

The BILD Positive Behaviour Support International Research and Practice Conference 2014

Defining PBS and promoting evidence based practice

8 - 9 May, Glasgow



BILD's 2014 Defining PBS and promoting evidence based practice – 8 May

Workshop 2

Positive pathways: training family carers of people
with autism in positive behaviour support

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BILD PBS Conference 2014
Defining PBS and promoting evidence based
practice



Training Family Carers in the Implementation of Positive Behaviour Support

Caroline Shaw



The Richmond Fellowship
Scotland



Plan for the Presentation

- The aims and content of the training programme
- Resources used by family carers
- Evaluating the programme
- Programme developments
- Share our thoughts and conclusions

The Richmond Fellowship Scotland

- Largest social care provider in Scotland
- Support over 2000 people across Scotland
- Support includes learning disability & autism
- Includes complex & challenging behaviours
- In-house team to lead implementation of PBS

Positive Behaviour Support Team

- Internal specialist behavioural resource, working throughout Scotland
- Established in 2000, developed our practice & skills over this time
- Published our work in journals
- 2010 winner of PBS award
- 2014 Care Accolades finalist

The Training Model

Overview of Training Programme

- 1 year grant from the Scottish Government's Autism Development Fund.
- Deliver training to family carers of adults with ASD in 2012
- 18 training groups across Scotland, including rural areas where there are fewer services
- Up to 10 family carers in training groups
- Practical training and support in PBS

Training Objectives

- Practical exercises to gain insight into their family member's behaviour
- Get behavioural advice around specific problems
- Exploring communication and social skills interventions
- Meet other family carers

Training Content

Workshop 1 – Introduction to Autism

Workshop 2 – Basics of Positive Behaviour Support

Workshop 3 – Communication

Workshop 4 – Social Skills

Workshop 5 – Reactive Strategies

Each workshop was 5 hours and a month apart



Common Themes for Carers

- Little support and understanding from family and friends
- Negative experiences with professionals who had little understanding of autism and challenging behaviour
- Very few training opportunities for carers whose family member is now an adult
- Isolated due to lack of services
- Worried about family member's future

Training Resources



Workshop 1

Introduction to Autism

Learning Outcomes

1. To learn about the triad of impairments
2. To learn about sensory differences

Extract from Triad of Impairments Exercise

Impairment of Communication:

- Language skills may appear to be good on the surface
- Repetitive speech especially when anxious

Impairment of Social Interaction:

- Difficulty understanding the unwritten rules of society
- Difficulty with awareness of others' feelings and emotions

Impairment of Flexibility of Thought:

- Function best with structure & predictability
- Likely to display difficulty with change and transitions

Extract from Sensory Exercise

Tactile

HYPOSENSITIVITY	Rarely	Some times	Often	HYPERSENSITIVITY	Rarely	Some Times	Often
Enjoys or seeks out touch				Dislikes textured surfaces			
Objects in hands fall through fingers				Strips off clothing /often adjusts clothes			
Uses unusual weight bearing				Avoids touch from others			

Workshop 2

Introduction to PBS

Learning Outcomes

1. To learn about proactive and reactive behaviour support planning
2. To carry out a functional assessment

Extract from Understanding Behaviour Exercise

<i>Describe the behaviour</i>	
When does it occur (most/least often)?	
During what activities is it most/least likely?	
Does it seem linked to certain events?	
In what environment is it most/least likely?	
Can it be associated with any medical issue?	
Is it linked to any change in the family?	

Workshop 3

Communication

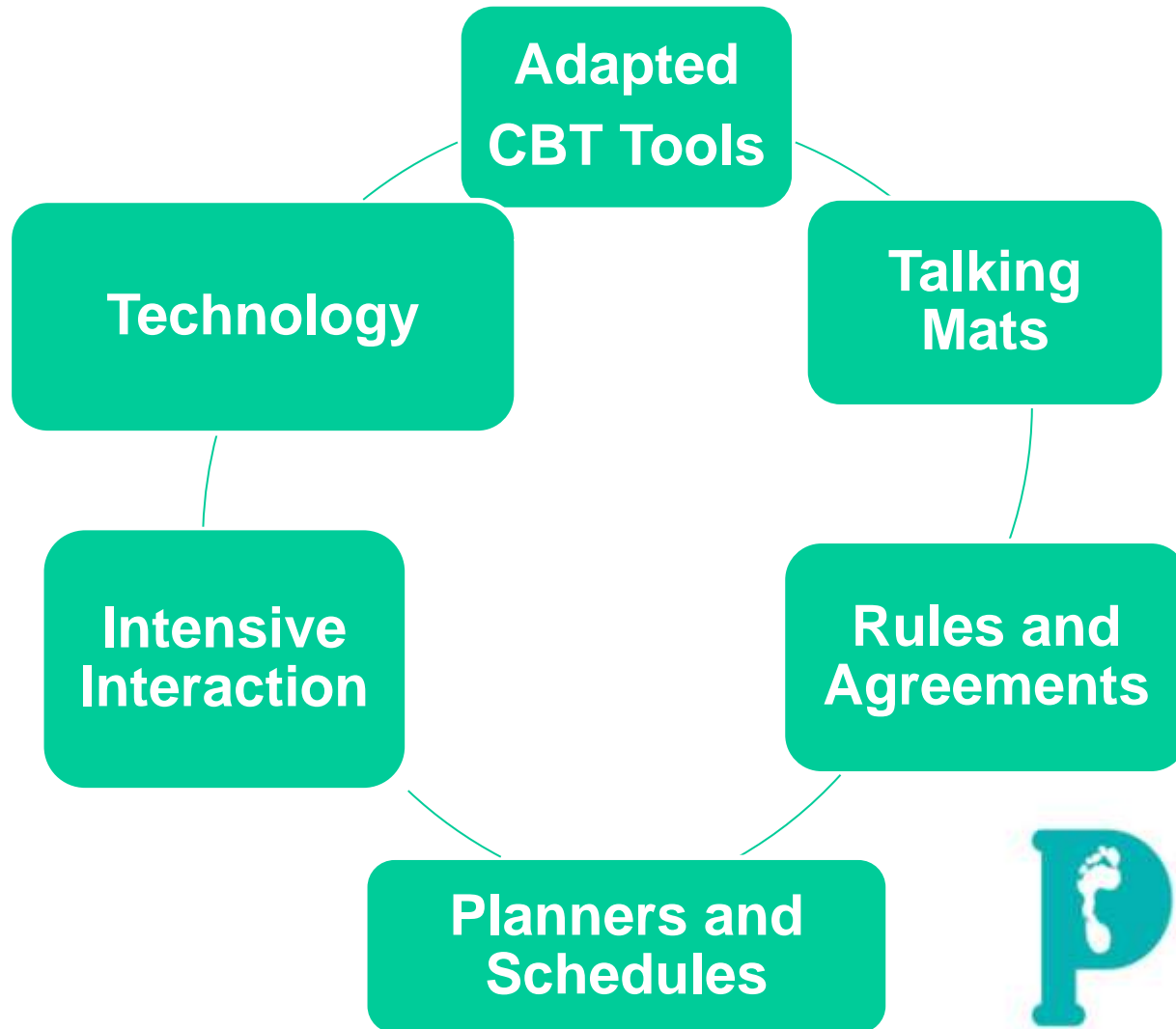
Learning Outcomes

1. To learn about issues of communication in autism
2. To learn about different communication methods
3. To improve understanding of individual's communication

Extract from Communication Exercise

Communication Message	WORDS What words and/or signs do they use?	ACTIONS What does the person do with their facial expressions & body language?
Feels bored		
Is tired		
Is hungry/thirsty		
Feels frustrated		
Feels sad		
Feels angry		

Examples of Communication Resources



Audio Tools



Workshop 4

Social Skills

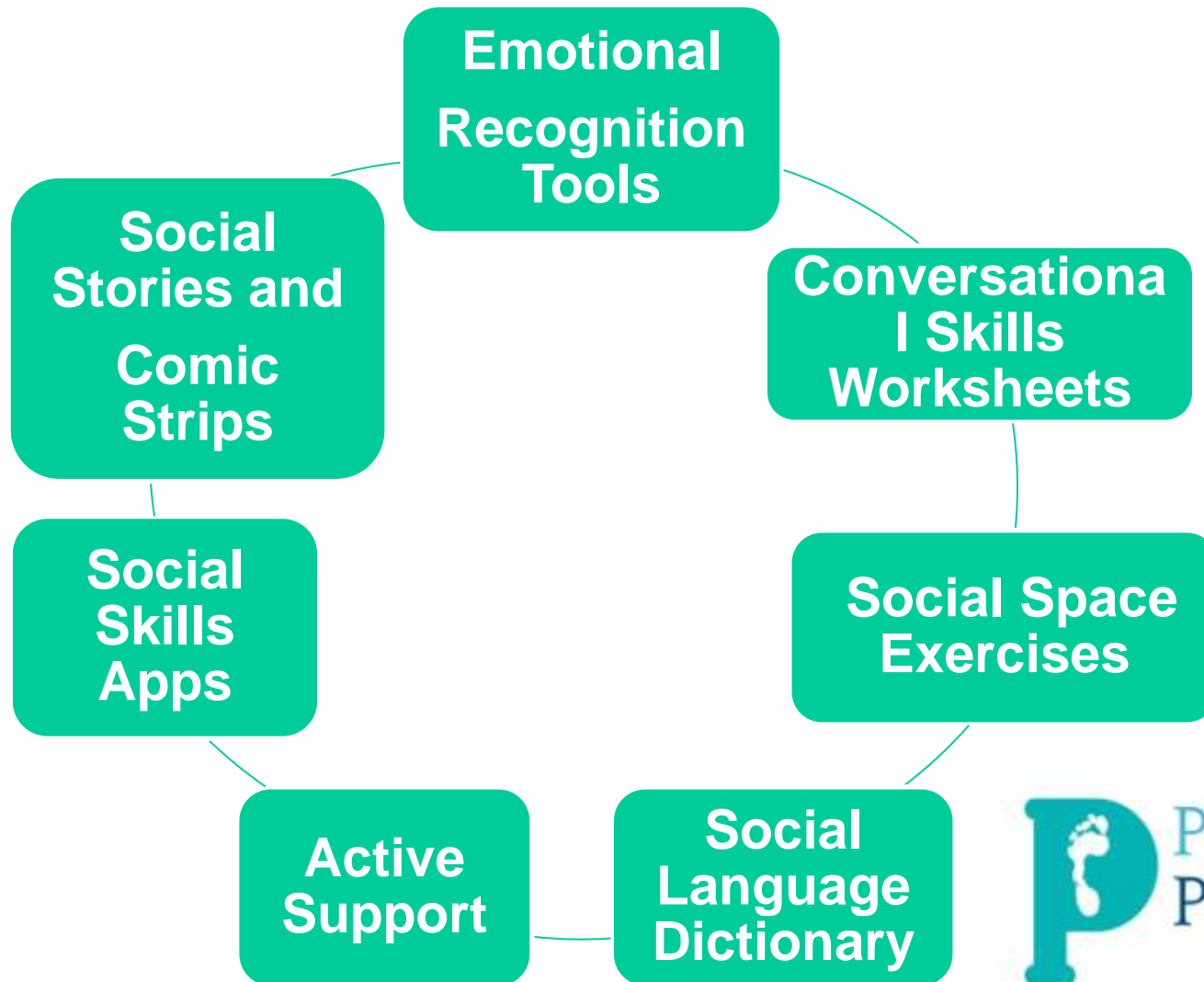
Learning Outcomes

1. To learn about factors that impact on social skills in autism
2. To learn how to support development of social skills

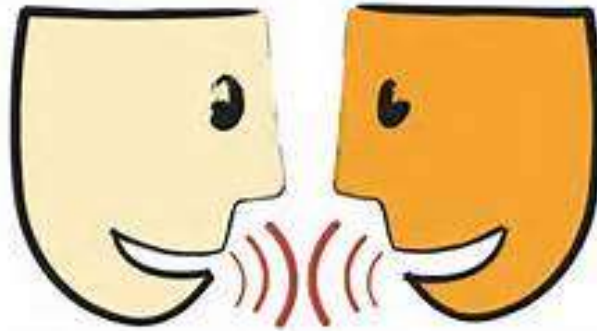
Extract from Social Difficulties Exercise

Areas of Social Difficulty	Examples
1. Difficulties in empathising <input type="checkbox"/> Understanding own and others' feelings and emotions	
2. Difficulties in seeing the whole <input type="checkbox"/> Learning connections between things	
3. Difficulties with doing more than one thing at once <input type="checkbox"/> Retaining information while doing something with it	
4. Difficulties with over systemising <input type="checkbox"/> Obsessional interests with focus on a system	

Examples of Social Skills Resources



Extract from Social Language Notebook



Word	Example	Meaning
Oh couldn't possibly! What are we going to do without you?	I asked manager for annual leave	Manager was being nice and meant that I would be missed, not that I couldn't go on holiday.
Rotten to the core	Susan said an old staff member was "rotten to the core"	Means that Susan doesn't like this person, not that any part of them is rotting.

Workshop 5

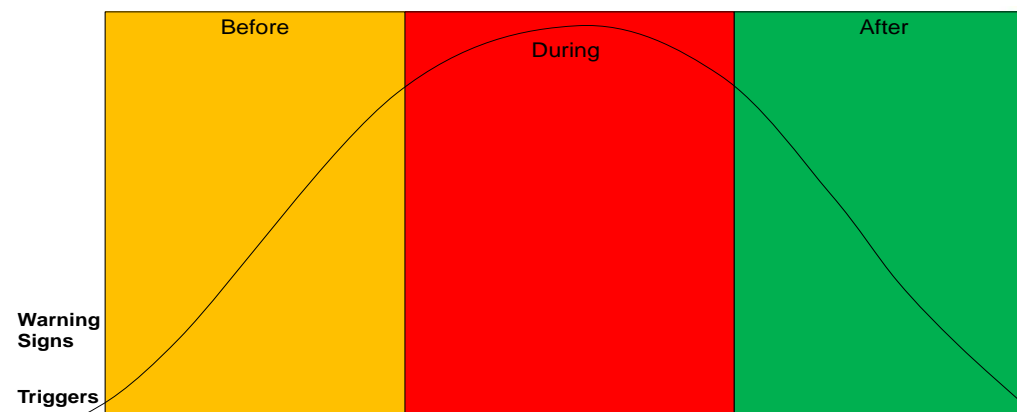
Reactive Planning

Learning Outcomes

1. To learn strategies to use in difficult times
2. To learn how to avoid difficult times

Extract from During a Challenge Exercise

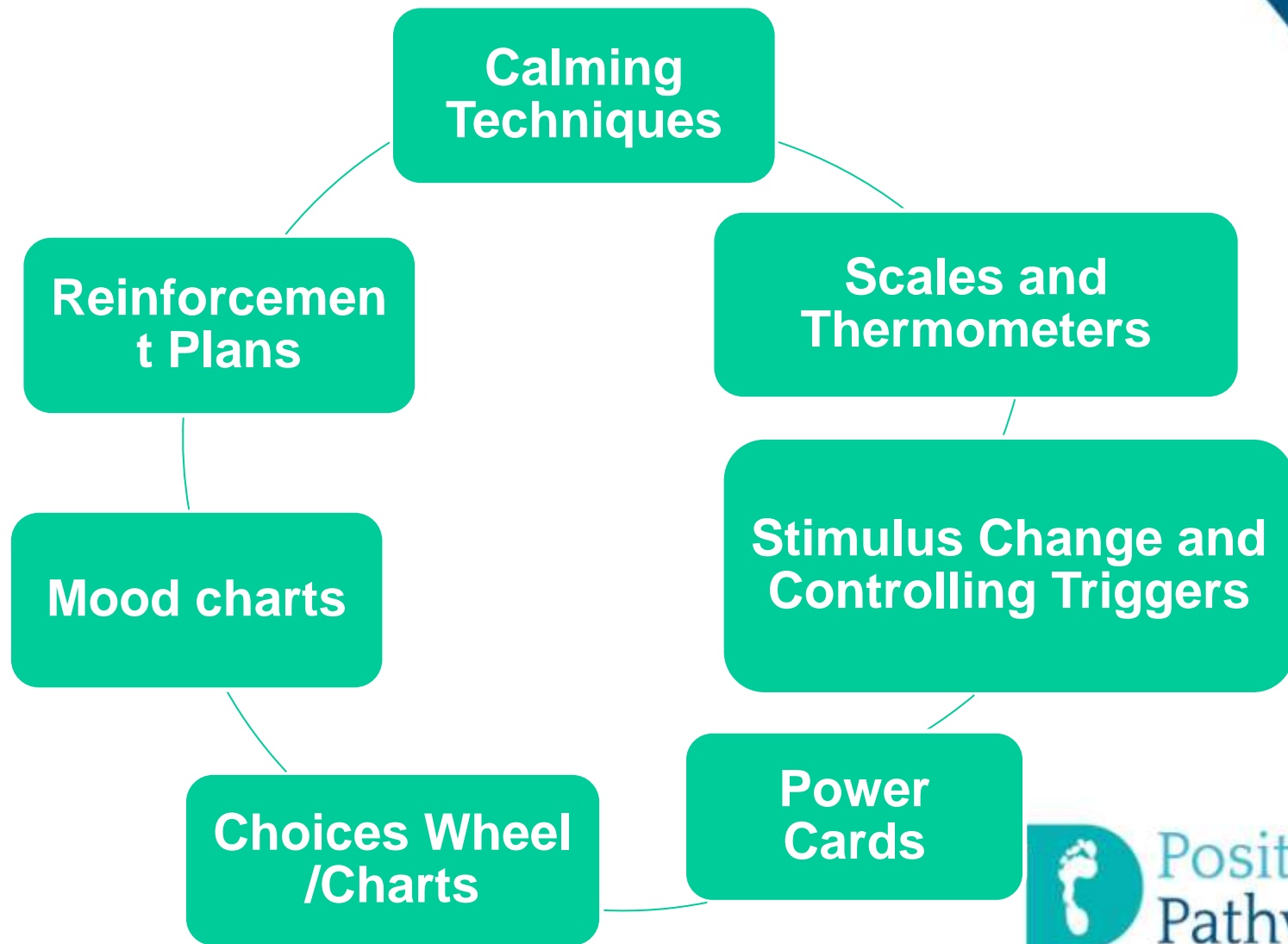
Arousal Curve



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1. What are the warning signs that your family member is likely to challenge?
2. What are the triggers for your family member's challenging behaviour?
3. How do they recover from an incident?

Examples of Reactive Resources



Power Cards



1. Luke Skywalker would be nice to Margaret. Patricia will be nice to Margaret.
2. Luke doesn't shout in church and Patricia doesn't shout in church.
3. Patricia will stay in her seat and look at the minister.

Dundee Group of Carers



Evaluation Process and Findings

Evaluation Tools



- **Aberrant Behaviour Checklist**
- **Stress Questionnaire**



**Three Things
Questions**

Aberrant Behaviour Checklist

(Aman et al, 1985)

- 58 questions to rate the individual's behaviour *over the last four weeks* on a scale between 0-3
- Snapshot of family member's perspective of how problematic the behaviour is
- Questions such as

Talks excessively

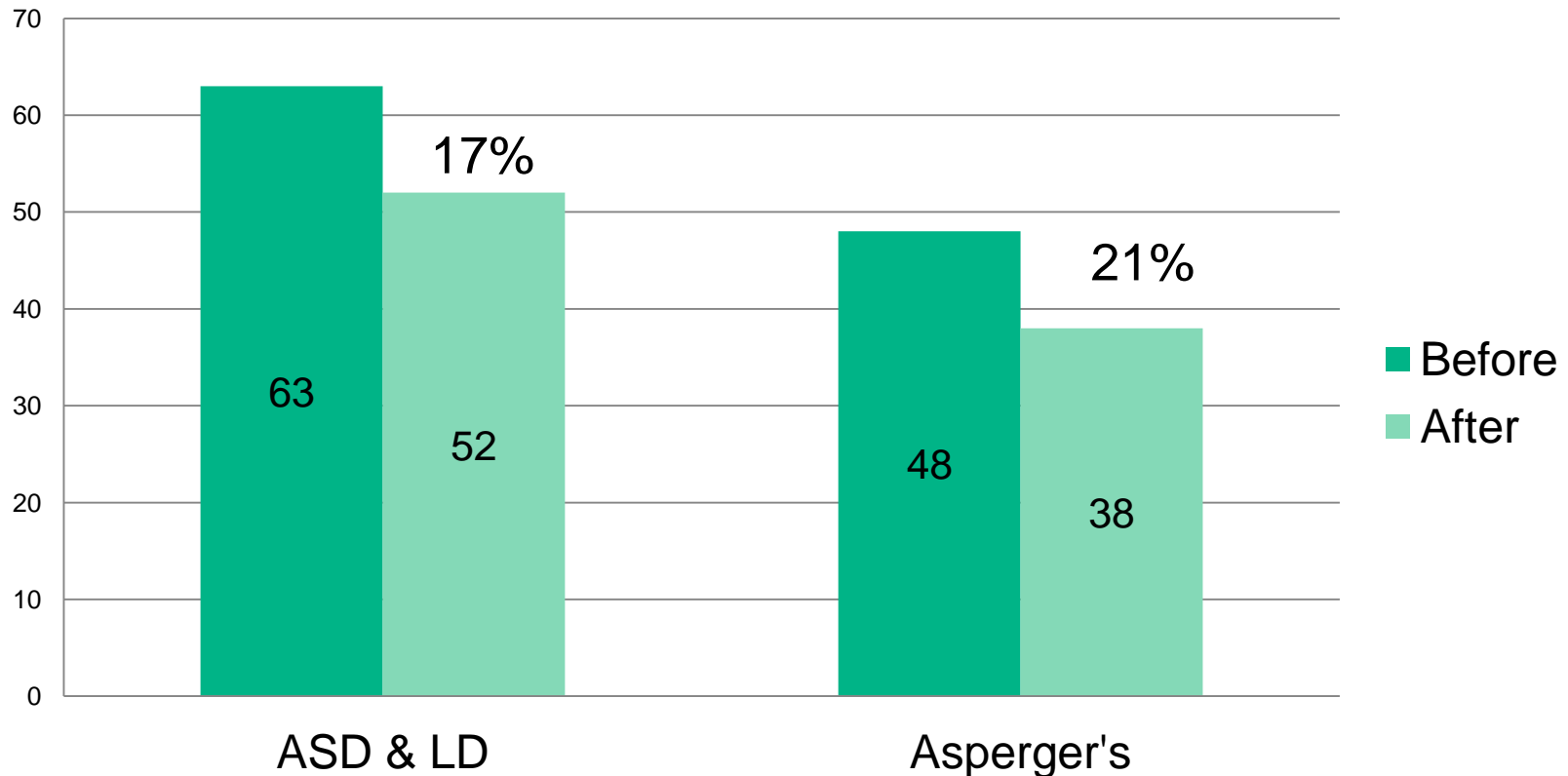
Aggressive to others (verbally or physically)

Seeks isolation from others

Rocks body back and forth repeatedly

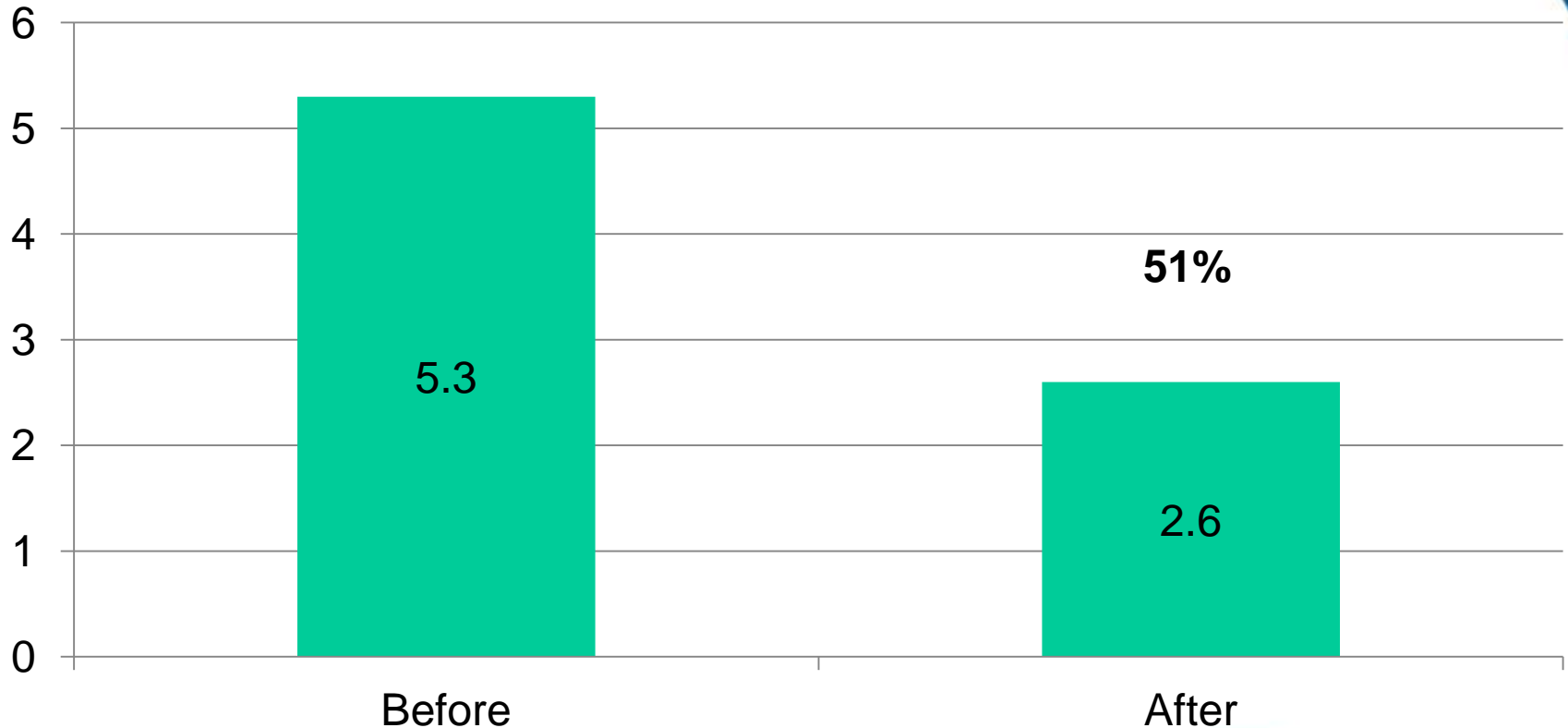
Aberrant Behaviour Checklist

Total Score: by Diagnosis



Aberrant Behaviour Checklist

Severe Behaviours



Quotes relating to behaviour

There has been a marked decrease in biting of fingers when getting ready to go out of the house

Motherwell

I did try the suggestion of using an electric toothbrush and this has made such a difference and his oral hygiene has improved

Shetland

Every thing Mathew has a ritual involved, most rituals are reduced to less than 5 times now, the power cards and contracts helped.

Inverness

Stress Questionnaire

(Holroyd, 1973)

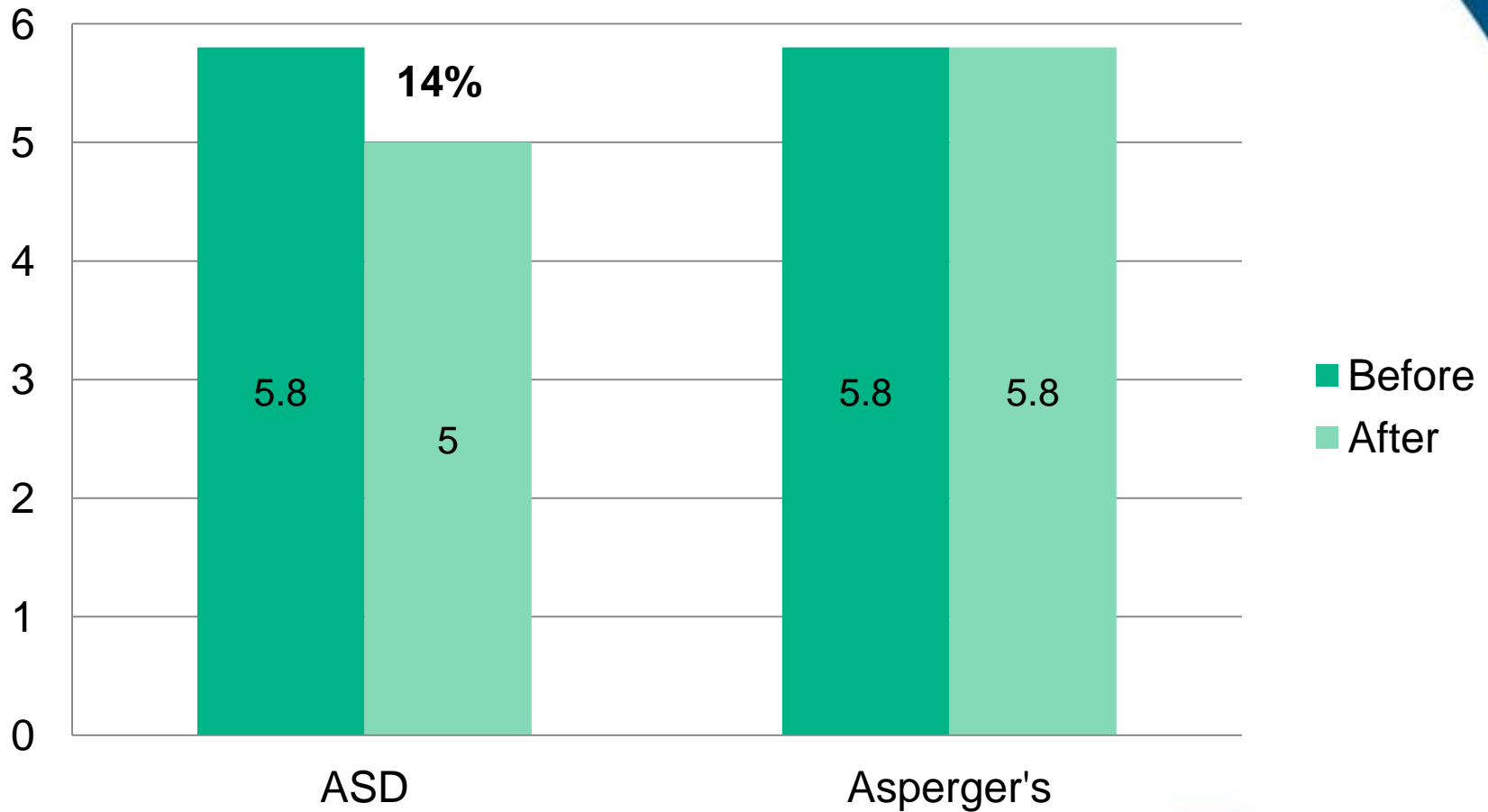
- Adapted from the Questionnaire on Resources and Stress
- Looks at stress for those in a caring role
- 25 questions focusing on their family member's life
- Family carers rate their own feelings of stress, 1-10
- Questions such as

I am worried much of the time

I get almost too tired to enjoy myself

I find it difficult to relax

Average Stress Score by diagnosis



Stress Quotes

Some of the things I learned have helped me in my relationship with Martin.

My approach to dealing with problems has been different. I now always put a positive slant on what I am trying to get across

Edinburgh

Really good way of stepping back and looking at the bigger picture. Come away with hope that things can get better.

Aberdeen

More optimistic about ability to improve our situation, and reduce stress

Stornoway

Telephone Interview

'Three Things'

(MacKay et al, 2007)

- 3 most important areas would like support with
- Follow up phone call to score area from 1-10; level of concern
- Post recordings completed March by post

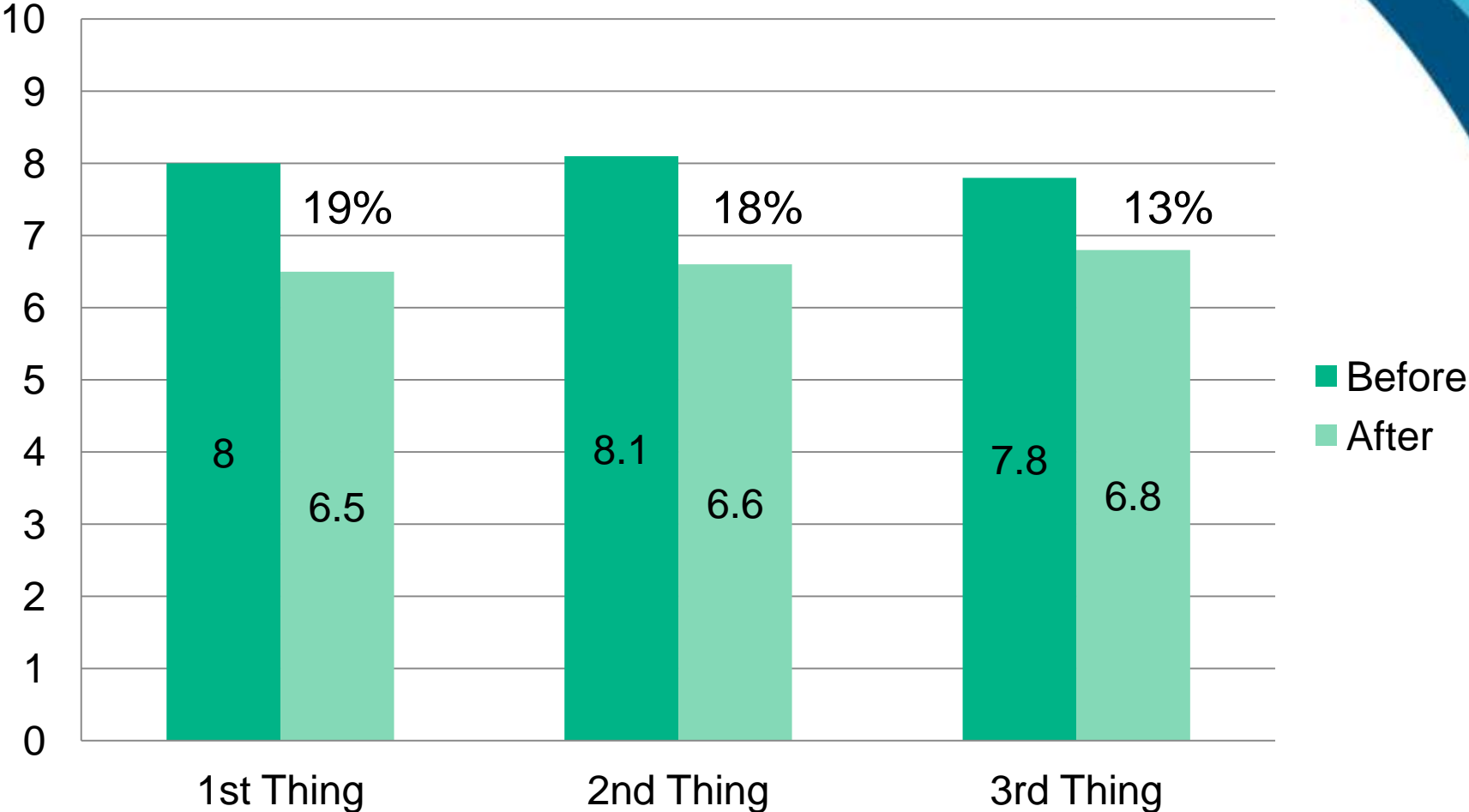
Comments written included

What to do and say when my son is shouting at people

For my daughter to interact with people of her own age

For my son to cope with change

Average Three Things Scores



Three Things Quotes

I wanted to help him socialise with his peers, he now goes to football on Wednesdays

Fife

Because we are understanding her better and pre emptying situations we are having fewer meltdowns. When they do happen I find I can cope with them better.

Inverness

Comments/feedback

My message to the Scottish Government would be to ensure that funding to provide this type of training to allow parents to become more aware and get more involved with the development of the people they care for.

Dunfermline

I have been to a few courses on autism over the last few years and I have to say that this has been the best in terms of its “person centred” approach, delivery and content

Stirling

Helped me to know I am not the only mother living a life dealing and coping with a man with autism and it does get better.

Paisley

Limitations

- Time commitment hard for some carers
- Focus when home on implementing strategies
- More intensive support would have been useful for some
- Difficulties arising between workshops
- Other areas of difficulty out with behaviour

Conclusions

- Reach the most isolated and rural communities
- Increased knowledge of how autism affects behaviour
- Reduction in severity and frequency of behaviour
- Impact on reducing family carers stress
- Improvement in quality of life
- Opportunity for carers support network

Programme Developments

- 2013-2014: new programme model
- Commissioned by City of Edinburgh Council, ASPIRE & PASDA
- Small groups targeted at adults with autism without a LD

PPE Overview

- Intensive input over 3 months
- Shorter sessions – more frequent both day and evening sessions
- Home visits – day/evening
- 1:1 sessions
- Addressing other needs through partnership working

Future Developments

- Continue localised training programmes
- Evaluate Positive Pathways Lothian
- Develop Positive Pathways Lothian for carers of adults with Autism and LD

PBS in Scotland

- Scottish Government paper for people with Learning Disabilities 'The keys to life', PBS is now *the* recommended approach to supporting people who have behavioural difficulties
- Supporting family carers is a key focus of the Scottish Strategy for Autism 2011
- Our findings have shown that positive outcomes can be achieved through training carers in PBS

Acknowledgements

- Scottish Strategy
- Keys to Life
- All the evaluators
- Do2learn site
- City of Edinburgh Council
- PASDA

Thank you

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