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**Ohrid, Republic of Macedonia, October 2013**  
**4<sup>th</sup> International Conference - Modern aspects of the special  
education and rehabilitation of persons with disabilities**

# **Teaching parents to understand and manage the behaviour of children on the autism spectrum**



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# Overview of presentation

- Why is parent education important to help parents manage the behaviour of their children on the autism spectrum?
- What needs to be included in parent education programmes?
  - Understanding of autism
  - Positive behaviour support
  - Dealing with crises/physical intervention
- Research into parent education in the field of autism in the UK
- Benefits of effective parent education

# Northamptonshire



- County in centre of England
- Population – 650,000
- Northampton – 200,000
- Child population – 100,000
- Child population with ASD – approx. 1,000

# Northamptonshire



# University of Northampton



# Impact of autism on the family

- Overwhelming evidence that autism can significantly affect family and family functioning
- Causes greater parental anxiety/stress than any other disability
- Wide range of challenges including:
  - Eating, toileting, self-care
  - Inappropriate social behaviour
  - Sleep issues
  - Impact of fixed routines
  - Behaviour problems

# Autism and challenging behaviour

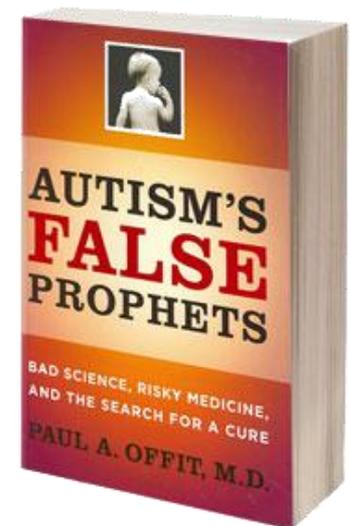
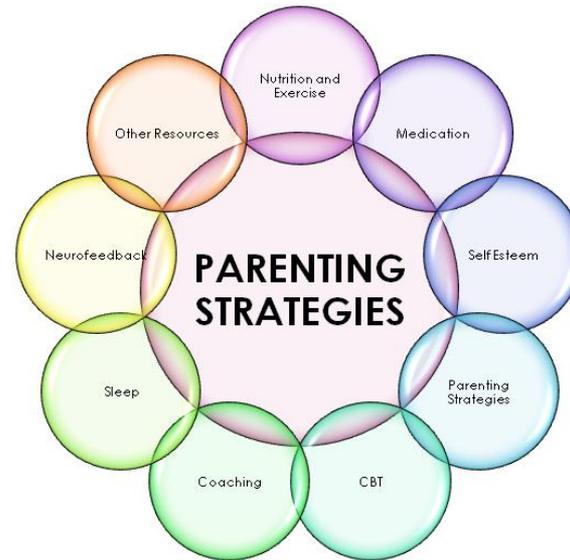
- Association with challenging behaviour
  - More likely to display self-injury, aggression, disruption to environment (McClintock *et al.* 2003)
  - Males more likely than females
  - Some behaviours reduce with maturation; some don't
- Major concern –
  - Murphy *et al.* (2005) Camberwell ( $n=173$ ): temper outbursts (52%); aggression (30%); destructive (30%)
  - Preece (2011) Northamptonshire ( $n=155$ ): 80% of parents reported some challenging behaviour

# Impacts of challenging behaviour

- Reduced likelihood of positive long term outcomes for family and individual
- Reduced family wellbeing
- Social exclusion
- Potential for family breakdown

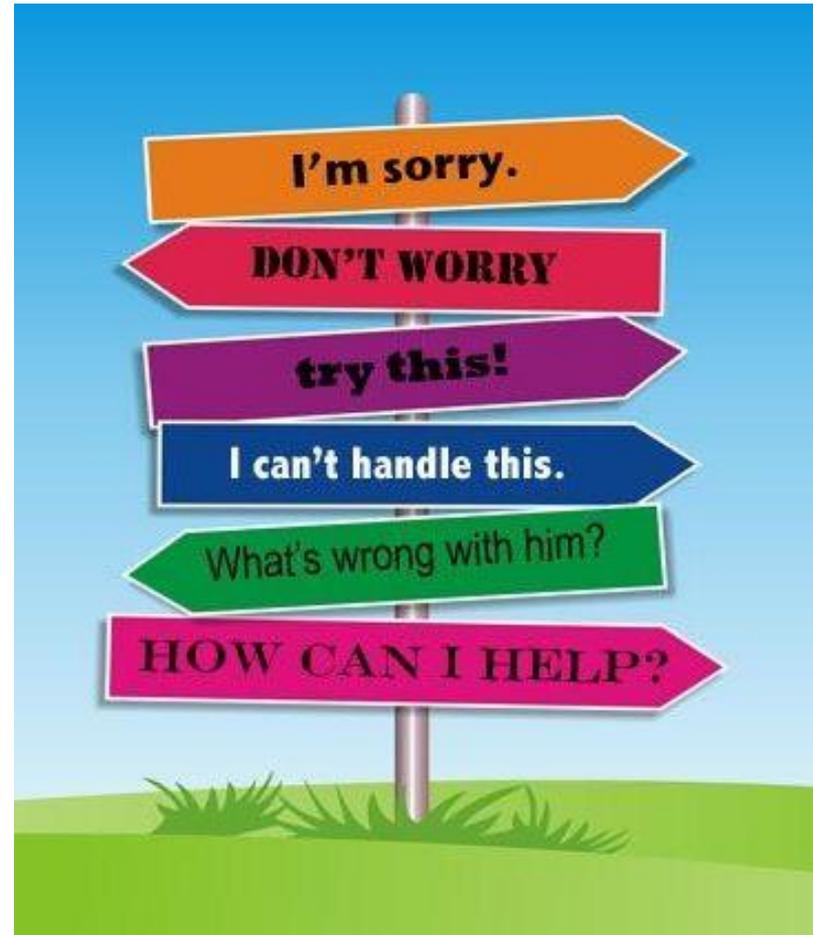
# Parent education

- Parent education – vital in field of autism
- Why?
  - Traditional/typical parenting strategies won't work
  - Develop skills, self-efficacy
  - Internet : minefield of unreliable approaches – so need to teach what is identified good autism practice



# What do parents need to know?

- Same things as professionals:
  - **General information about autism**
  - **Positive strategies for managing behaviour**
  - **Strategies for dealing with crises**



# Information about autism

- Range of basic parent education models in existence
- Some models based on specific intervention approaches
  - TEACCH (e.g. Schopler *et al.*, 1984)
  - ABA (Ingersoll & Dvortcsak, 2006)
- UK and more widely the National Autistic Society EarlyBird programme has provided basic general model (Birkin *et al.*, 2008; Shields, 2001; Whitaker, 2002)
- Basic model
  - Course of weekly sessions, small no. of parents (6-15)
  - Often differentiated by child's age (under-5, 5-12, 13+)

# Information about autism– content of EarlyBird-style model

- What is autism
- Developing social interaction
- Communication
- Restricted interests
- Using structure and visual supports
- Understanding and interpreting behaviour
- Parent/professional issues (e.g. liaison with nursery/school)
- Emotional well-being

# Research into impact

- Educating parents about autism is valued by parents (Whitaker, 2002)
- Shown to reduce parental stress (Brookman-Frazee & Koegel, 2004)
- Benefits maintained over time (Koegel *et al.* , 2002)
- But...problems with attendance, child care, waiting times, access, distance, intrusiveness (Birkin *et al.*, 2008; Ingersoll & Dvortcsak, 2006; Whitaker, 2002)

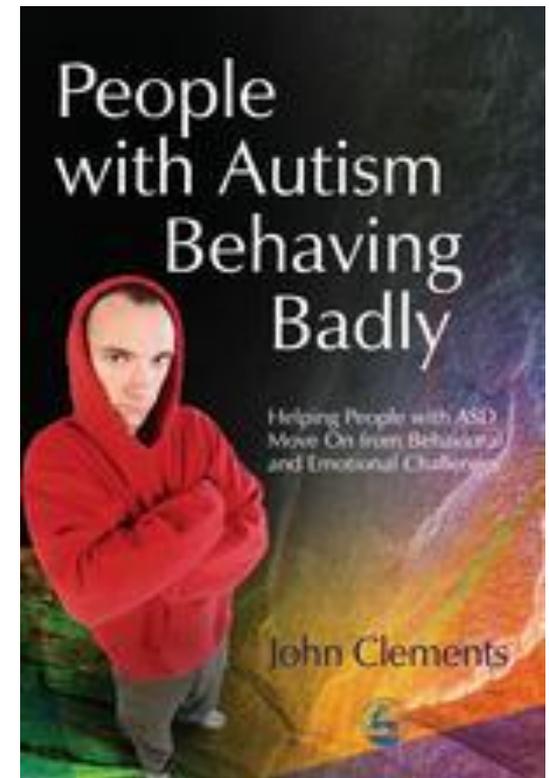
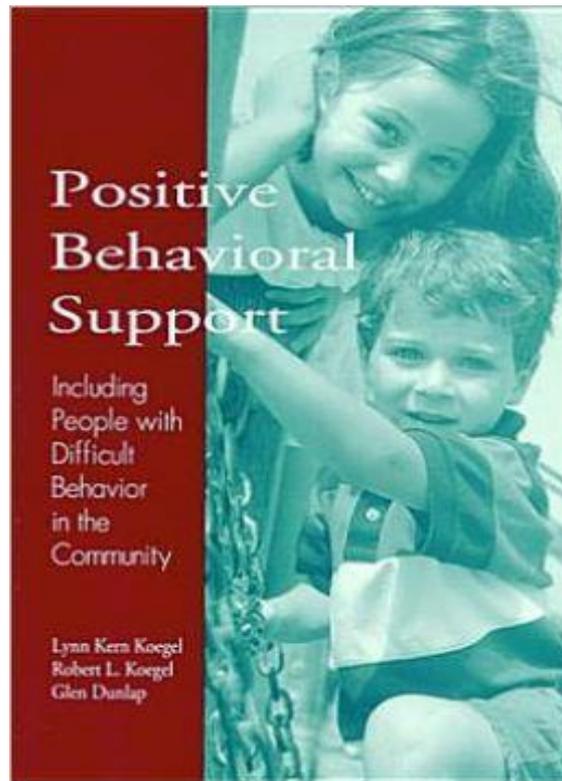
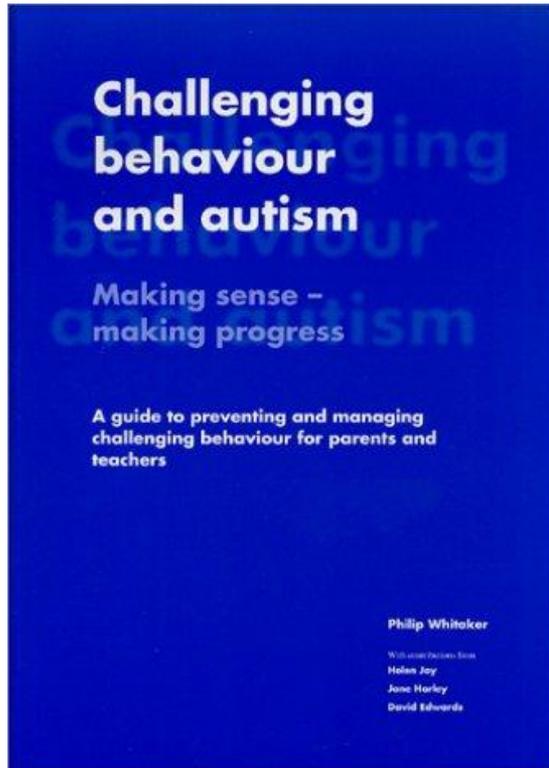
# Positive behaviour support

- Problem-solving techniques to support socially adaptive and appropriate behaviour
- Strategies to bring about long-term change in behaviour – proactive not reactive
- Ethically-based: enable individuals to
  - participate in society
  - make choices
  - improved competence and self-efficacy

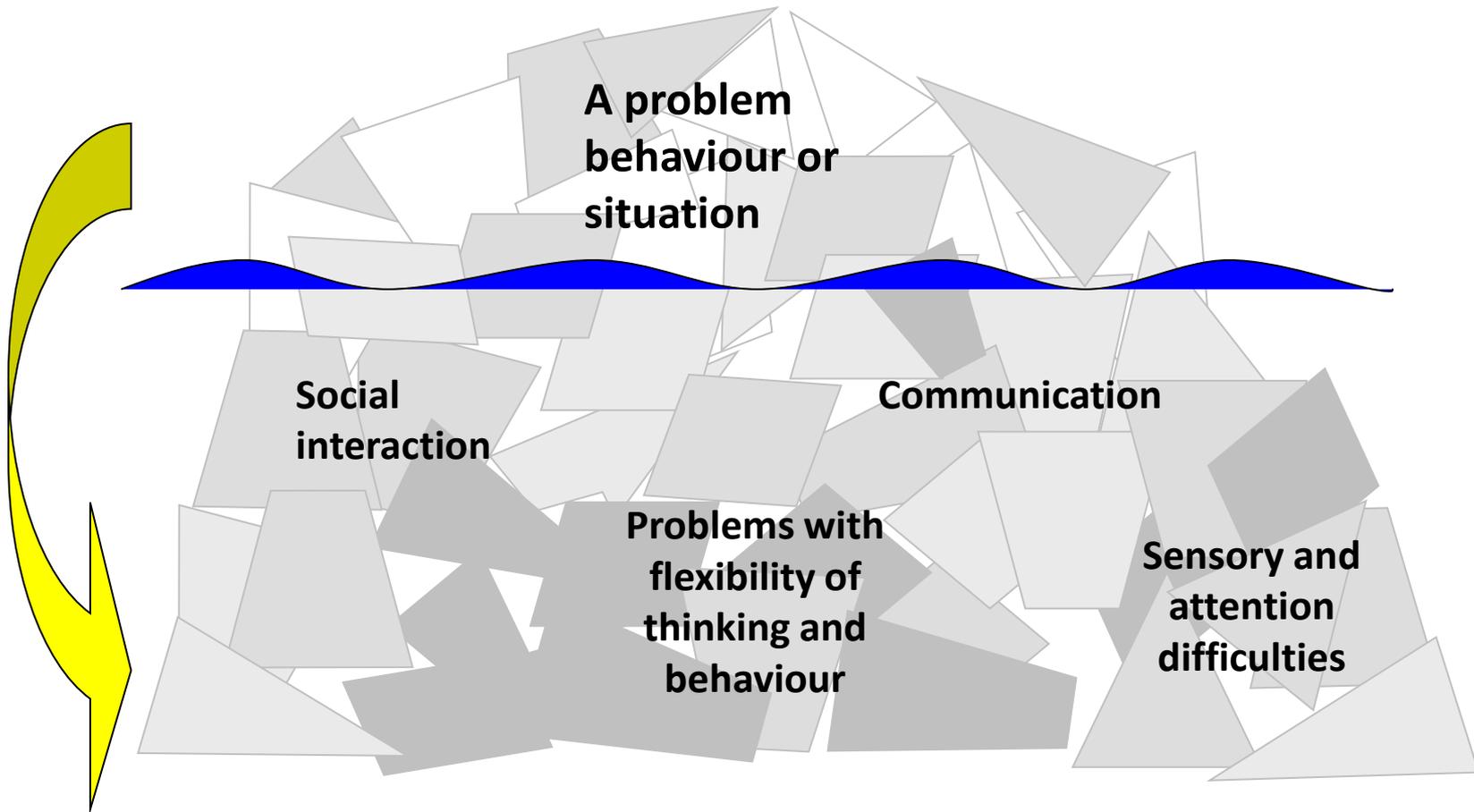
# Positive behaviour support

- Typical approaches based on applied behaviour analysis
- Factors considered include:
  - how to adapt ecological conditions that increase likelihood of undesirable behaviour
  - individual needs (e.g sensory) and communication style
  - using differential and non-contingent reinforcement
  - teaching new socially adaptive strategies to develop individual's social skills

# Positive behaviour support



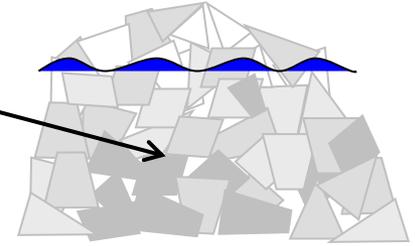
# Understand the autism: look below the waterline



**How do the person's difficulties in each area of the 'triad of impairments' (and sensory issues) affect their ability to cope with what's expected?**

Adapted from Whitaker (2013) in Howley and Preece (eds) *Supporting Pupils on the Autism Spectrum*.  
(Schopler's TEACCH Iceberg model)

**1. Understand the autism: looking below the waterline**



**2. Make sense of the behaviour:  
ask the right questions**

Settings

Triggers

Results

**3. Stop and think—what does it mean:**

- What results is he/she trying to achieve?
- What does it say about how he/she is feeling?

**4. Plan for prevention**

**5. Replace the problem: teach new skills—‘grow’ other behaviour**

**6. Change the results of the behaviour**

# Research into positive behaviour support

- Body of literature identifying benefits of positive behaviour support approaches:
  - Impact on individual's behaviour (Horner et al., 2002)
  - Impact on family (Vaughn et al., 2002)
  - Impact on individual's quality of life (Carr & Horner, 2007)

# Crisis intervention

- As part of a positive behaviour support approach, and to manage incidents/protect individuals, ***crisis intervention*** may be necessary
- Ethical reactive strategies
  - de-escalation and distraction
  - evasion
  - minimal physical intervention techniques: use of force to protect self and others, minimise impact of behaviour and prevent injury

# Crisis intervention: UK situation

## professionals

- Training in crisis intervention techniques mandatory for staff working in educational, nursing and care settings with individuals who display challenging behaviour
- Training must
  - be accredited by British Institute of Learning Disabilities
  - comply with BILD Code of Practice
- Failure to train staff – criminal offence



Physical  
Interventions  
Accreditation  
Scheme

# Impact of training professionals

- Research shows that providing appropriate crisis intervention training:
  - reduces staff burnout, absence and turnover (Mills and Rose, 2011)
  - reduces injuries to staff (Sanders, 2009)
  - reduces overall level of physical intervention and restraint (Luiselli, 2009, Richmond, 2010)

# Crisis intervention: UK situation - parents

- Situation very different
- Despite benefits shown by training professionals, parents often left to fend for themselves
- Why?
  - No legal requirement to provide training
  - Concerns about monitoring & control of interventions, & potential abuse
  - Concerns about liability if children injured
- Result – parents still physically intervening...but without training

# Impact of training parents in crisis prevention techniques

- Little published research into training parents in crisis prevention techniques:
  - Woodcock *et al.* (2006) Qualitative study, reports on training provided to parents of young people aged 7-23
  - Hawkins *et al.* (2009) Five sets of family members, qualitative & quantitative data being collected. Initial outcome data in preparation.
  - Preece (2013) Evaluation study of pilot training course for parents of children on autism spectrum (*discussed in following slides*)

# The training

- Training held at local special school
- 2 x qualified trainers (1 based at school) + support
- 2 x 6 hr sessions, + follow-up at 12 weeks
- 11 adults trained, associated with 8 children
- Children
  - all male
  - Aged 7-11 (mean =9.7, SD=1.3 yrs)
  - 7 diagnosed on autism spectrum, 1 with ADHD

# Content of training

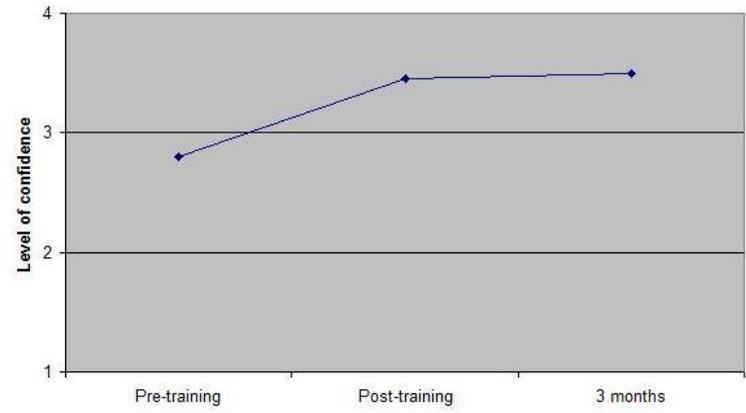
- Positive behaviour support components
  - understanding challenging behaviour, understanding emotions, communication, de-escalation
- Legal issues
  - rights, responsibilities, law concerning physical interventions
- Physical interventions
  - responding to biting & hair-pulling, separating fights, safe holding, safely getting out of holds to arms, neck and body.

# How was the research carried out?

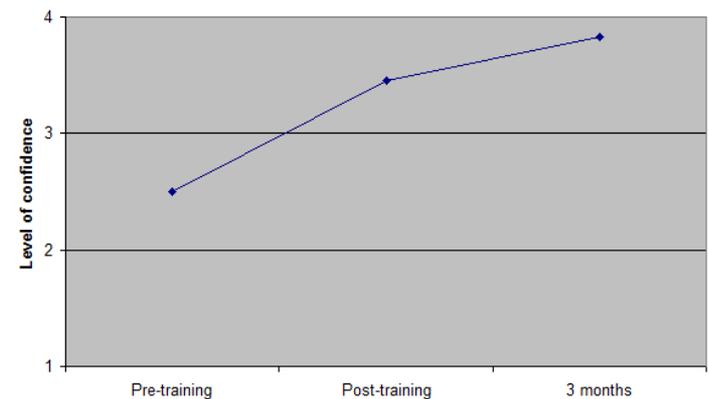
- Participants surveyed via self-completion questionnaire
- before training
- immediately after training
- at 12 weeks
- Qualitative data
  - Intervention log
  - Semi-structured interviews with trainers
- Costings

# Findings

- Participants reported increased confidence in understanding and managing their child's behaviour after training
- Confidence remained above baseline score at 12 weeks



**Confidence in managing child's behaviour**



**Confidence in ability to keep child, family & themselves safe**

# Findings

- Reduction in number of physical interventions
  - pre-training: frequent intervention, 3 children restrained daily
  - post-training: 4 of the 8 families used no interventions over 12 week period
  - used alternative management techniques, e.g. de-escalation, communicating more effectively

# Findings

- What did parents find most helpful?
  - understanding function(s) of challenging behaviour
  - learning positive behavioural approaches
  - knowing how to physically intervene safely gave confidence to try other approaches
  - training alongside other parents
  - association with school & ongoing support
- As with Woodcock *et al.* (2006) promising findings – further research needed

# Conclusions

- Parent education
  - can improve parental self-efficacy, reduce dependence, improve experience of daily life
  - Cost of such support per person compares favourably with other models of support (*e.g. cost of crisis intervention training per person in Preece (2013) study was similar to e.g. 1 x night of respite care*).
- Include as integral part of preventive, proactive strategy?
- Research predominantly UK/US focus – what about elsewhere?
  - Cultural appropriateness (Corbett & Perepa, 2007)
- More research needed to investigate these issues



*Thank you  
for listening*



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