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Conference or Workshop Item

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

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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

Adapted from Whitaker (2013) in Howley and Preece (eds) *Supporting Pupils on the Autism Spectrum*
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
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
  – 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

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