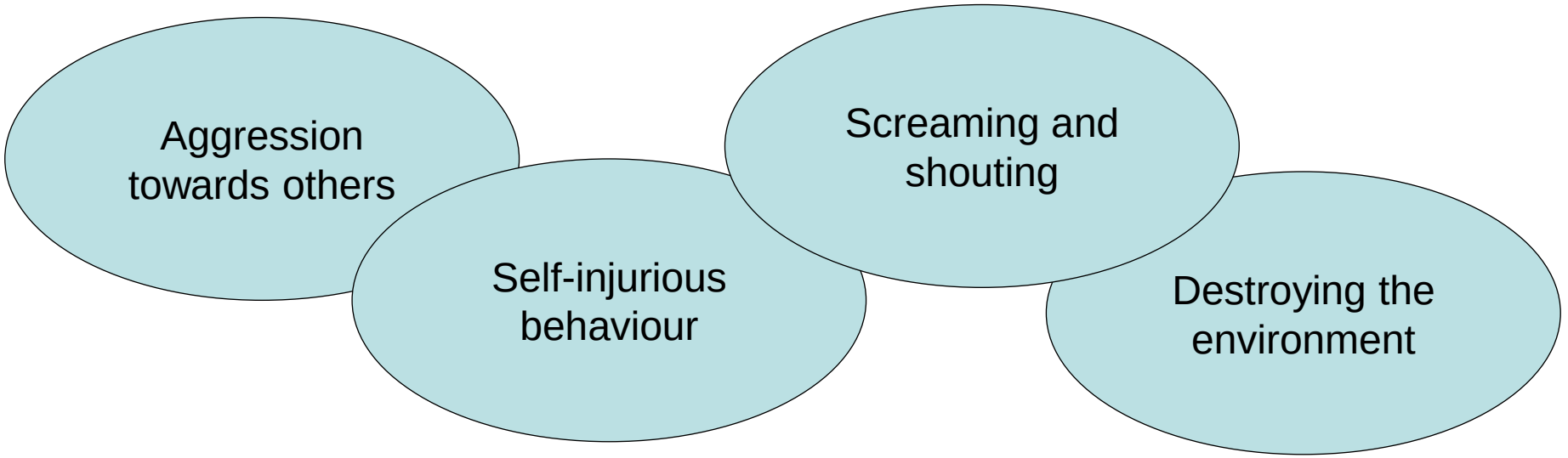
Eric Emerson:

“Challenging behaviour is defined as "culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities"



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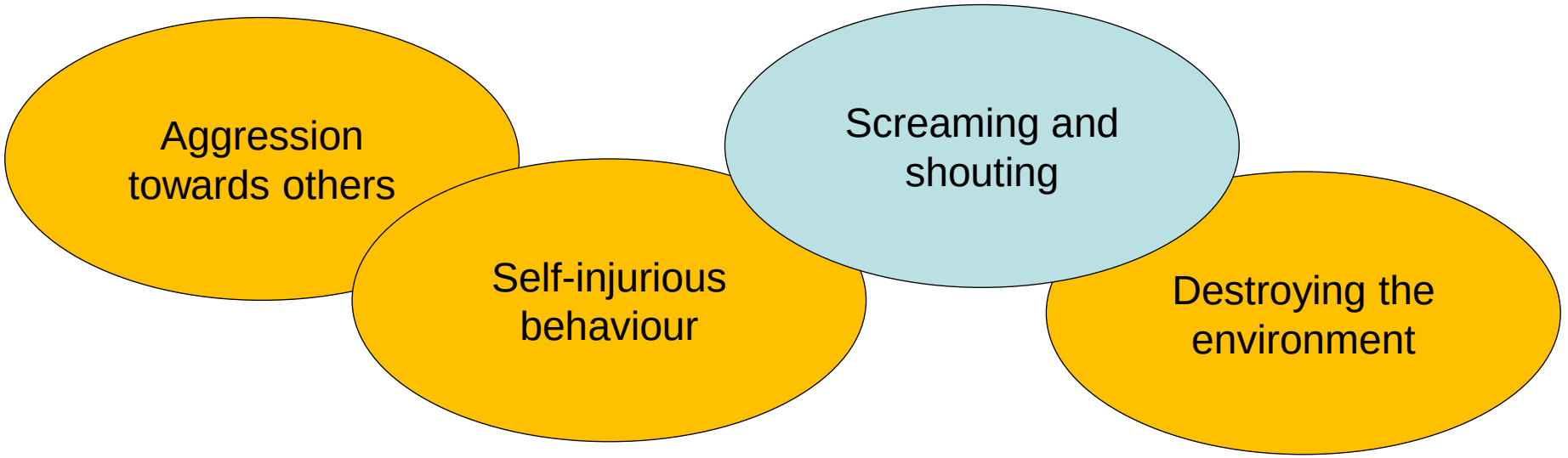


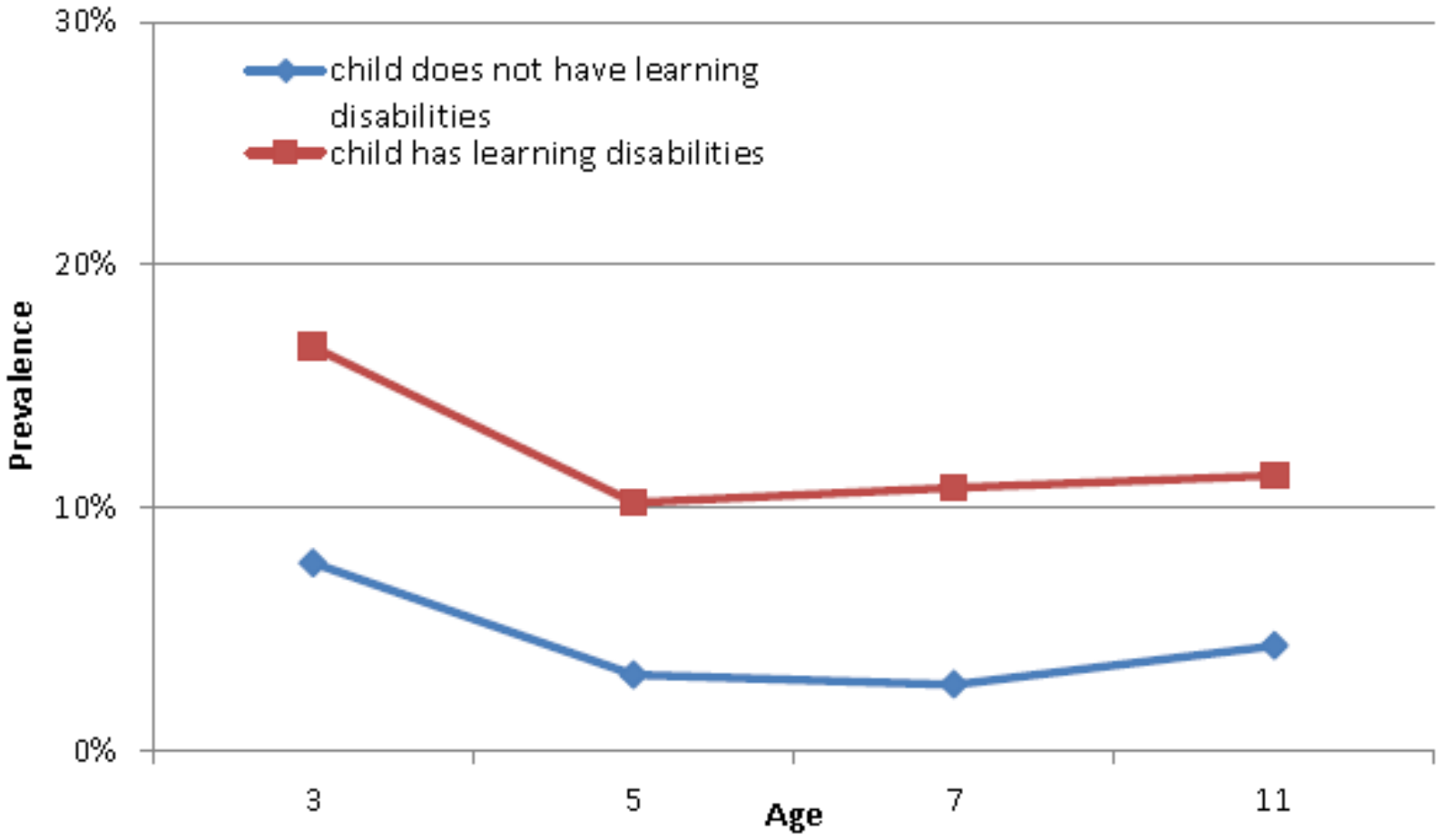
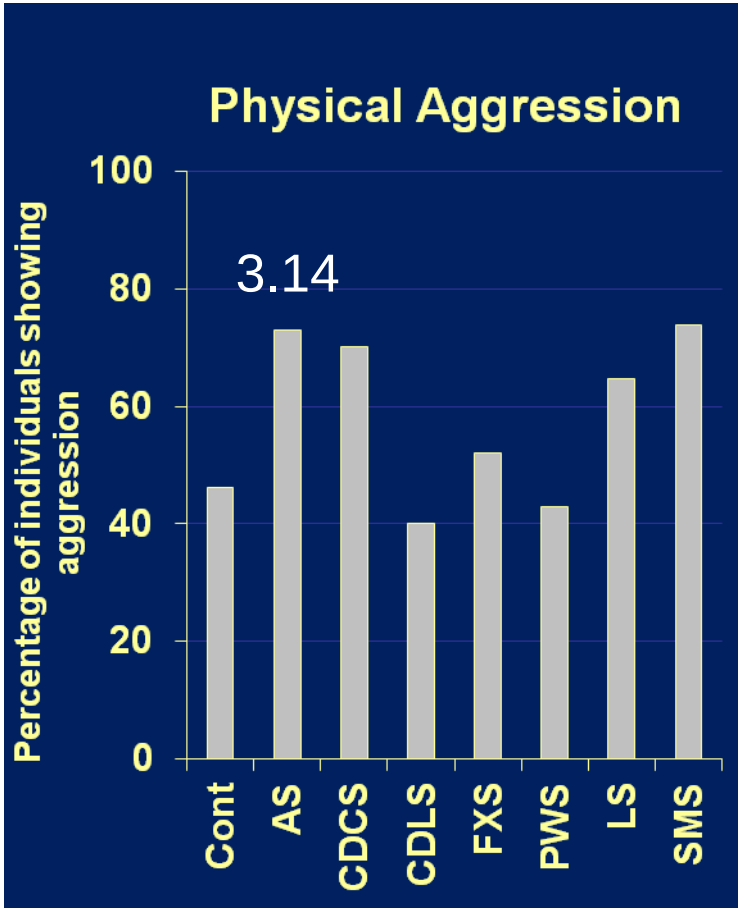


Figure 1: Prevalence of behaviours that challenge at ages 3, 5, 7, and 11 years



- Heightened rates in some syndromes; dissociation *within* syndromes *between* behaviours. A biological driver?

Arron, K., Oliver, C., Berg, K., Moss, J. and Burbidge, C. (2011).

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BEOND

Behavioural and Emotional Outcomes in individuals with Neurodevelopmental Disorders

An online survey exploring behaviour, sleep, emotion, mental health, physical health, caregiver wellbeing and more! Due to launch later this year—the BEOND study will look at a range of genetic syndromes

Find out more and stay updated at:
https://www.cerebranetwork.com/beond

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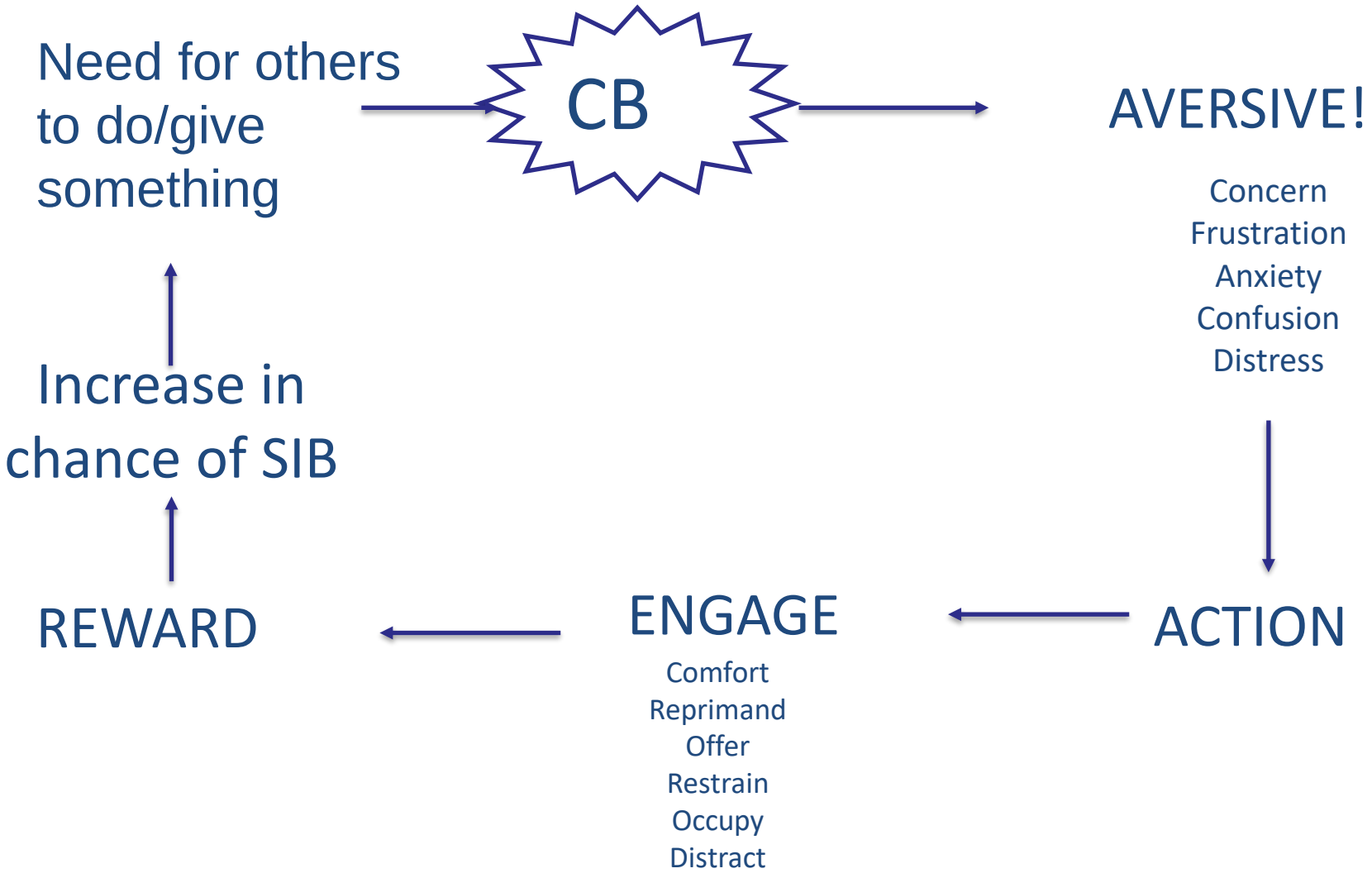
How do we understand behaviours that challenge?

An operant behaviour, sensitive to environmental reinforcement


Need for others to do/give something
CB
AVERSIVE!
Concern
Frustration
Anxiety
Confusion
Distress
ACTION
ENGAGE
Comfort
Reprimand
Offer
Restrain
Occupy
Distract
REWARD
Increase in chance of SIB

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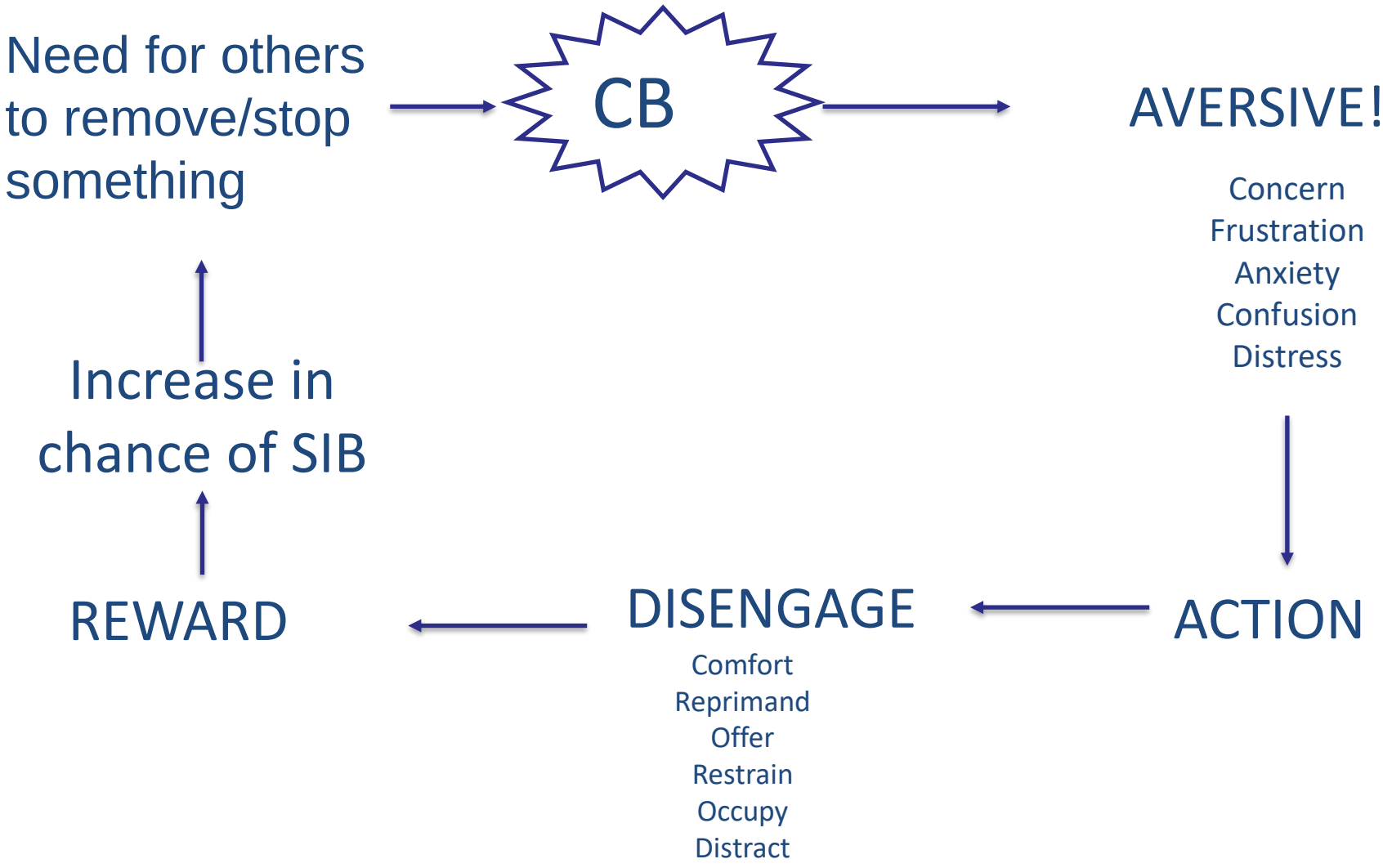

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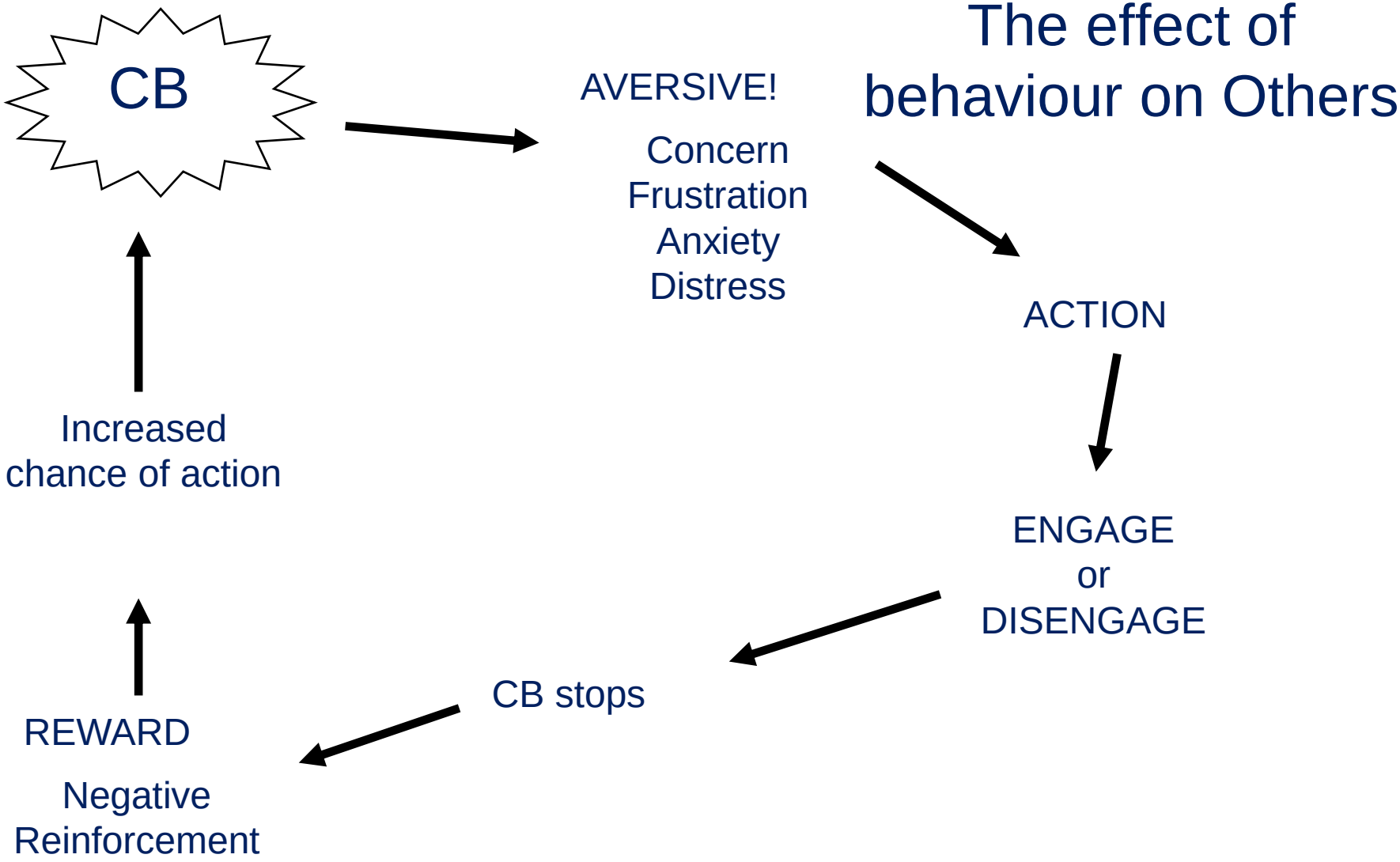
The effect of behaviour on Others



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A rewarded person

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A rewarded person

Two other rewarded people

-Behaviour can be learnt over time

-Access to attention/tangible items

-Escape from situations/demand

-Sensory stimulation

Learning is not intentional

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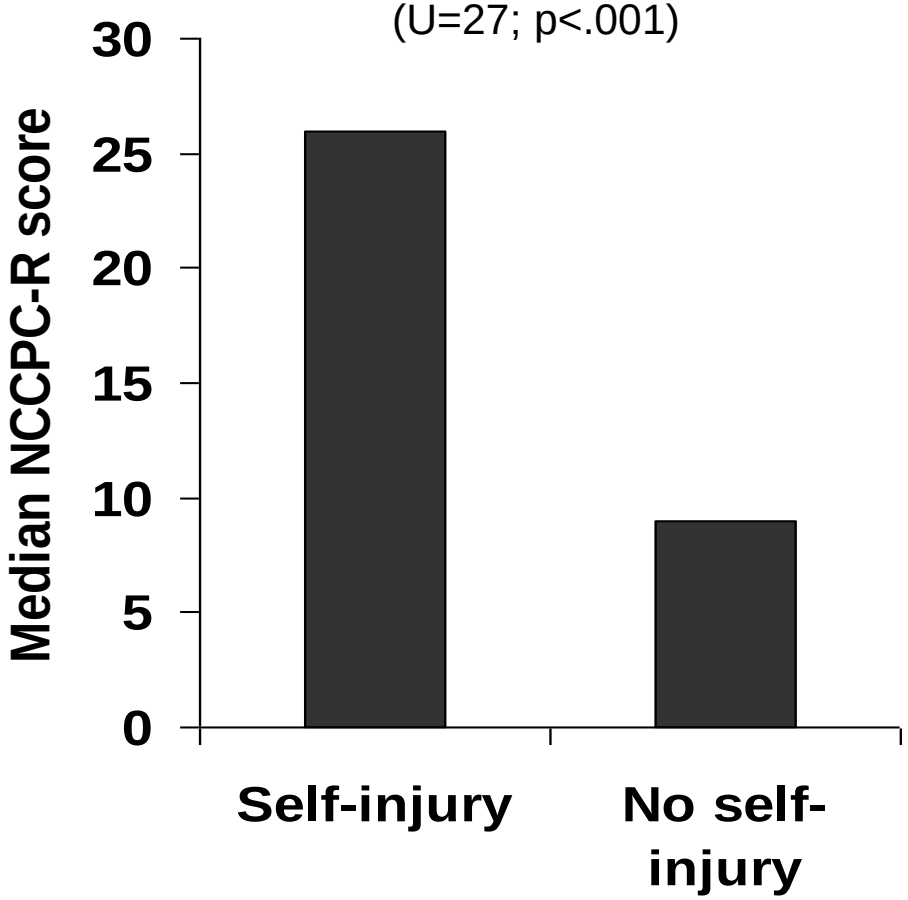
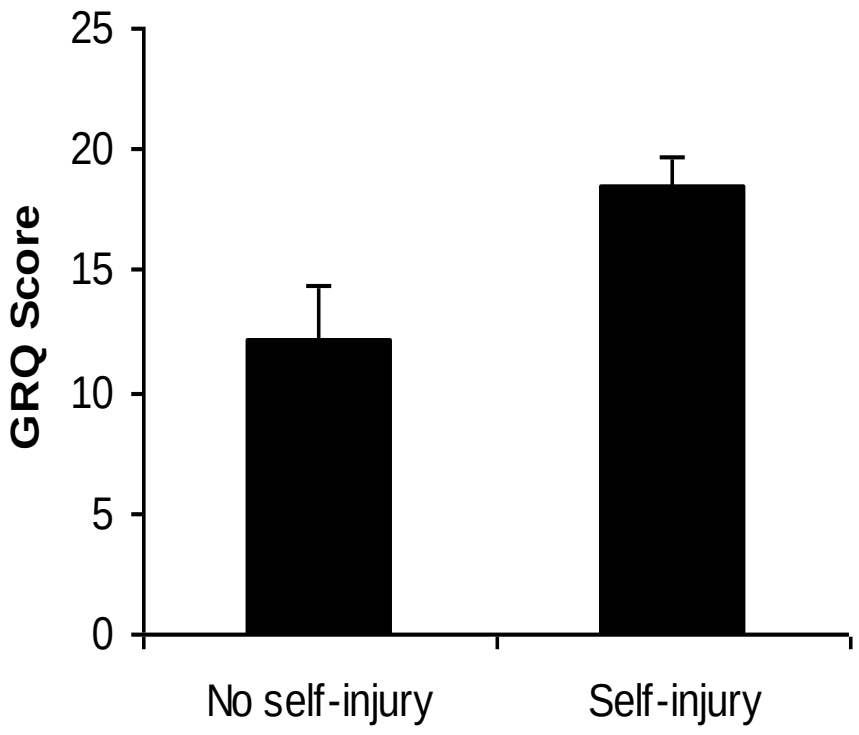
Comparison of pain behaviours in children with Tuberous Sclerosis Complex

(U=27; p<.001)



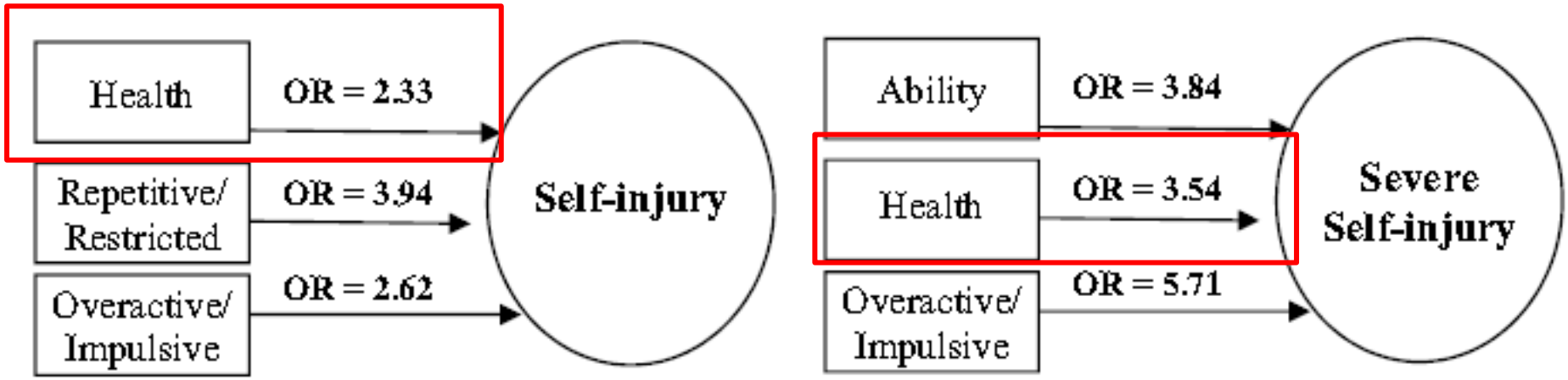
Eden, de Vries, Moss, Richards & Oliver, 2014

Cornelia de Lange syndrome: Self-injurious behaviour, gastro-intestinal disorders, middle ear infections, dental abnormalities and disorders



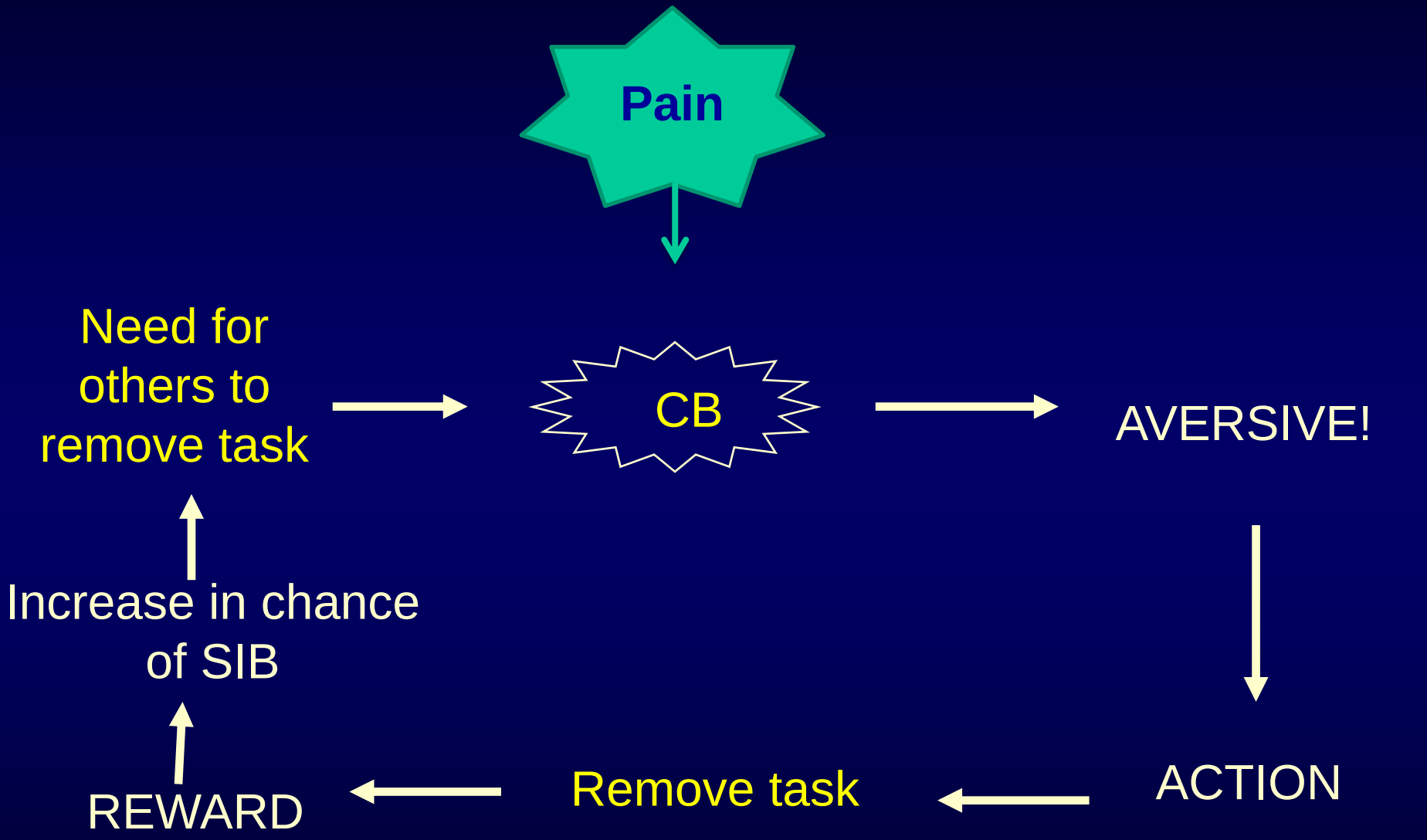
- Arch his/her back
- Lie over object on stomach
- Salivate excessively
- Fidget/wriggle
- Fingers in mouth
- Chew clothes
- Grind teeth
- Scratch/rub chest/throat
- Drink excessively
- Cough/gag/regurgitate
- Discomfort
- Refuse food
- Indecisive about food
- Wake during the night
- Sleep sitting or propped up
- Bad Breath
- Respiratory tract infections

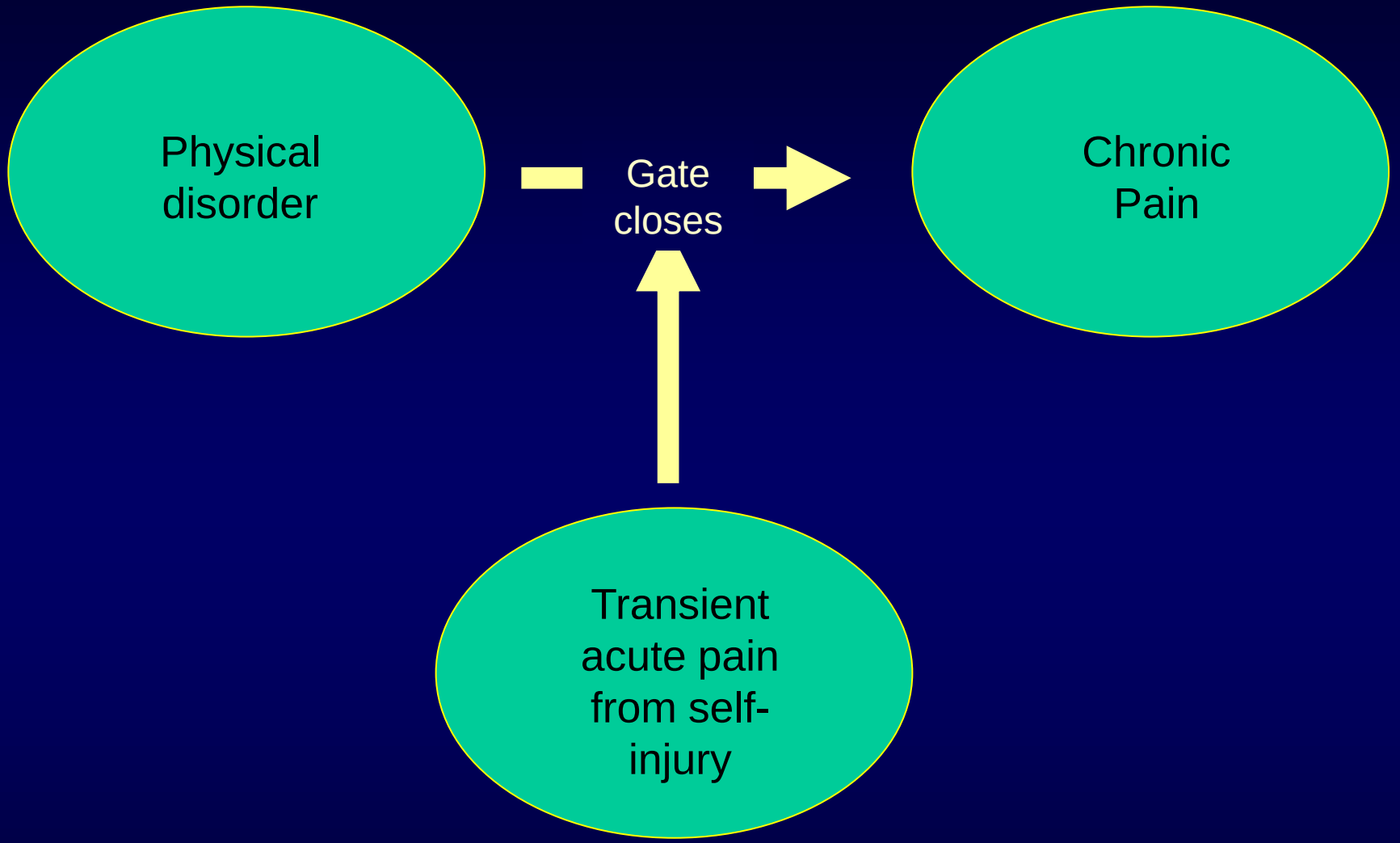
Pain and self-injury in autism



Richards *et al.*, 2017

Pain & the Operant Learning Model





Pain gate theory and learning to self-injure

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The problem of health problems and pain

1. Identify
2. Label
3. Communicate

Pain and discomfort are a key, internal cause of behaviour that challenge, but they are unlikely to be the only ones…

- Tiredness
- Low mood
- Anxiety

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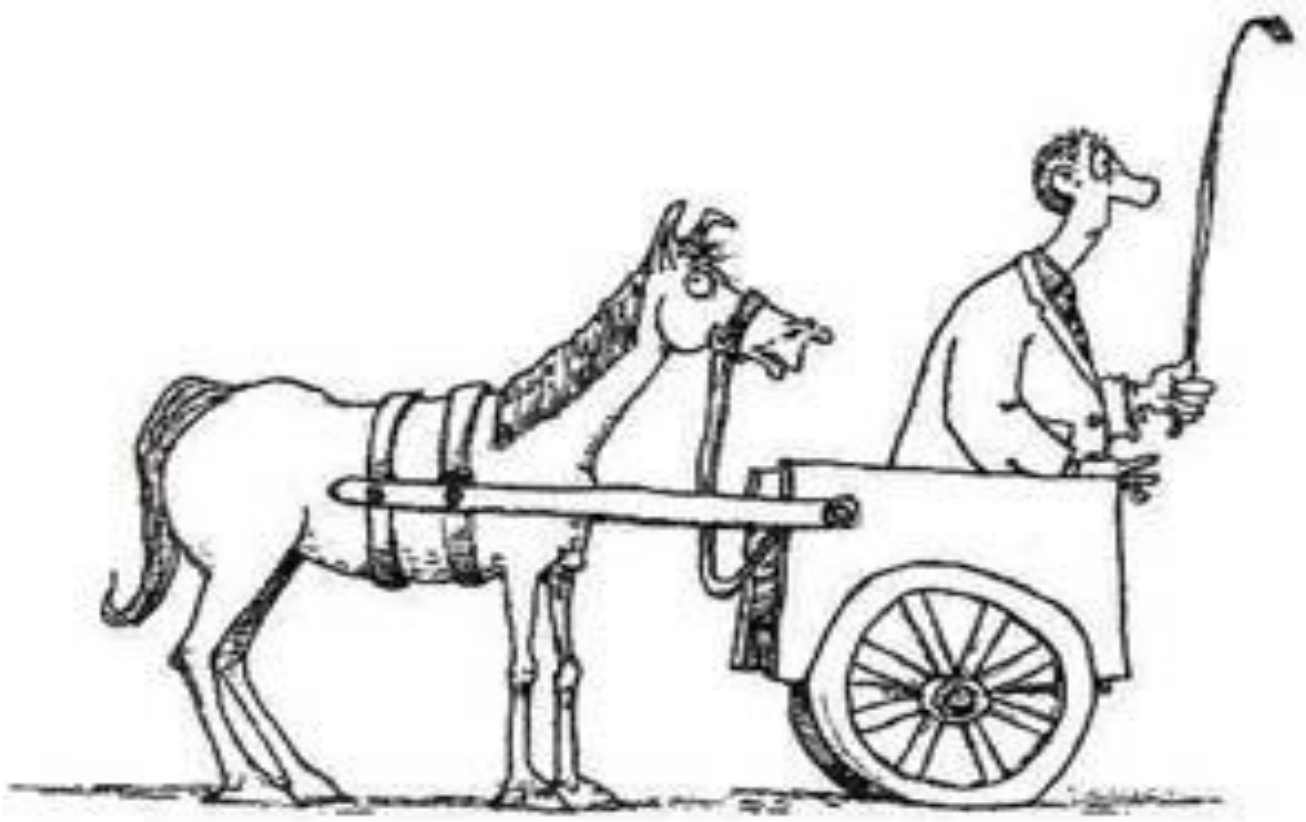
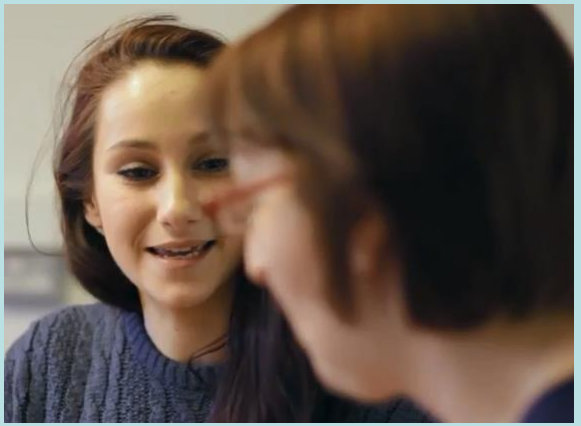


Interventions must be **preceded** by assessments that correctly identify the causes of behaviour

Careful, systematic behaviour monitoring

- Takes time
- May disconfirm your initial ideas

Seek support



- An important step
- May need to fight for services and support

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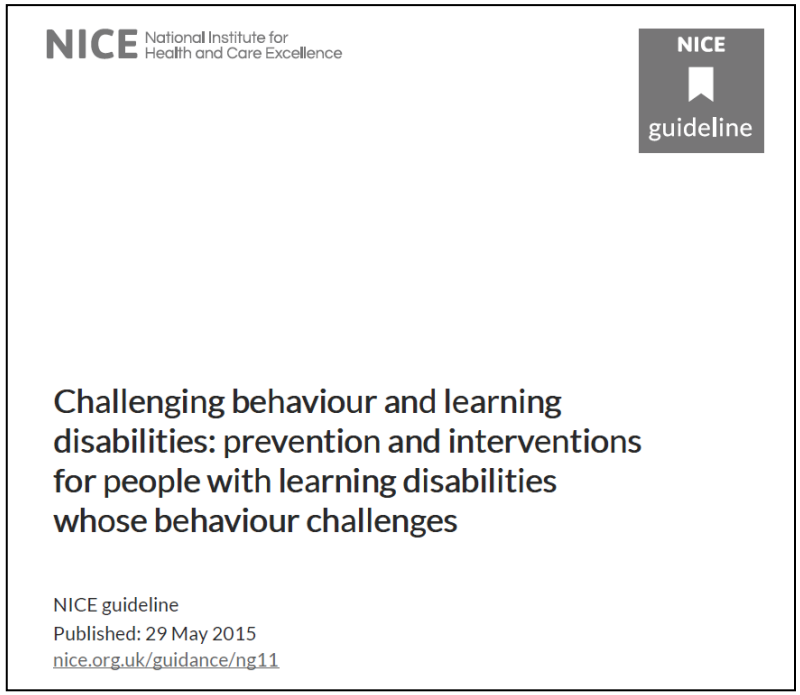
How do we intervene in behaviours that challenge?

Antecedent → Behaviour → Consequence


NICE National Institute for Health and Care Excellence

NICE guideline

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges

NICE guideline
Published: 29 May 2015
nice.org.uk/guidance/ng11

Change the 'A'

Visual schedules, increase availability of attention, reduce task complexity/difficulty

Teach a new 'B'

Functional communication training

Modify the 'C'

Reduce or remove reinforcement

1. Identify
2. Label
3. Communicate

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The FLACC Pain Scale

Sometimes it is difficult to assess pain in children who are non-verbal. The FLACC Pain Scale is a system that can help parents and professionals assess pain levels in children who have limited or no expressive communication. The diagram shows the categories for scoring. Zero, one or two points are given to each of the five categories: Face, Legs, Activity, Cry and Consolability.

Interpreting the Behaviour Score
Each category is scored on the 0-2 scale, which results in a total score of 0-10

- 0 relaxed and comfortable
- 1-3 mild discomfort
- 4-6 moderate pain
- 7-10 severe discomfort or pain or both

Categories	Score Zero	Score One	Score Two
Face F	No particular expression or smile	Occasional grimace or frown, withdrawn, disinterested.	Frequent to constant quivering chin, clenched jaw.
Legs L	Normal position or relaxed	Uneasy, restless, tense.	Kicking, or legs drawn up.
Activity A	Lying quietly, normal position moves easily.	Squirming, shifting back and forth, tense.	Arched, rigid or jerking.
Cry C	No crying (awake or asleep)	Moans or whimpers; occasional complaint	Crying steadily, screams or sobs, frequent complaints.
Consolability C	Content, relaxed.	Reassured by occasional touching hugging or being talked to, distractable.	Difficulty to console or comfort

If a child is showing these behaviours, it doesn't necessarily mean that they are in pain, as some of the behaviours measured by the FLACC scale can happen for other reasons. However, parents are advised to follow up high scores with a professional.

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Positively Different
REGISTERED CHARITY NO. 1089812

REFERENCE Merkel, S. I., Voepel-Lewis, T., Shayevitz, J. R., & Malviya, S. (1997). The FLACC: A behavioral scale for scoring postoperative pain in young children. *Pediatric Nursing*, 23(3), 293–297.

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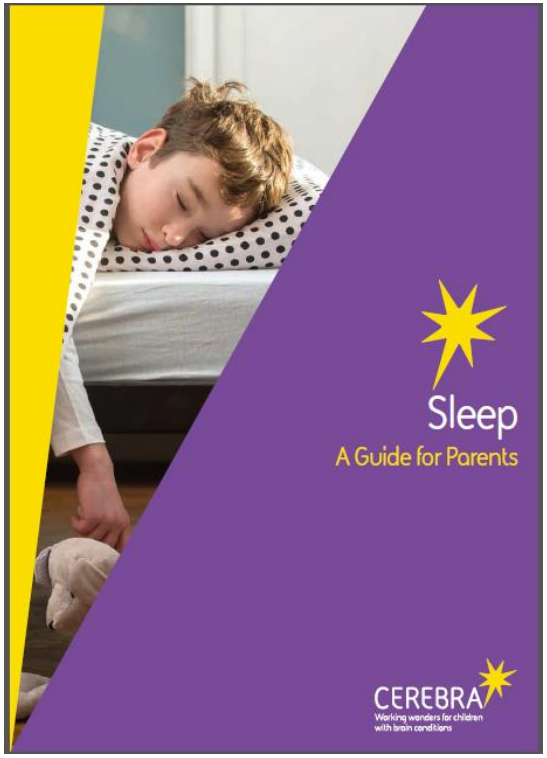
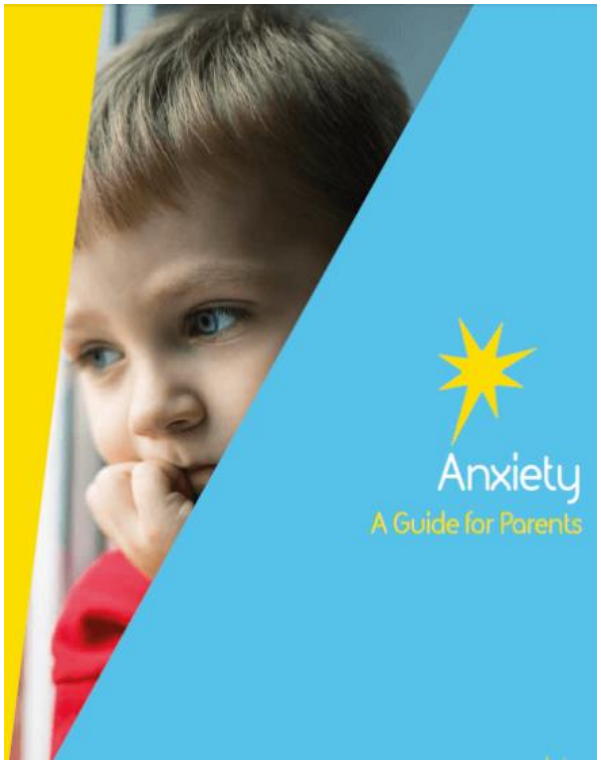
Internal causes of behaviour





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1. A known syndrome? Seek more information (family groups).
2. Pain and discomfort. Assertive referral, support for access, advice on pain relief.
3. Background factors effecting wellbeing (mood, hunger, fatigue etc.). Ways to alleviate.
4. Assessing environmental factors.
5. Intervening in the environment. Seek advice from clinical psychology and others with training in behavioural approaches
6. Keep records and evaluate what you do
7. What next?:
    a. Specific goals and small steps (who will do what, by when)
    b. Review systems
    c. Tenacity and advocacy (it doesn't have to be like this)