Remote Consultancy for Self-injurious Behaviour in Children with Autism Spectrum Disorders: A Pilot Project.

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Cerebra

Positively Different

The Cerebra Centre for Neurodevelopmental Disorders

UNIVERSITY OF BIRMINGHAM

Self-injurious Behaviour

'Any non accidental behaviour, initiated by the individual, which directly results in physical harm to that individual. Physical harm (includes) bruising, lacerations, bleeding, bone fractures and breakages, and other tissue damage.'

Murphy and Wilson (1985)

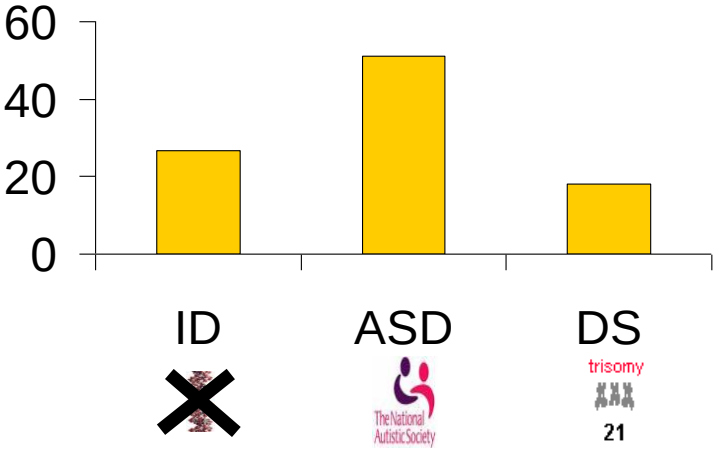
Group	Hits self with body	Hits self against object	Hits self with object	Bites self	Pulls self	Rubs/ scratches self	Inserts
ASD	1.99	0.95	3.93	1.39	1.70	1.33	0.80
Down syndrome	0.29	0.35	0.33	0.42	0.44	0.65	1.15
Fragile X syndrome	1.63	0.61	0.76	**5.66**	2.62	1.02	1.02

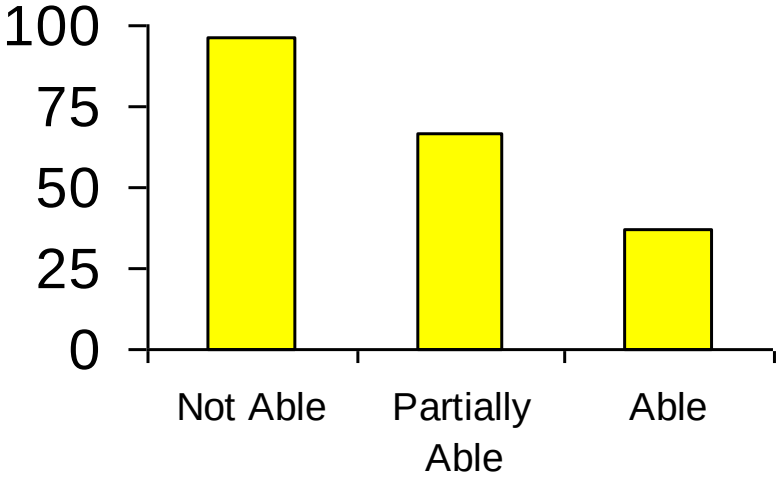
How common and persistent is self-injury in autism spectrum disorder?

- Two surveys
- Across causes of ID

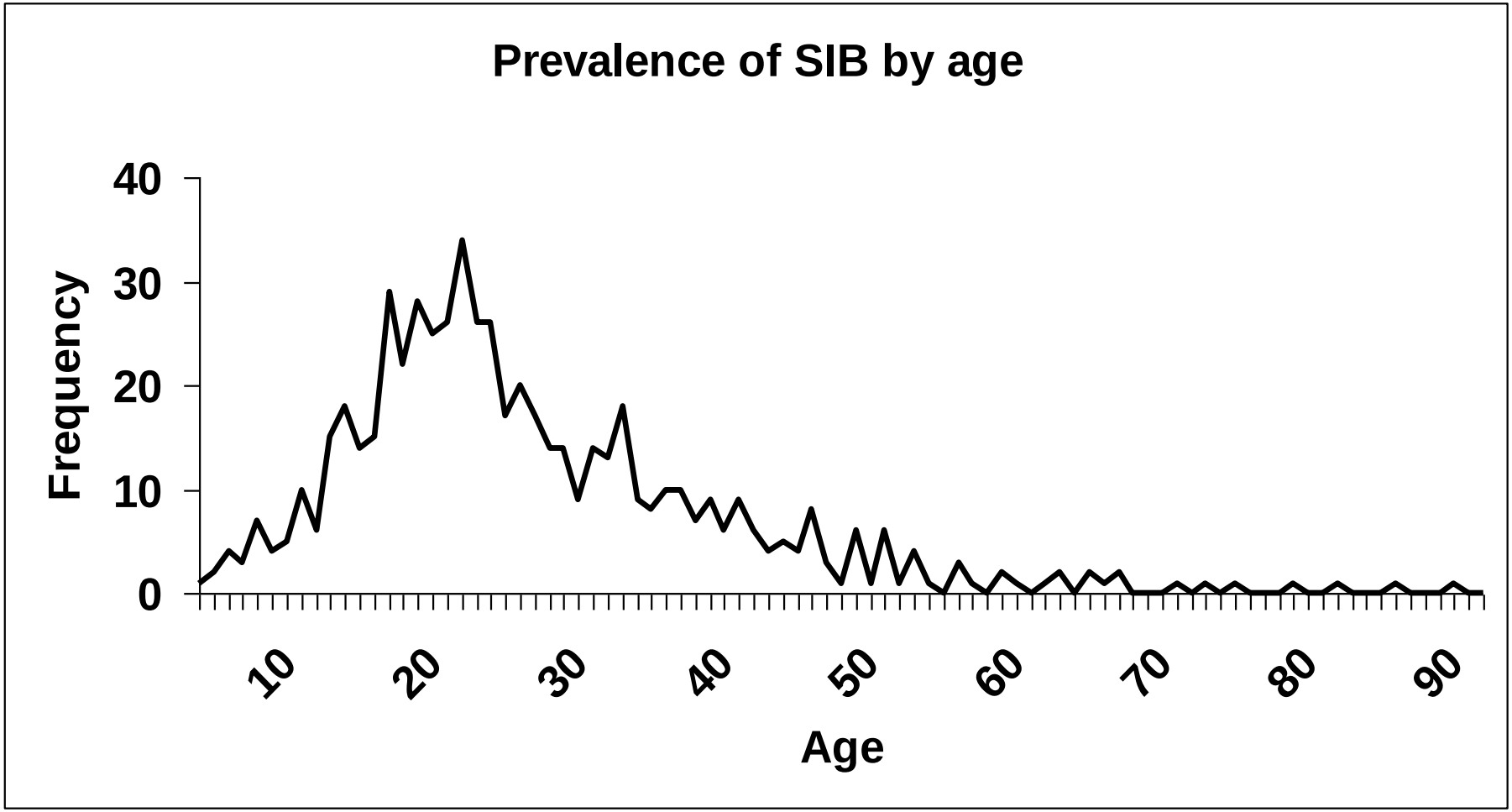
- Persistence over 3 years

- Degree of ID
- Behavioural markers

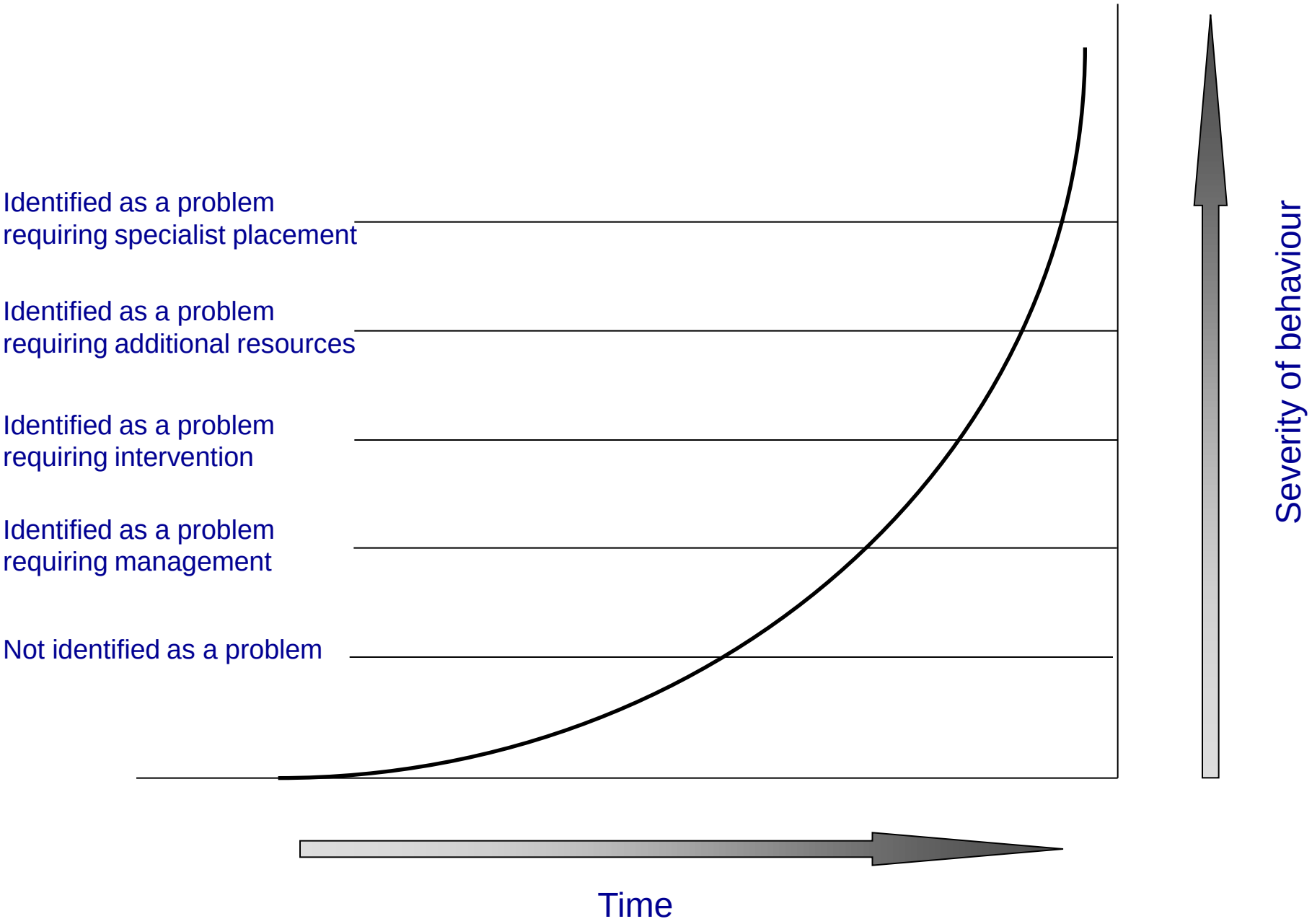




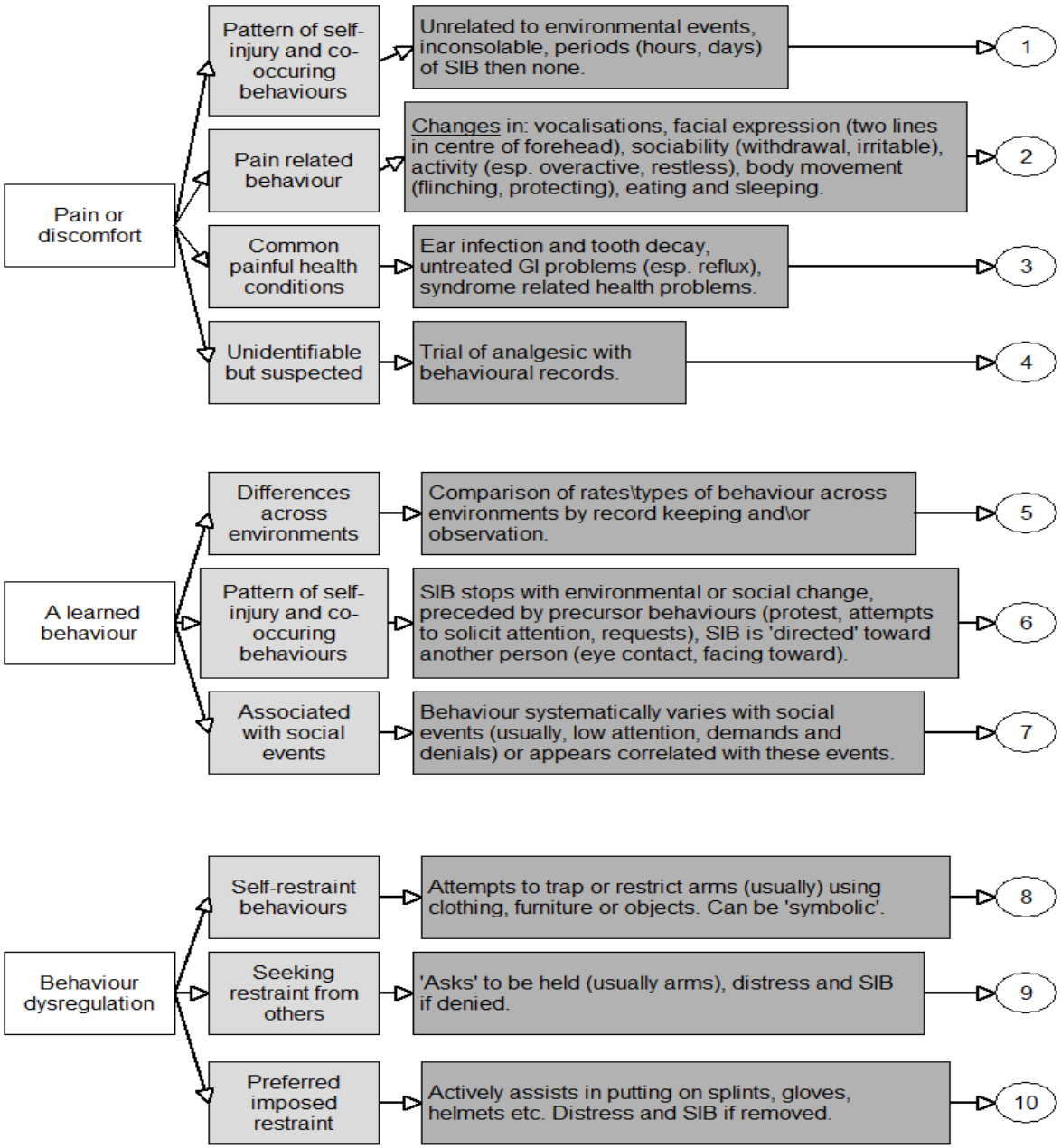
Prevalence data on 943 children aged 4-18 years attending SLD schools in Birmingham 2003/04
Jane Petty. PhD. University of Birmingham

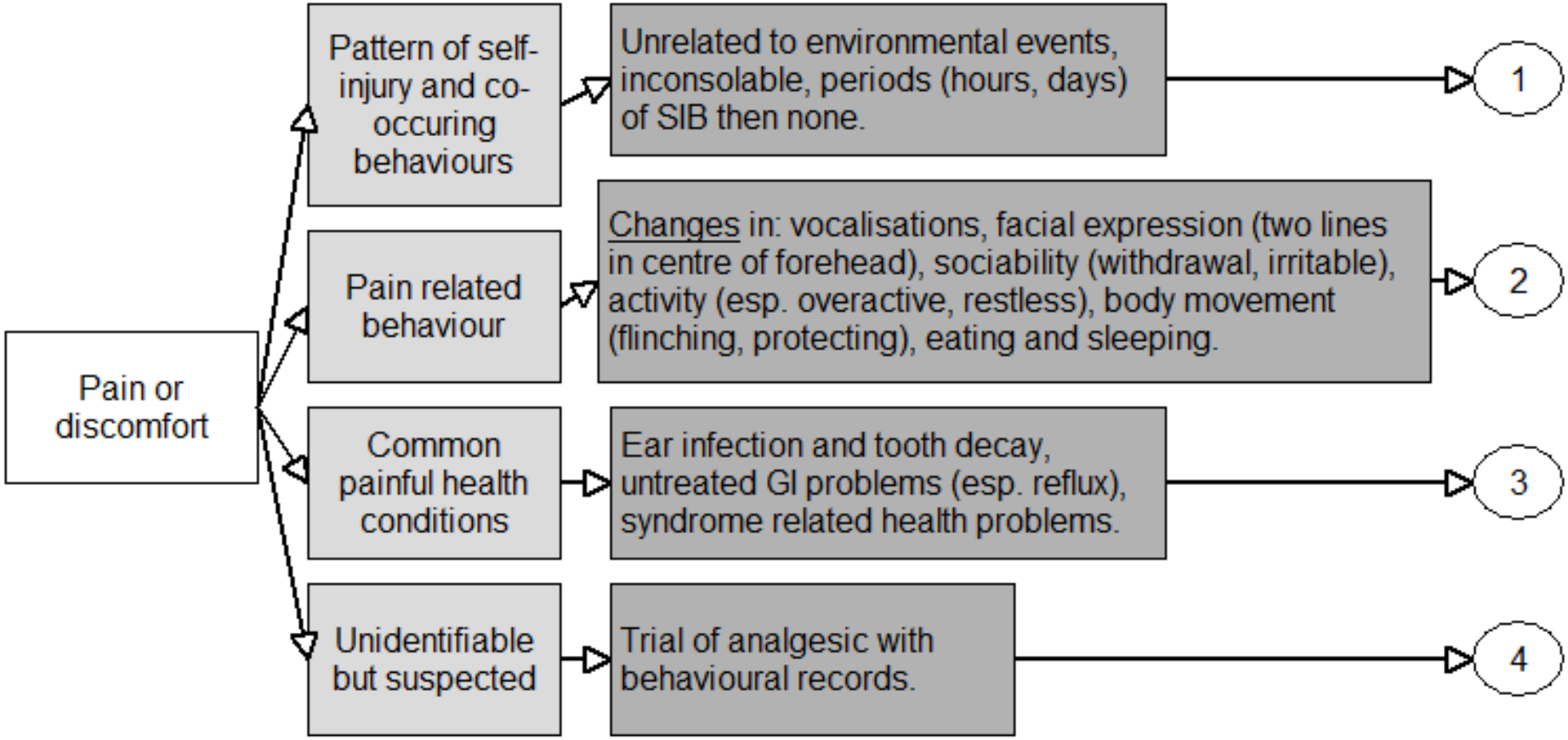

Prevalence of SIB by age
Frequency
40
30
20
10
0
10
20
30
40
50
60
70
80
90
Age

Development of SIB



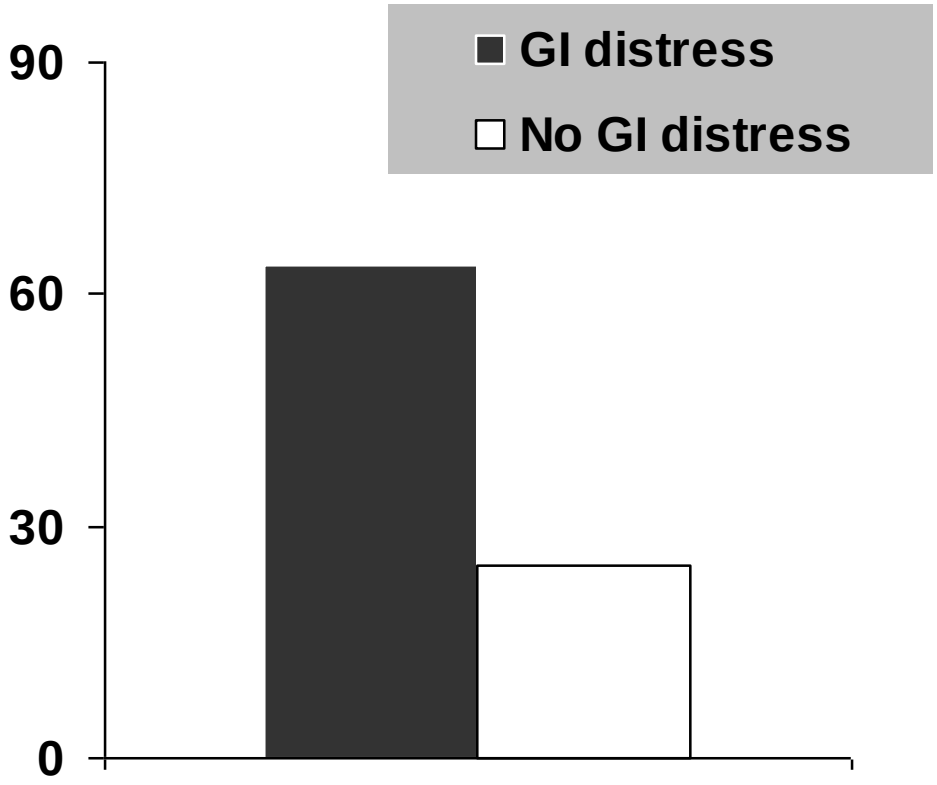
Common causes and drivers of Self-injurious behaviour




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

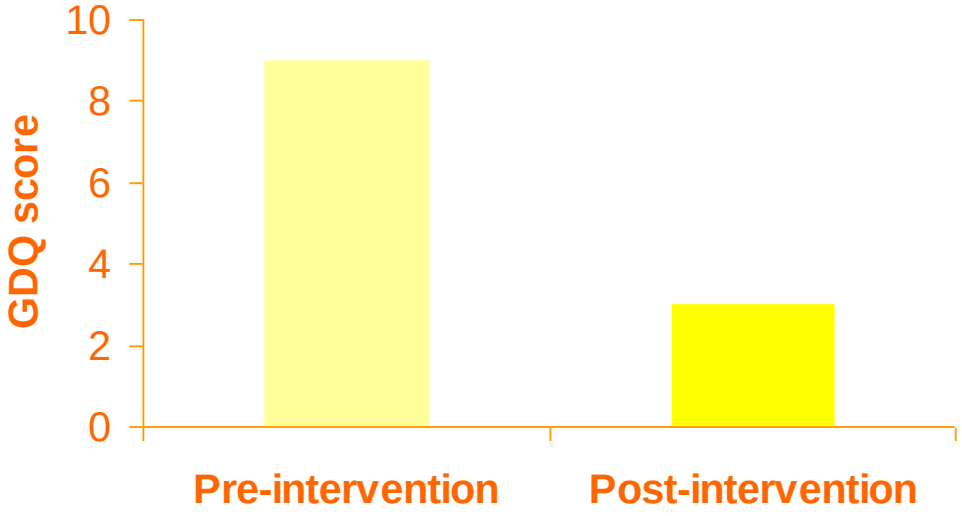
Arch his/her back
Lie over object on stomach
Salivate excessively
Fidget/wriggle
Fingers in mouth
Chew clothes
Grind teeth
Scratch/rub chest/throat
Drink excessively
Cough/gag/regurgitate
Discomfort
Refuse food
Indecisive about food
Wake during the night
Sleep sitting or propped up
Bad Breath
Respiratory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

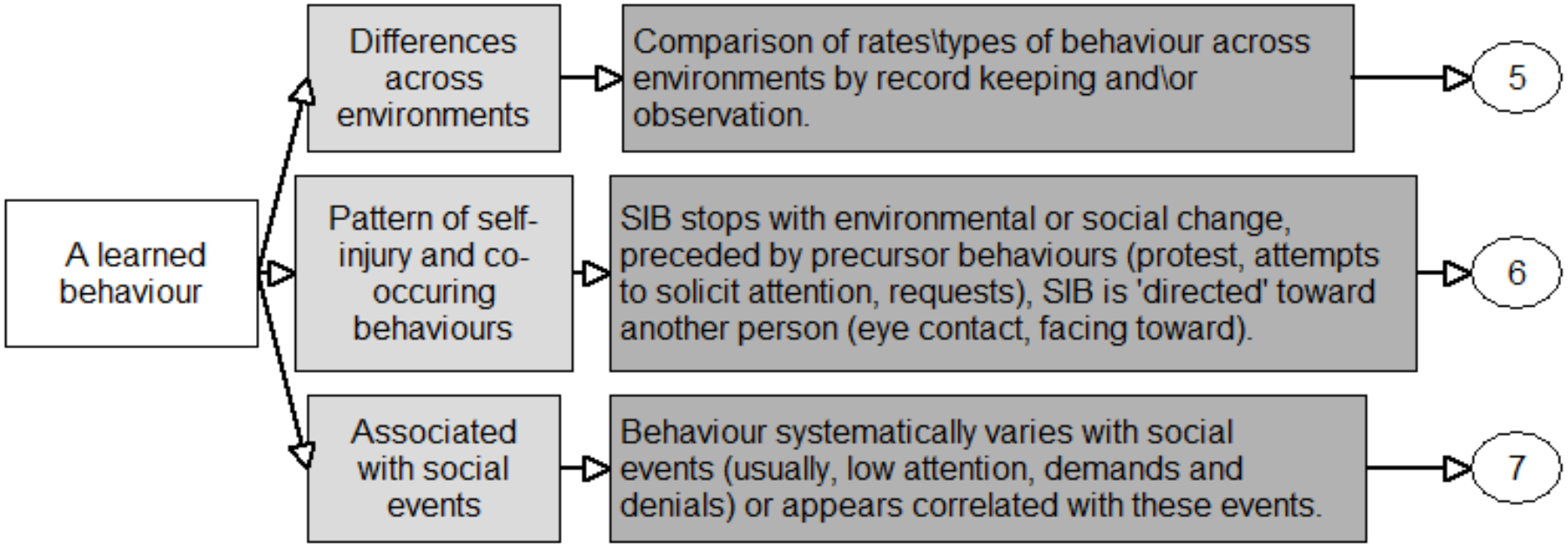
Gastro-intestinal distress and SIB in ASD



Case Study

- Participant 3 – 9 years old
- Self-injury
  - hitting his body, head banging hitting himself with hard objects, biting his hand, biting hard objects, scratching his face
- Observations
  - Severity; stopping observations; out of nowhere, inconsolable
- Intervention




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

Learned behaviour

	Reinforcement
Positive (access to)	Adding something Strengthens behaviour
Negative (avoidance or escape from)	Removing something Strengthens behaviour
Extinction	Removal of reinforcement following a behaviour that was previously reinforced reduces the likelihood of that behaviour occurring again

Common Autism specific functions

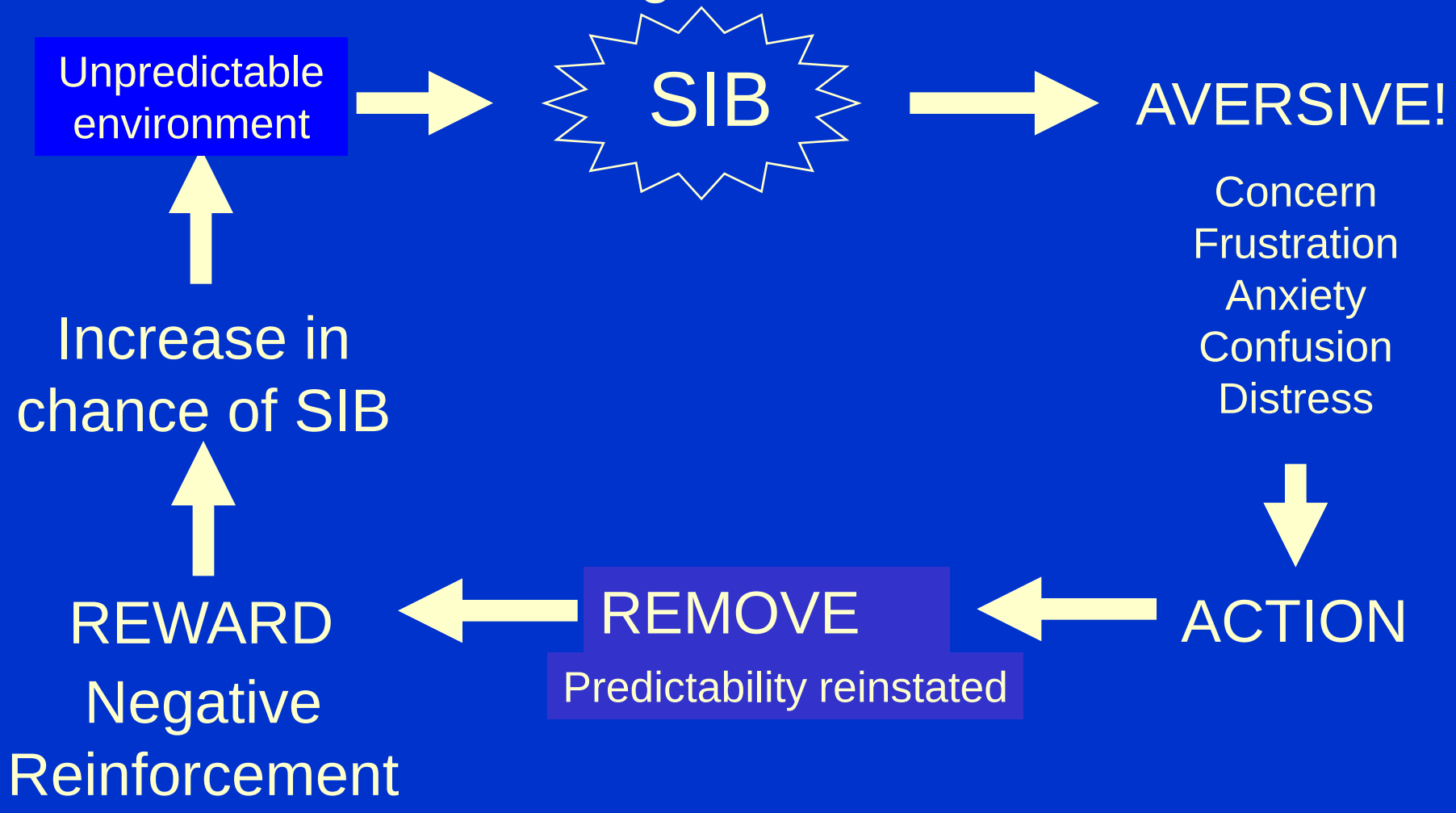
Positively reinforced SIB
Access to Attention
Access to tangibles
Access to ritual or routine

Negatively reinforced SIB
Demand-escape
Social-escape
Sensory-escape

Automatically reinforced SIB
Positive / negative

Transition related SIB – Can be both of above

Social Communicative Function of Challenging Behaviour: Negative Reinforcement

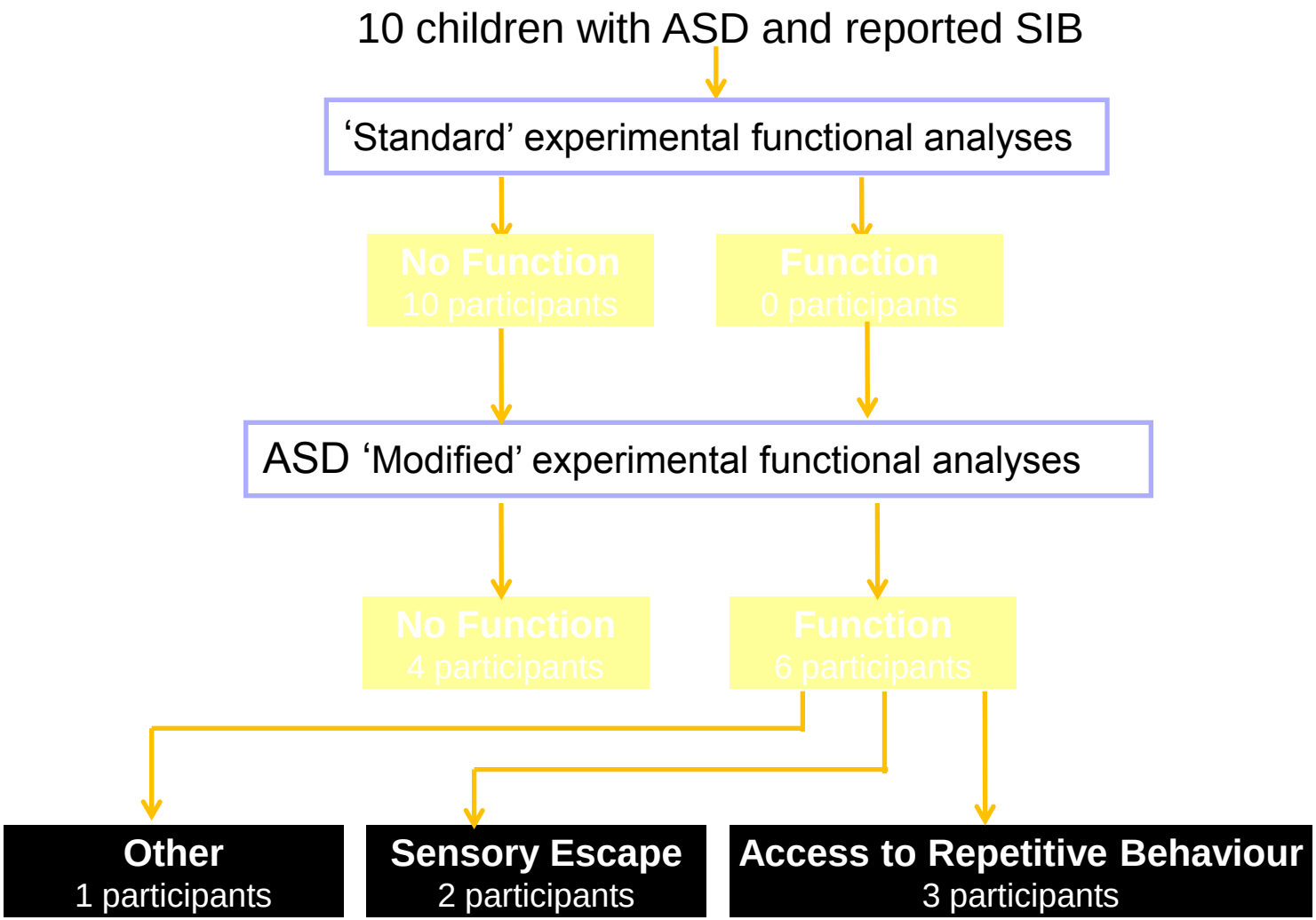


Which of the following behaviours would you be most worried by?

So which ones are you likely to respond to?

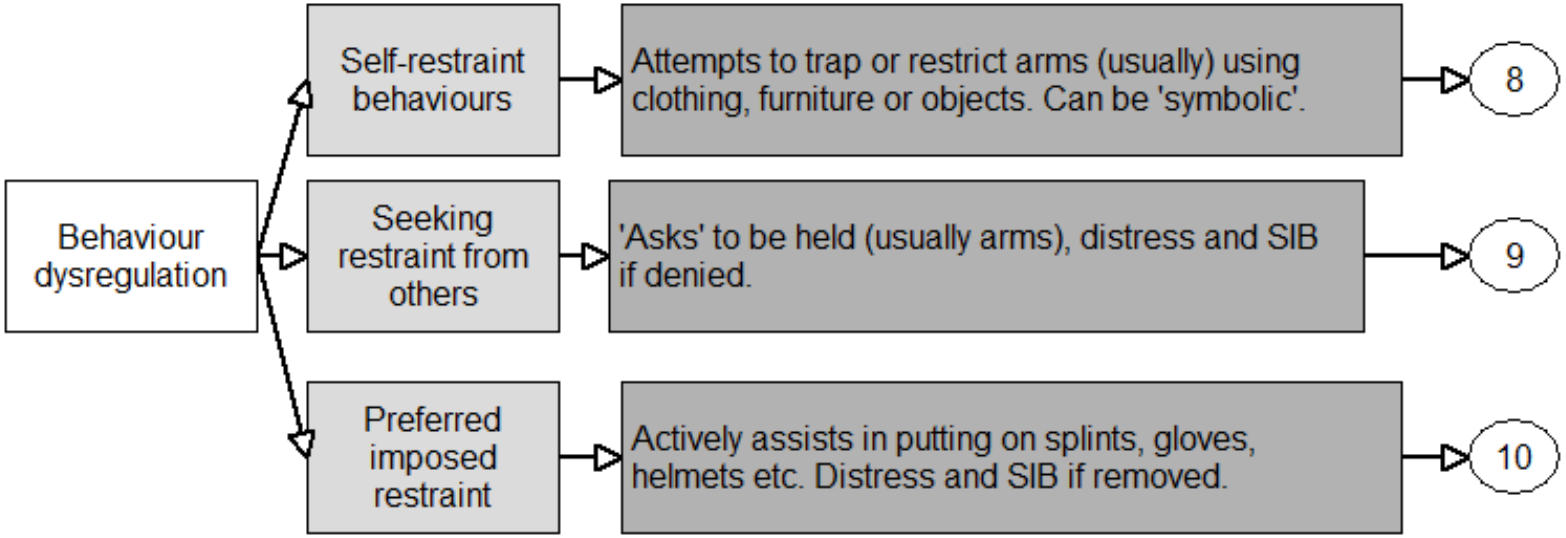
And which ones are likely to be reinforced?

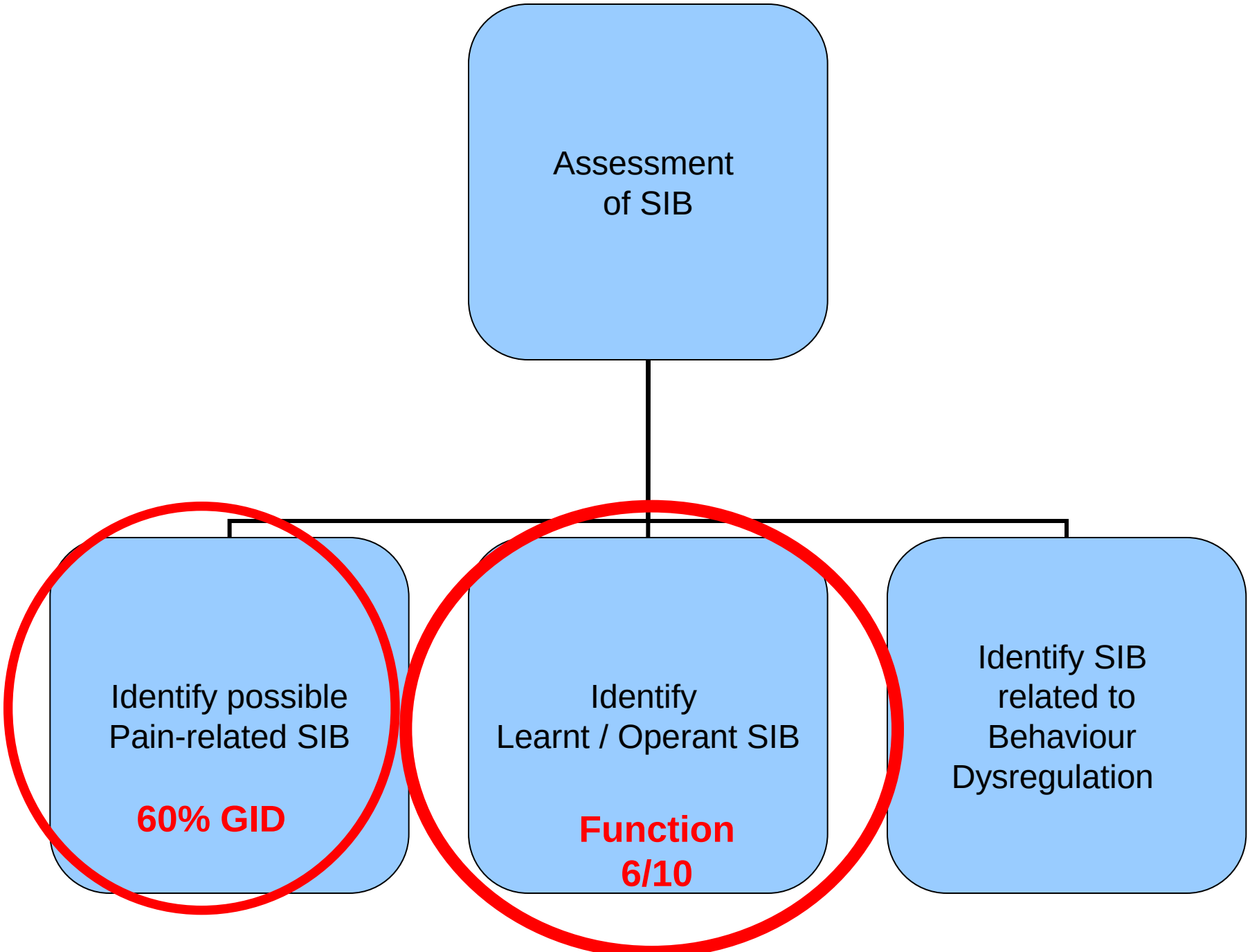
- Slap on the thigh
- Headbang on a coffee table
- Scratching an open wound
- Biting sibling's hand
- Punch near the eye
- Headbang on carpeted floor
- Scratching unbroken skin
- Slapping sibling's arm



6 in 10

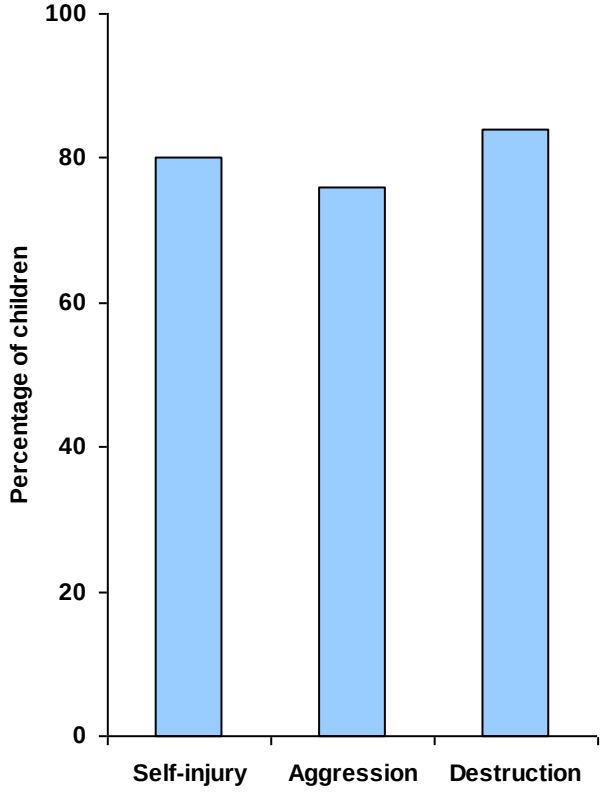
- Function for self-injury


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

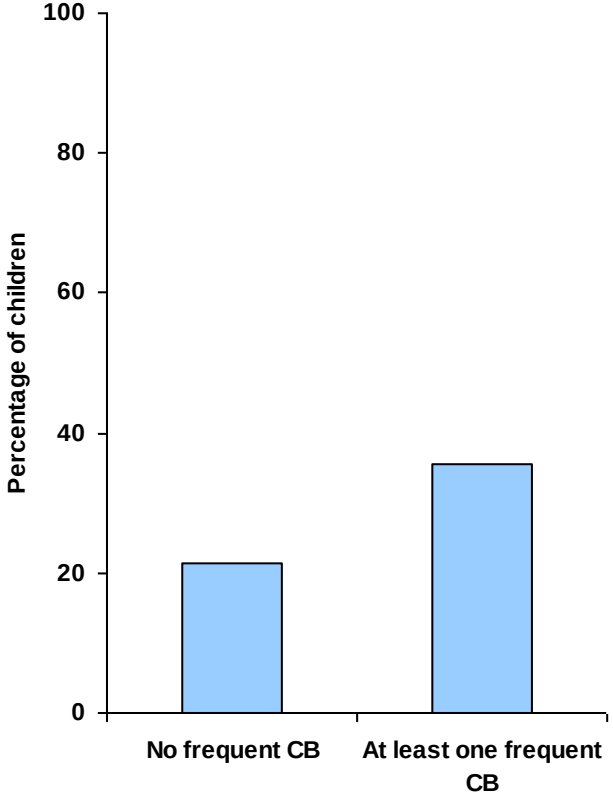

Assessment of SIB
Identify possible Pain-related SIB
60% GID
Identify Learnt / Operant SIB
Function 6/10
Identify SIB related to Behaviour Dysregulation

Survey of 296 parents of children with severe intellectual disability in Birmingham

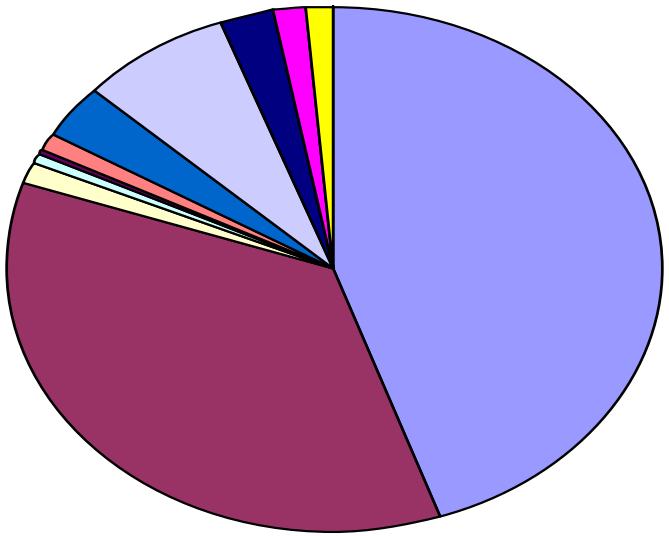
Percentage of parents needing help for children showing frequent CB



Percentage of parents who have seen psychology, psychiatry or community nurse in last three months



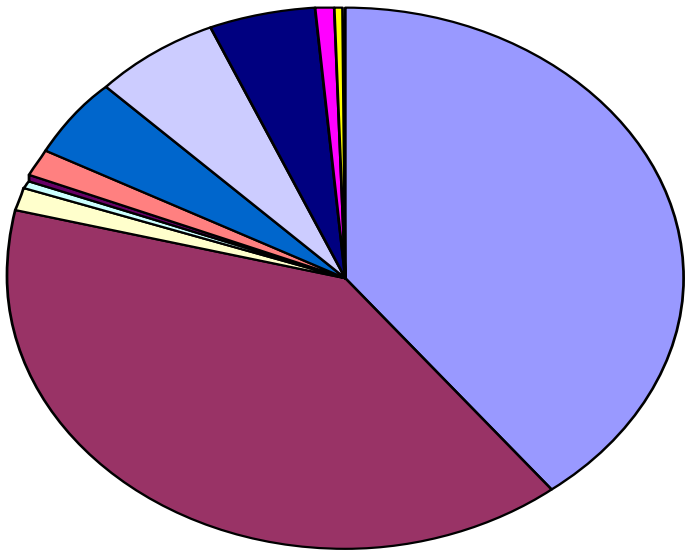
Oliver, C., Petty, J., Davies, L., Ruddick, L. and Bacarese-Hamilton, M. (2009). The children of Birmingham with Severe Intellectual Disability who show Challenging Behaviour. *Clinical Psychology and People with Learning Disabilities*, 7, 15-21.



2001 - 2005

5,271 publications

(Self-injury 1.25%)



2006 - to date

13,222 publications

(Self-injury 0.086%)

What to do?

- A high percentage of SIB may be treatable but this is dependent on behavioural expertise
- Behavioural expertise is scarce (Jacobson 2000)
  - need to think creatively
- Behavioural expertise needs to be disseminated to those who need it most – but how?
- Consultancy?
- But to who? Who is responsible for managing SIB on a daily basis?
  - Families / Schools / Psychologists
- Research tells us that external behavioural consultancy is most effective when there are on-site staff trained in basic behavioural methods and procedures
- Behavioural methods and procedures can be complex and require high levels of precision, therefore frequent and on-going feedback is required
- Difficulty – Time and financial cost of consultant / research team visiting widespread geographical sites is high –
  - Remote consultancy?

Research Questions

- Can Remote Consultancy lead to a reduction in self-injurious behaviour?
- Can we train school staff to independently:
  - assess the causes and drivers of self-injurious behaviour?
  - analyse and interpret the results of the assessment?
  - Design intervention programs to reduce SIB?
  - Evaluate interventions?
- Is the Remote Consultancy model feasible and practical?

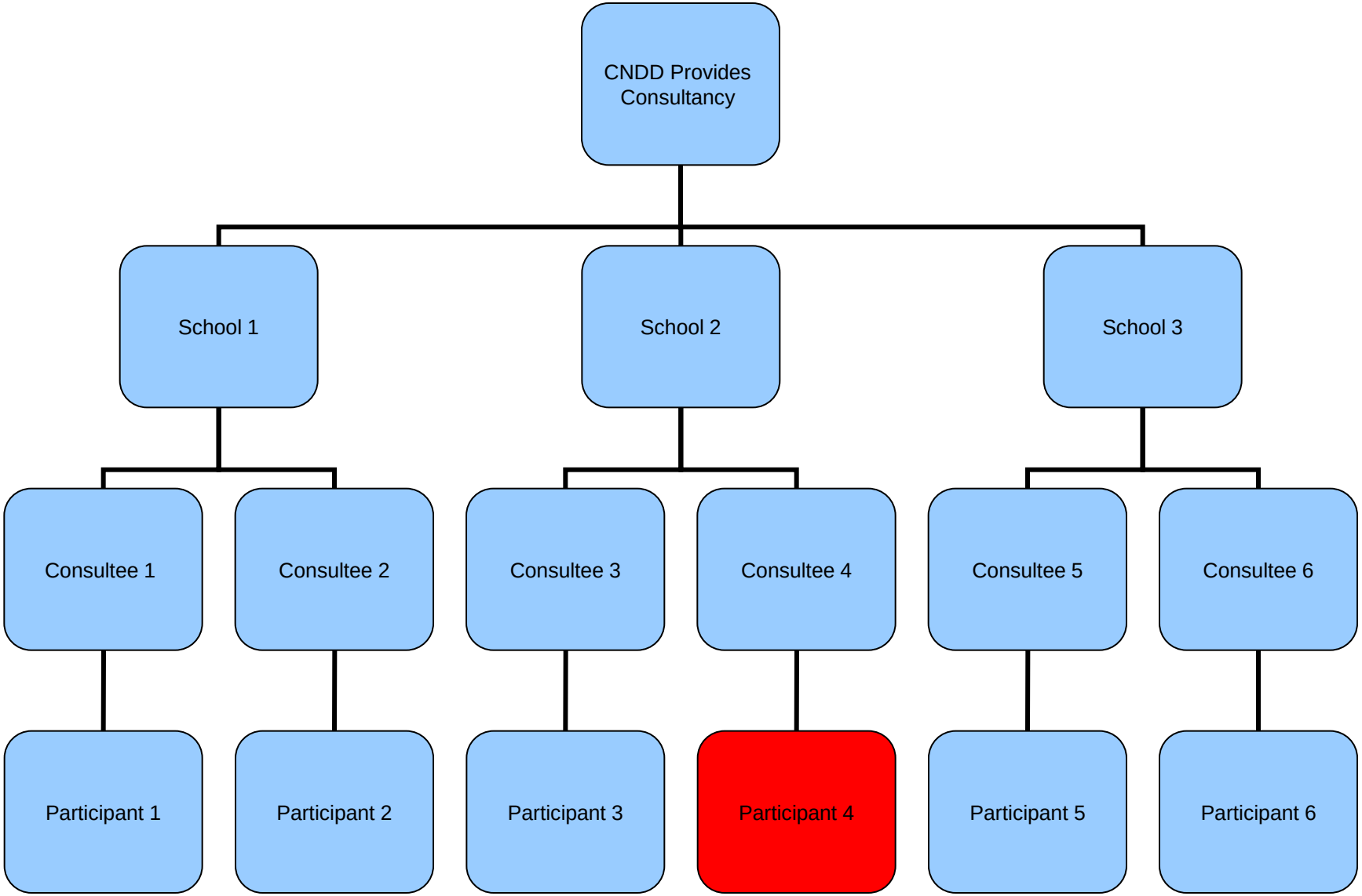
Recruitment

- School
  - Participation in previous research
- Consultees
  - Recommended characteristics
  - Time commitment
- Participants
  - Present SIB at least daily
  - ASD
  - No known additional genetic disorders
  - Intellectual Disability
  - <16y

Participants

Child	Age	Gender	VABS score
1	15y 2m	F	46
2	13y 8m	M	57
3	8y 6m	M	68
5	14y 9m	M	67
6	14y 10m	M	67

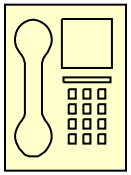
Participant 4 - parental withdrawal before the study began


CNDD Provides Consultancy
School 1
School 2
School 3
Consultee 1
Consultee 2
Consultee 3
Consultee 4
Consultee 5
Consultee 6
Participant 1
Participant 2
Participant 3
Participant 4
Participant 5
Participant 6

How was training and consultancy delivered?

- Training Workshops 4 X 2 days

- Monthly 1-2 hr individual consultation via Webex



- Fortnightly Email and Telephone drop-in clinics – individual consultation

School

- Site visits to schools – 2 per school

Training Content – not exhaustive list

What is self-injurious Behaviour?
Defining target behaviours
Collecting video samples
Conducting observations
Conducting / scoring questionnaires and interviews
Recording target behaviours
Reliability assessment
Reinforcement
- Postitive / negative
- Schedules

Extinction
- Burst

Functional Assessment of behaviour
- Informant-based
- Descriptive
- Experimental Analysis

Interventions matched to function -
Antecedent strategies
Environmental enrichment
Curriculum enrichmen
Consequence strategies
Reinforcement
Extinction
Teaching replacement behaviour
DTT
Prompting strategies (L>M / GG)
Chaining (forward and backward)
Shaping
Functional Equivalence
Matching Law
Treatment Integrity
Treatment Acceptability
Pain-related SIB
Behaviour Dysregulation
Operant / learnt behaviour

Active Remote Consultancy Phase

Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sept
	*	*		*				*		

Recruitment

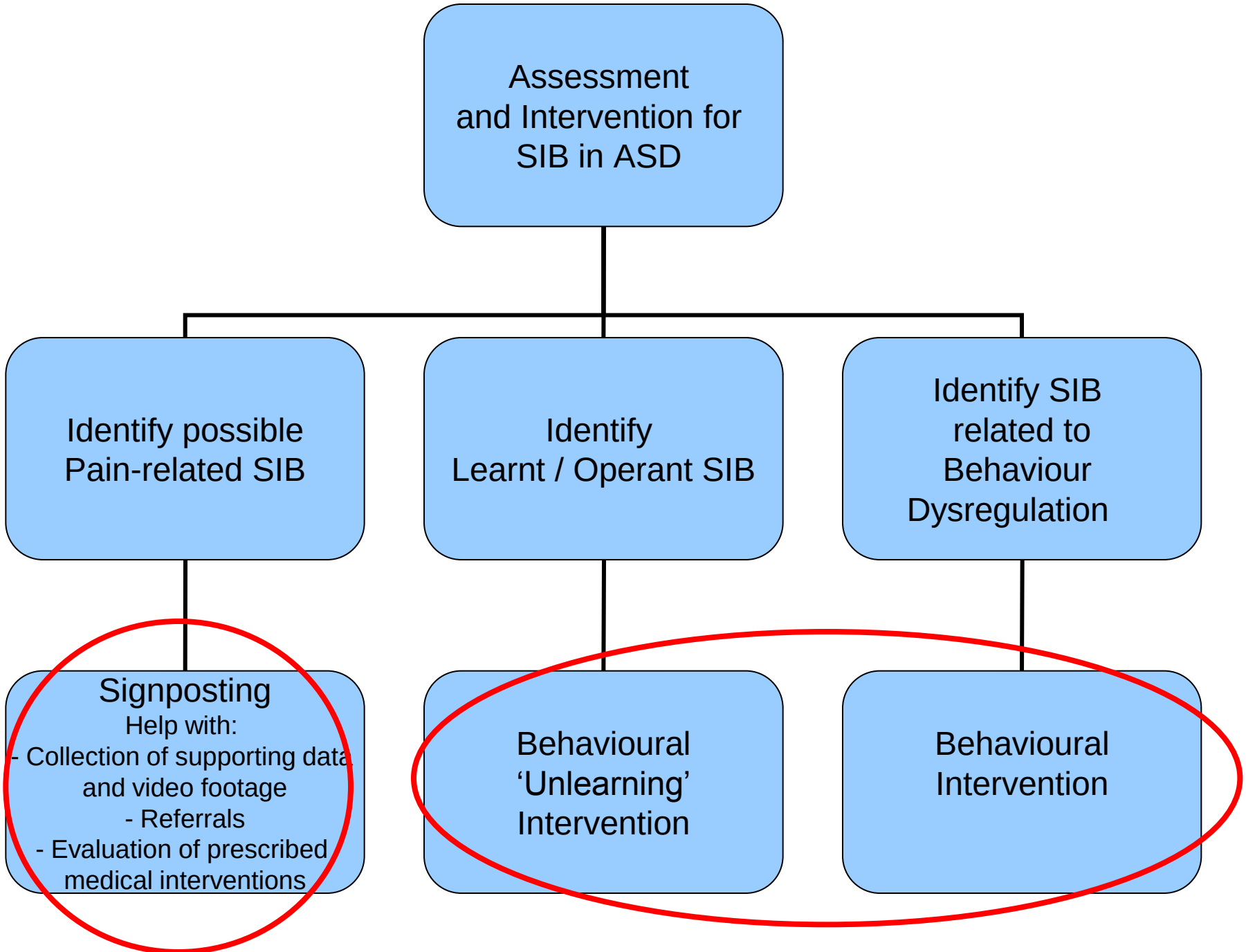
Assessment

Intervention

Follow-up drop-in clinics

Total of 31 weeks of Consultancy and training (excluding school holidays)

Duration of intervention was between 2 and 6 weeks – wide variation on intensity / frequency of delivery


Assessment and Intervention for SIB in ASD
Identify possible Pain-related SIB
Identify Learnt / Operant SIB
Identify SIB related to Behaviour Dysregulation
Signposting
Help with:
- Collection of supporting data and video footage
- Referrals
- Evaluation of prescribed medical interventions
Behavioural 'Unlearning' Intervention
Behavioural Intervention

Assessment of SIB

Informant based Measures
questionnaires and interviews

Collect video clips of children under a variety of naturalistic environmental conditions known to be common ‘high risk’ situations for SIB in individuals with ASD and record the frequency / duration of SIB under each condition

Informant-based Measures

Pain and discomfort

- Gastro-oesophagael Distress Questionnaire (GDQ)
- Non-Communicating Child Pain Checklist (NCCPC)
- Health and Background questionnaire

Functional Assessment

- Questions About Behavioural Function Questionnaire
  - (QABF modified)
- Functional Analysis Interview

Behaviour Dysregulation

- Self-Restraint Questionnaire (SRQ)

Self-injurious behaviour

- Challenging Behaviour Interview (CBI)

- **Demand Escape**
  When child is in an adult-led teaching situation (individual if that is typical for the child or in a group).

- **Low attention**
  When a child does not have an adults attention or the attention is divided

- **Access to Tangible (free v's restricted access)**
  When access to a preferred activity or item has to end.

- **Access to Rituals and Routines (free v's restricted access)**
  When a child is no longer allowed to engage in those routines or rituals or when routine is changed.

- **Sensory-Escape**
  When a child is exposed to commonly occurring non-preferred sensory stimuli.

- **Control**
  When a participant has an adults full undivided attention and access to preferred items, activities, routines and rituals.

- **AND any other high risk environmental condition highlighted for each child during informant-based assessment or direct obs.**
  - Social escape / Alone condition or no consequence condition if automatic reinforcement suspected

- **Transitions**
  When a child is required to transition from activity to activity, room to room, setting to setting, staff member to staff member etc.

Identification of cause / driver of SIB

- Informant based questionnaires and interviews (5)
- Observation of video-based samples (2)
- Direct clinical observation from the CCND (3)

	Evidence of Pain / discomfort	Evidence of Operant function	Evidence of Behavioural Dysregulation
1	-	+	-**
2	-	+	-
3	Hayfever* / Reflux*	+	-**
5	-	+	-**
6	Hayfever*	+	-

*Thought to be managed by medication ** No S/R observed but intolerant to delay

Across all assessment methods, the following functions were identified

	Positive Reinforcement Access to:				Negative Reinforcement Escape from / avoidance of:			
	Attention	Tangibles (items / activities / locations)	Sensory	Routines / rituals repetitive behaviours / restoring sameness	Specific sensory stimuli	Specific social stimuli	Demands or Non-preferred activities	Pain / discomfort
1	+	+		+			+	
2	+	+		+			+	
3		+	+		+		+	+
5		+					+	
6		+	+	+	+		+	+

Transitions were reported to be a high risk situation for all participants

Competing behaviour model (O'Neill et al., 1997)

- Identify contingencies maintaining SIB
- Identify and train an alternative behaviour that produces the same consequence as the problem behaviour (functionally equivalent)
- Identify methods whereby antecedents, behaviours and functional consequences can be altered so that the problem behaviour becomes irrelevant, ineffective and inefficient

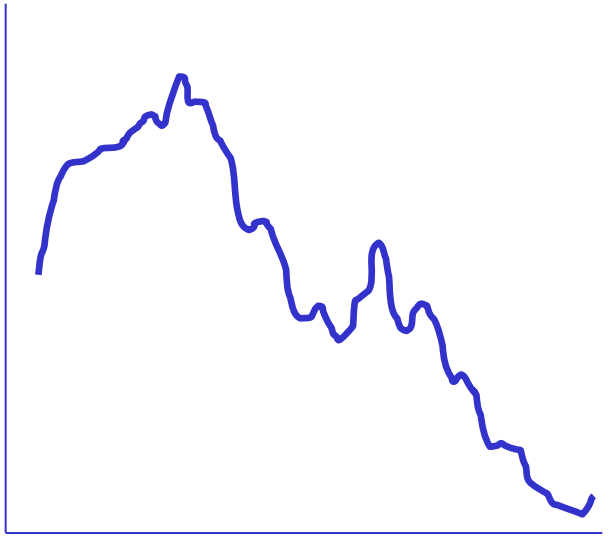
General Intervention principles

First further clarify understanding of the behaviour

- Antecedent
  - Positive Reinforcement (Access to)
    - Increase access to reinforcer and items / activities similar to the reinforcer
    - Increase predictability of reinforcement
  - Negative Reinforcement (Escape from)
    - Identify aversive properties of environment / activity and improve
    - Build tolerance and endurance to above environment if appropiate
- Consequence
  - Reinforce (and train) a ‘functionally equivalent’ replacement behaviour
  - Stop reinforcing Self-injury (Extinction)

Extinction

- Reinforcement is no longer delivered following SIB
- Extinction bursts are thought to occur in aproximately 20% of cases
- Emotional and novel behaviour (intensity or topography)



Access to preferred activity (playing outside)

"Come on Dan, It's time to go inside"

SIB occurs

"Alright then, five minutes more…"

Decreased likelihood of challenging behaviour in the future given similar antecedent conditions

Extinction

Withold reinforcement for SIB

Reinforcement

Reinforce an alternative functionally equivalent response

Increased likelihood of communicative response in the future given similar antecedent conditions

Transition-related SIB

- All transitions (insistence upon sameness / behavioural rigidity)
- Unplanned transitions (predictability)
- Specific transitions (preferred or neutral to less preferred activity / location / member of staff etc)
- Physical difficulty crossing threshold (appear physically stuck)

Participant 1

Self-injurious behaviour

•Hand biting

•Dropping to floor

Functions addressed

Transition related behaviour?

•Access to attention

•Escape from Demand

•Access to tangibles

•Tolerance to delay

Setting

Getting ready to go home at the end of the school day

Intervention

•Mini visual Schedule (non-verbal prompting)

•One staff member

•Teach participant to put coat on independently

•Initially no waiting (later teach tolerance to delay using visual timer)

•Initially conduct intervention when other children and staff are absent (gradually increase distraction)

•Teach participant to request to go to the minibus when she has completed her visual schedule

Participant 2

Self-injurious Behaviour
Slapping head with an open hand

Functions addressed

•Transition-related (threshold)?

•Access to attention

•Access to sensory stimulation

Setting

Transition from hall to playground after lunch (sometimes via classroom)

Intervention

•Deliver high levels of appropriate social contact during transition

•Withdraw social contact during transition refusal

•Reinforce successful transition with access to hand-games

•Teach participant to request hand-games once in the playground

Participant 3

Self-injurious behaviour

Head banging

Teeth tapping

hand biting

Eye poking

Chin banging

Functions addressed

Access to Tangibles

Setting

Access to the swing at playtime

Intervention

•Teach participant to request access to the Swing using PECS

•Teach tolerance to delay

Participant 5

<u>Self-injurious Behaviour</u>

Head banging against object

Head / face slapping

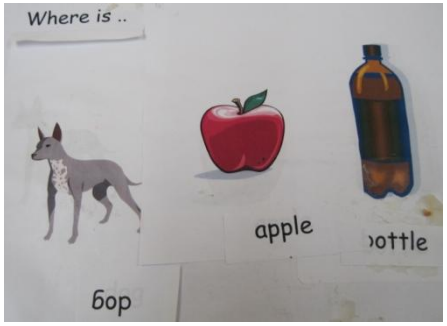
<u>Functions addressed</u>

Access to tangibles

Escape from demand

<u>Setting</u>

Full school day



<u>Intervention</u>

- Improve and increase general functional communication (PECS)
- Curriculum enrichment
- Environmental enrichment
- Reinforcer assessments
- Daily schedule and timer
- Increase physical protection for staff
- Teach participant to request a break

Participant 6

<u>Self-injurious Behaviour</u>

Head banging against object / knee

Biting toes

<u>Functions addressed</u>

Access to tangibles

Access to sensory items

Escape from demand

<u>Setting</u>

Full school day

<u>Intervention</u>

Same as participant 5

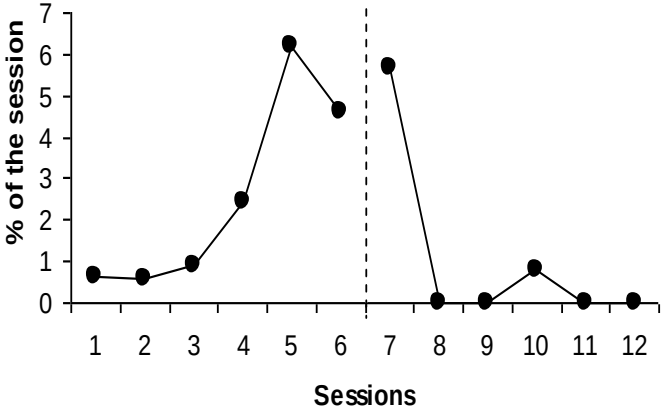
+

Query Gastro-Oesophageal Reflux?

Outcome Evaluation (efficacy)

- Comparison of individual pre-intervention and post-intervention:
  - CBI scores for SIB
  - Frequency / duration of SIB recorded from videotape of HIGH RISK conditions
  - Data collected as part of the School Incident Recording System (SIRS) on:
    - Weekly rates of SIB
    - Weekly rates of Restrictive Physical Intervention (RPI) use
      - Weekly rates and duration of seclusion

1


% of the session
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7
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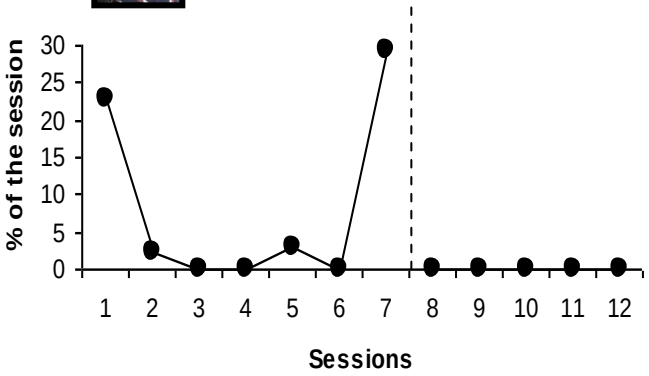
Sessions

2


% of the session
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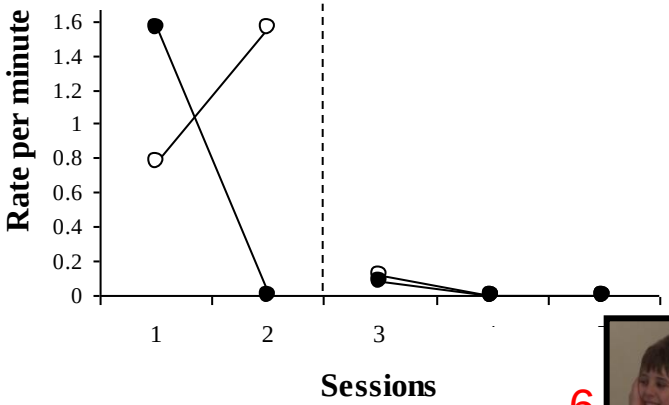
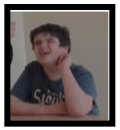
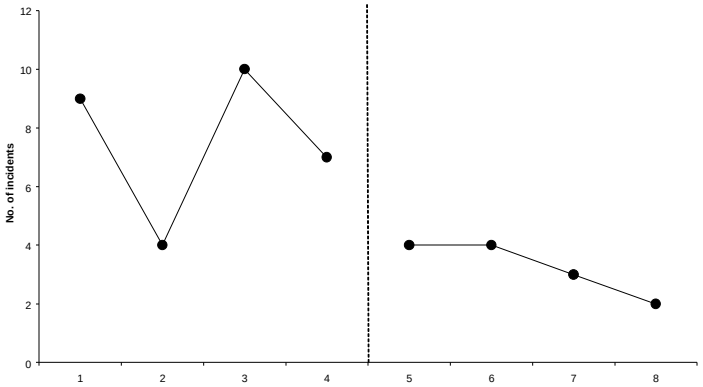
30
1 2 3 4 5 6 7 8 9 10 11 12
Sessions

3

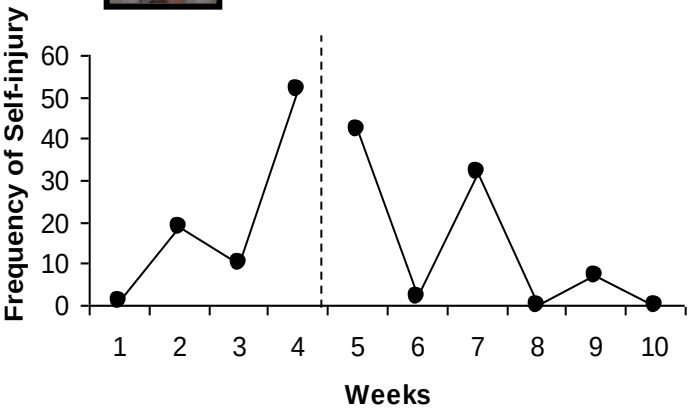

Rate per minute
0
0.2
0.4
0.6
0.8
1
1.2
1.4
1.6
1 2 3
Sessions

5

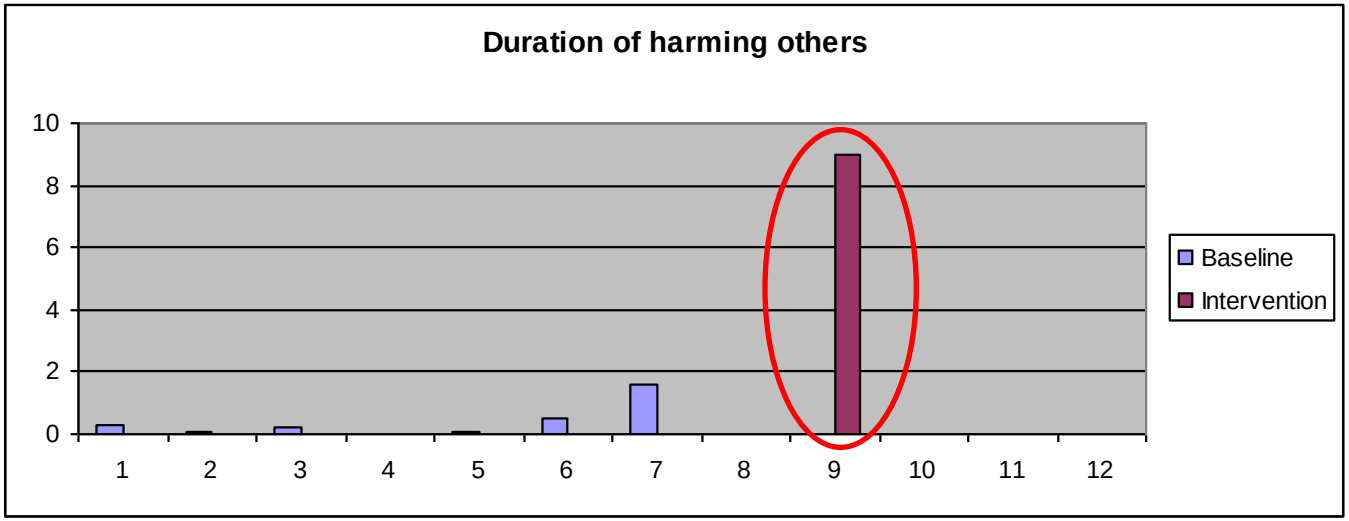


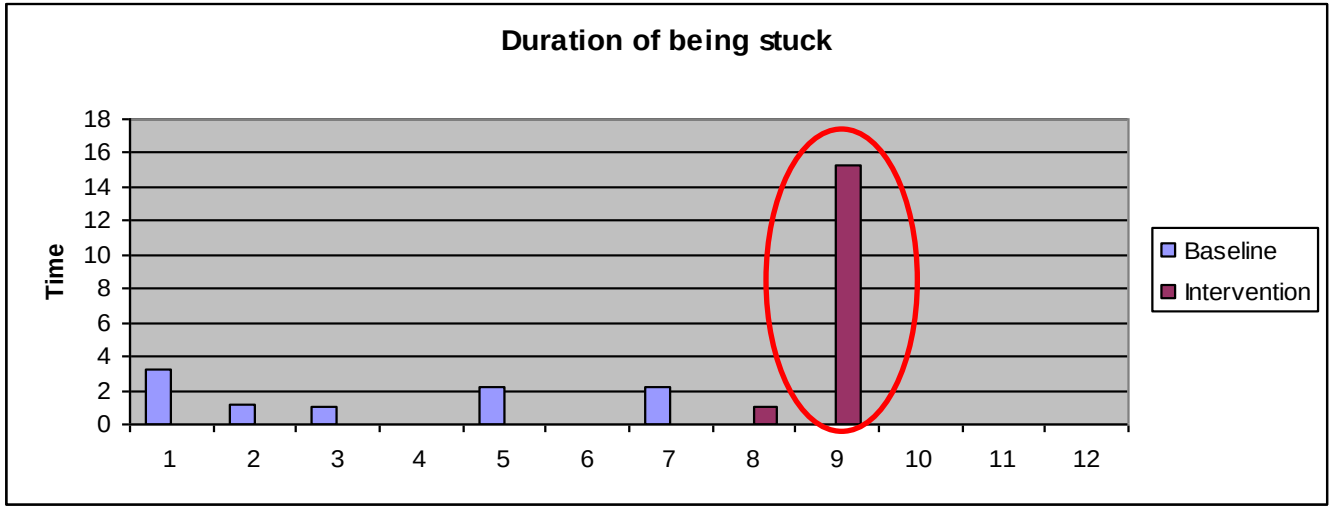

No. of incidents
0
2
4
6
8
10
12
1 2 3 4 5 6 7 8

6


Frequency of Self-injury
0
10
20
30
40
50
60
1 2 3 4 5 6 7 8 9 10
Weeks

Evidence of an extinction burst?

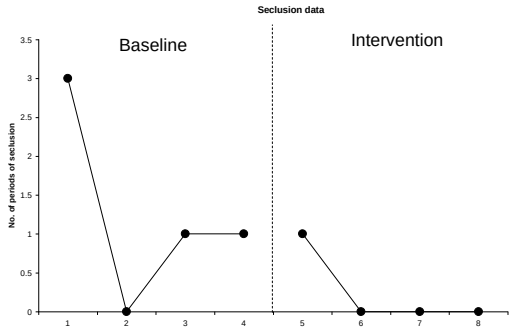




Child	CBI (1)	CBI (2)	RCI	Scope of Intervention	Intervention time	Significant reduction
1	23	18*	**1.71***	1 High Risk Situation (multiple functions)	<1hr	Session 2 (10 mins)
2	18	19	0.34	1 High Risk Situation (multiple functions)	<1hr	Session 1 (10 mins)
3	26	28	0.68	1 High Risk Situation (single function)	<1hr	Session 1 (2-3 mins)
5	31	17.5*	**4.61***	Multiple function / environment package	4 weeks (Week 1-2 partial implementation)	Week 3 (5 days full)
6	25	20.5	1.54	Multiple function / environment package	6 weeks	Week 4 (20 days)

Use of RPI and Seclusion

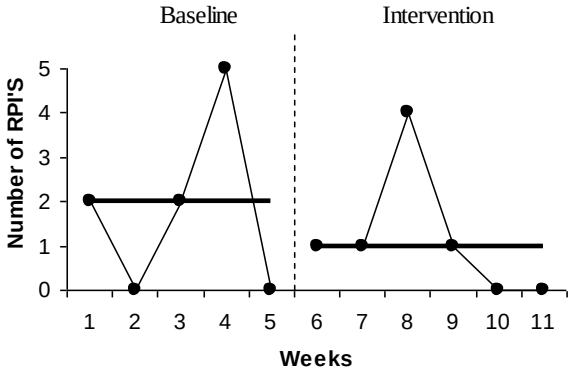
5



Seclusion used for a total of 56 mins during baseline (4 wks) and 2 mins 40 Seconds during intervention (4wks)

Weekly average
14m (Baseline) v's 45s (Intervention)

6



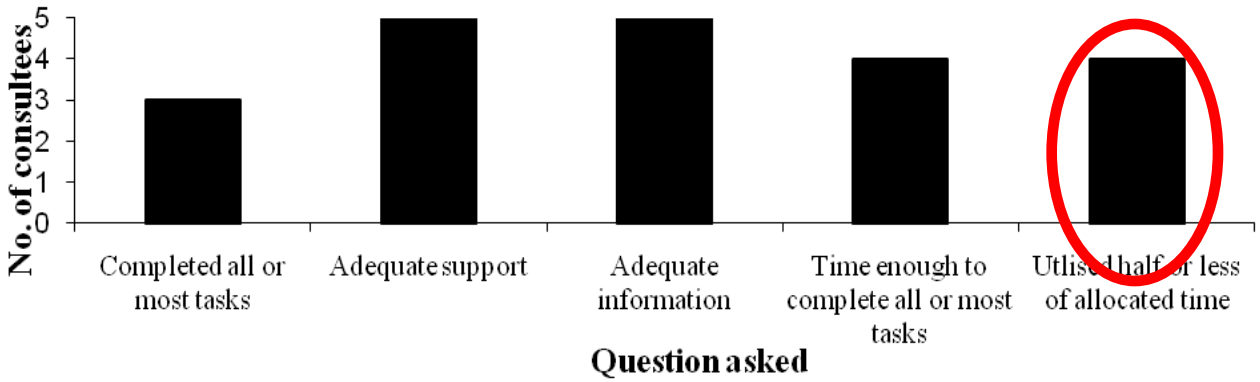
Process Evaluation (Feasibility / Practicality)

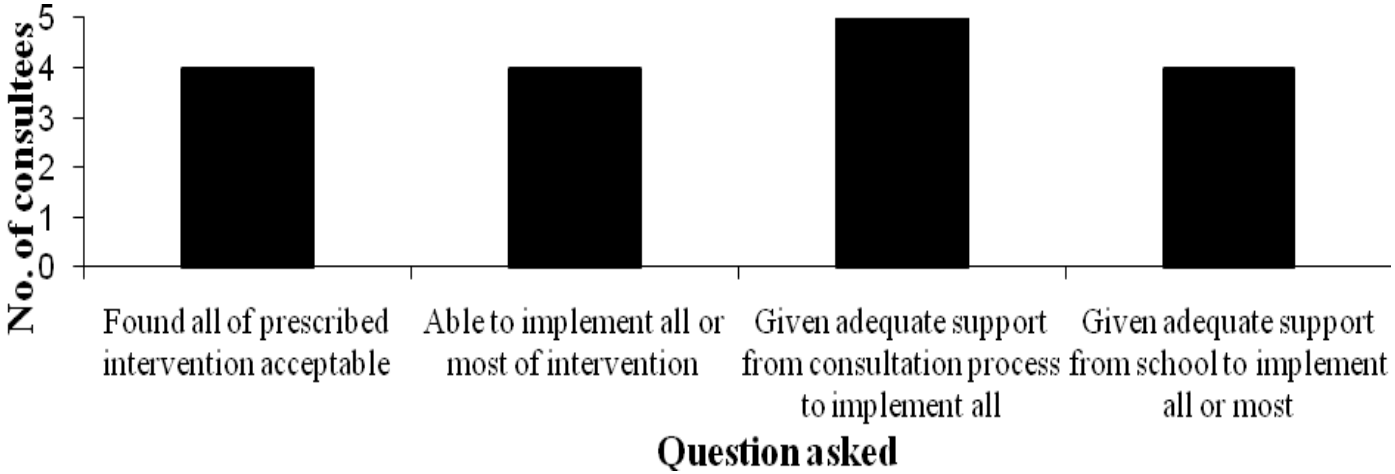
- Delivery of Remote Consultancy and Uptake
- Consultee feedback
- Technology use
- Piloting assessment method
- Content of training

Consultancy

Consultancy	No. expected	No. offered	% uptake
Site visits	6	23	91
Workshops	8	7.5	88
1-2h monthly Individualised Consultation	21 < 50% Via Webex	21	71
Drop-in Clinic Optional	6	11	25
Drop-in clinic Compulsory	6	6	61

Consultee Feedback





Feasibility of Remote Consultancy

- Staff time
  - Less than 50%
    - No time to complete reading
    - Extra site visits?
- Technology
  - Telephone
  - Email
  - Webex
    - Webinars
    - Document sharing
    - Video sharing – extra site visits

Conclusions

- Remote Consultancy led to a:
  - Reduction in SIB in all participants
  - Reduction in the use of RPI's (and more specifically seclusion) in 2 participants
  - Reduction in the number of staff required to manage a participant during a high risk time for at least 1 participant
  - Teaching of at least one communicative response in all children

- Remote consultancy was feasible and practical with the exception of:
  - On-line video sharing
  - Allocation of consultee time on the project

Limitations of the present study and future research

- Intervention and Outcome evaluation
  - Outcome evaluation was way too early
  - Only one function or high risk situation was addressed (exception: comprehensive package for participants 5 and 6)
  - Only school setting involved directly in intervention
  - Reliability of the data
  - No generalisation data
  - No follow-up data
  - True baseline data??
  - Simple AB design

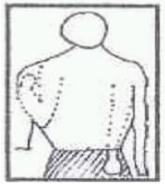
- Assessment
  - Only 2 / 5 consultees used the proposed assessment method (Effective in those 2 cases)
  - Videotaping caused possible reactivity effects in 1 or 2 cases
  - Consultees found it difficult during initial assessment and baseline – duty of care
  - Potential pain and self-restraint was not picked up by the informant measures

Participant 6

Pain and Discomfort				Operant				Behaviour dysregulation
NCCPC	H&B	GRQ	CNDD CO	QABF	FAI	Video Assess	CNDD CO	SRQ
-	Hayfever Reflux	+	?	+	+	+	+	+

After clinical Observation…..

2 Pull their arms out the sleeves and push them part or all of the way into the main body of the clothes that they are wearing?



ALL OF THE TIME	MOST OF THE TIME	HALF THE TIME	SOME OF THE TIME	NEVER
☐	☐	☐	☐	☐

9. Wrap a blanket, sheet, towel or other large piece of material around themselves, if it is available?

ALL OF THE TIME	MOST OF THE TIME	HALF THE TIME	SOME OF THE TIME	NEVER
☐	☐	☐	☐	☐

Clinical Observation – Participant 6

Although not picked up by the NCPCC or GDQ, there was some evidence of pain / discomfort related SIB

Although not picked up by the SRQ, there was multiple evidence of self-restraint

Thank you

- Participants
- Consultees
- Teachers
- Schools
- Gemma Warren & Rachel Carter
- Irina Roncaglia & Georgina Gomez de la Cuesta
- National Autistic Society
- Cerebra
- Research Autism

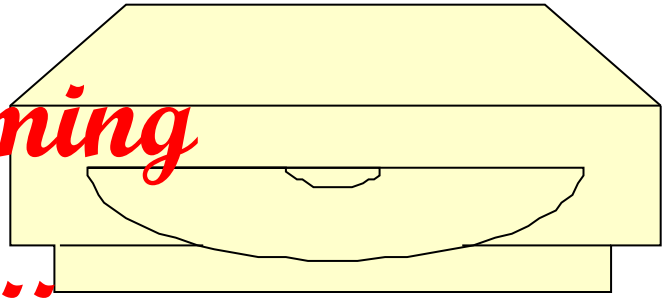
The Cerebra Centre for Neurodevelopmental Disorders

The National Autistic Society

The National Autistic Society

Assessment and Intervention for Self-Injurious Behaviour in Autism: An Evaluation of Five Children

DVD Coming soon….



Dr Debbie Allen, Prof. Chris Oliver, Rachel Carter & Gemma Warren.

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School of Psychology,
University of Birmingham

The Cerebra Centre for Neurodevelopmental Disorders