



This work has been submitted to **NECTAR**, the **Northampton Electronic Collection of Theses and Research**.

Conference or Workshop Item

Title: Teaching parents to understand and manage the behaviour of children on the autism spectrum

Creators: Preece, D.

Example citation: Preece, D. (2013) Teaching parents to understand and manage the behaviour of children on the autism spectrum. Keynote presented to: *4th International Conference: Modern Aspects of the Special Education and Rehabilitation of Persons with Disabilities, Ohrid, Macedonia, 17-19 October 2013.*

Version: Presented version

<http://nectar.northampton.ac.uk/5897/>



Ohrid, Republic of Macedonia, October 2013
**4th 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



David Preece PhD, MEd, CSS
Centre for Education and Research
School of Education
University of Northampton



WE ARE NORTHAMPTON.AC.UK

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

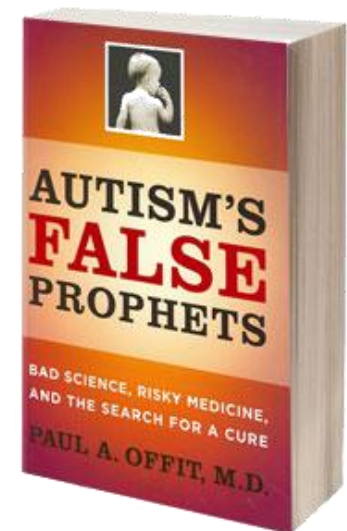
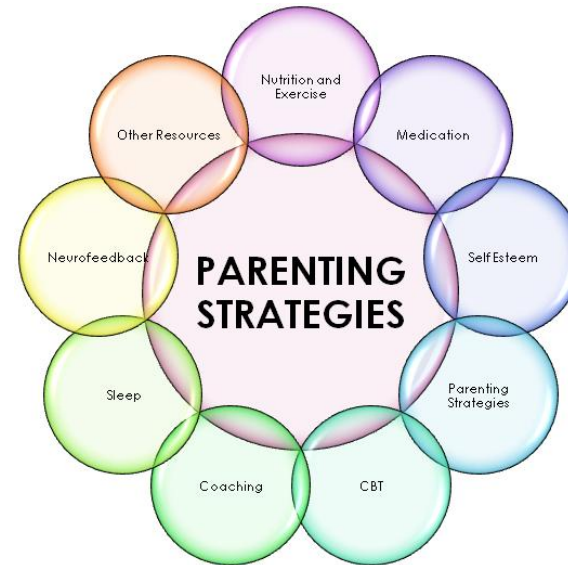
- Association with challenging behaviour
 - More likely to display self-injury, aggression, disruption to environment (McClintock *et al.* 2003)
 - Males more likely than females
 - Some behaviours reduce with maturation; some don't
- Major concern –
 - Murphy *et al.* (2005) Camberwell ($n=173$): temper 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)

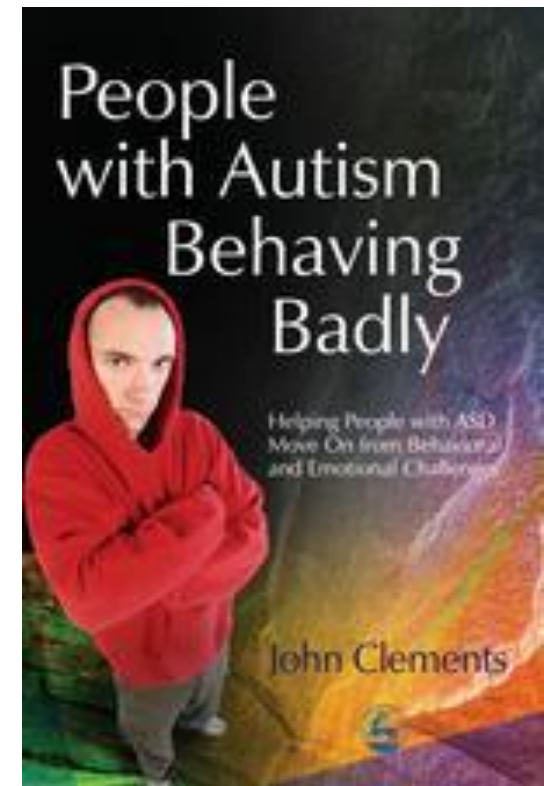
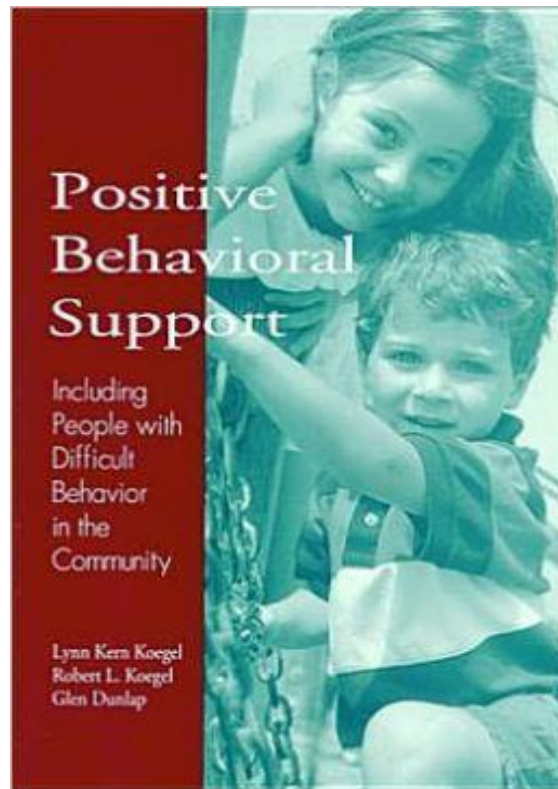
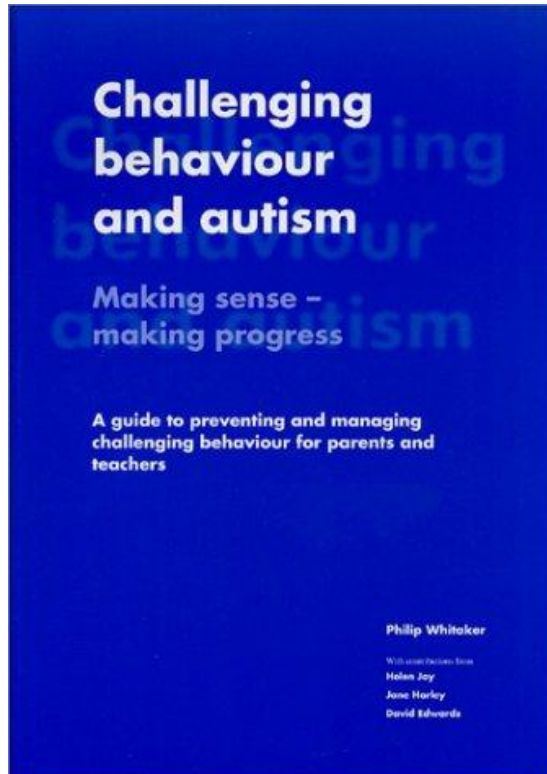
Positive behaviour support

- 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

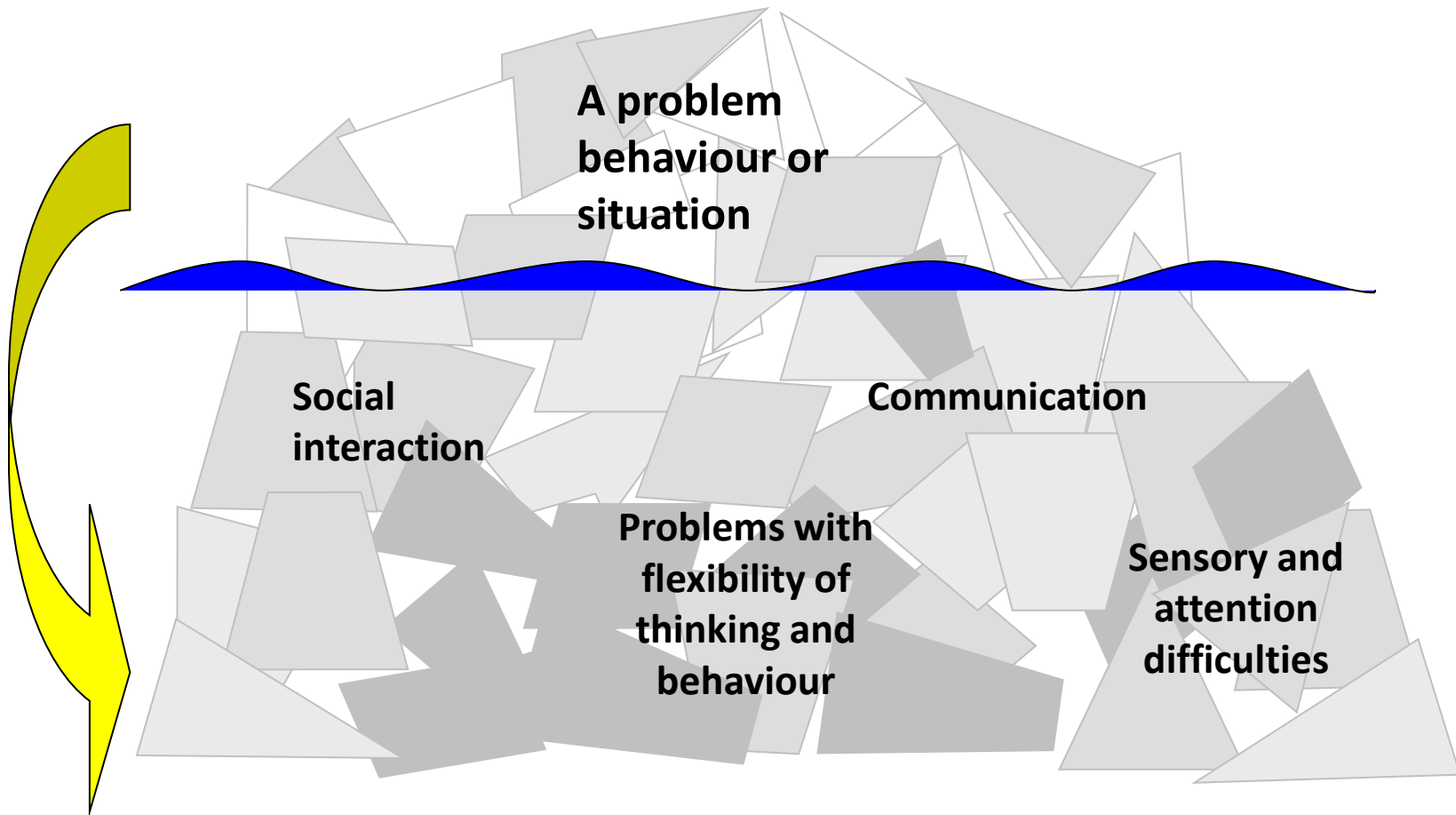
Positive behaviour support

- 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



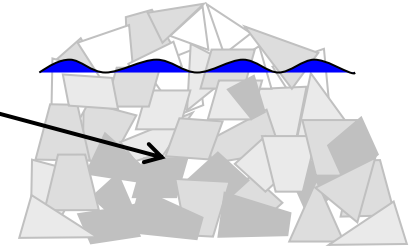
Understand the autism: look below the waterline



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

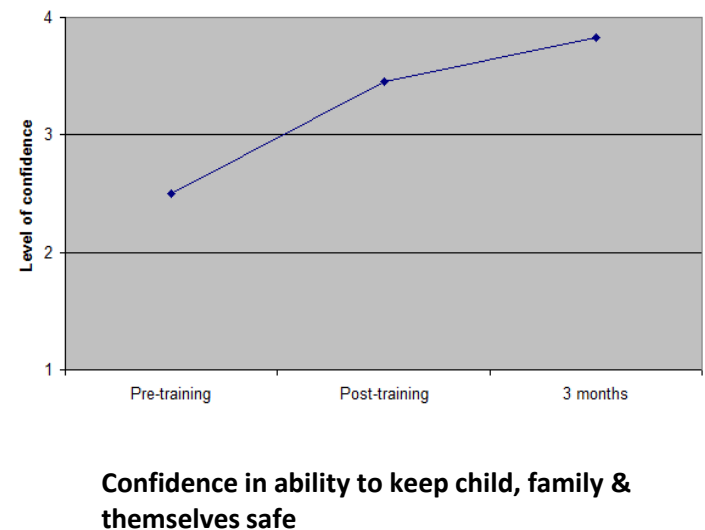
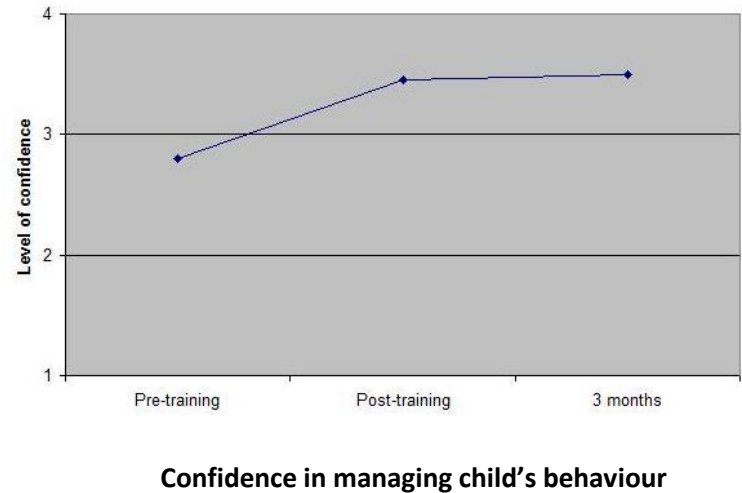
- Positive behaviour support components
 - understanding challenging behaviour, understanding emotions, communication, de-escalation
- Legal issues
 - rights, responsibilities, law concerning physical interventions
- Physical interventions
 - responding to biting & hair-pulling, separating fights, safe 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



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*



WE ARE NORTHAMPTON.AC.UK

Dr David Preece

Senior Lecturer, Centre for Education and Research

School of Education

University of Northampton Park Campus

Boughton Green Road

Northampton NN2 7AL

david.preece@northampton.ac.uk

References

- Birkin, C. *et al.* (2008) A parent-focused early intervention program for autism: who gets access? *Journal of Intellectual and Developmental Disability*, **33**, 108-116.
- Brookman-Fraze, L. & Koegel, R.K. (2004) Using parent/clinician partnerships in parent education programs for children with autism, *Journal of Positive Behavior Interventions*. **6**, 195-213.
- Carr, E.G. & Horner, R.H. (2007) The expanding vision of positive behaviour support. *Journal of Positive Behavior Intervention*, **9**, 3-14.
- Corbett, C. & Perepa, P. (2007) *Missing out? Autism, education and ethnicity: the reality for families today*. London: National Autistic Society.
- Hawkins, S. *et al.* (2009) Physical interventions and family carers. In D. Allen, (ed) *Ethical Approaches to Physical Interventions*. BILD: Kidderminster.
- Horner, R.H. *et al.* (2002) Problem behavior interventions for young children with autism: a research synthesis. *Journal of Autism and Developmental Disorders*, **32**, 423-446.
- Ingersoll, B. & Dvortcsak, A. (2006) Including parent training in the early childhood special education curriculum for children with autism spectrum disorders. *Journal of Positive Behavior Interventions*, **8**, 79-87.

References

- Koegel, R.L. *et al.* (2002) Parent education for families of children with autism living in geographically distant areas, *Journal of Positive Behavior Interventions*. **4** 88-103.
- Luiselli, J.K. (2009) Physical restraint of people with intellectual disability: a review of implementation reduction and elimination procedures. *Journal of Applied Research in Intellectual Disabilities*, **22**, 126-134.
- McClintock, K. *et al.* (2003) Risk markers associated with challenging behaviour in people with intellectual disabilities: a meta-analytic study. *Journal of Intellectual Disability Research*, **47**, 405-416.
- Mills, S. & Rose, J. (2011) The relationship between challenging behaviour, burnout and cognitive variables in staff working with people who have intellectual disabilities. *Journal of Intellectual Disability Research*, **55**, 844-857.
- Murphy, G. *et al.* (2005) Chronicity of challenging behaviours in people with severe intellectual disabilities and/or autism. *Journal of Autism and Developmental Disorders*, **35**, 405-418.

References

- Preece, D. (2011) *Autism, Family Life and Short Breaks*. Saarbrücken: VDM Verlag Dr Müller.
- Preece, D. (2013) Providing training in positive behavioural support and physical interventions for parents of children with autism and related behavioural difficulties (*under review*).
- Richmond, D. (2010) Reducing and eliminating restraint of people with developmental disabilities and severe behaviour disorders: an overview of recent research. *Research in Developmental Disabilities*, **31**, 1142-1148.
- Sanders, K. (2009) The effects of an action plan, staff training, management support and monitoring on restraint use and costs of work-related injuries. *Journal of Research in Intellectual Disabilities*, **22**, 216-220.
- Schopler, E. *et al.* (1984). Helping autistic children through their parents: the TEACCH model. In. E. Schopler & G.B. Mesibov (eds) *The Effects of Autism on the Family*. New York: Plenum,

References

- Shields, J. (2001) The NAS EarlyBird programme: partnership with parents in early intervention. *Autism*, **5**, 49-56.
- Vaughn, B.J. *et al.* (2002) Family-centered intervention to resolve problem behaviors in a fast-food restaurant. *Journal of Positive Behavior Interventions*, **4**, 38-45.
- Whitaker, P. (2002) Supporting families of preschool children with autism. *Autism*, **6**, 411-426.
- Whitaker, P. (2013) Challenging behaviour and autism: prevention and management. In M. Howley & D. Preece (eds) *Supporting Pupils on the Autism Spectrum*. London: Optimus.
- Woodcock, L. *et al.* (2006) Parent training on the management of challenging behaviour that we nearly didn't do! *Good Autism Practice*, **7**, 7-42.