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**Conference or Workshop Item**

**Title:** Effective respite care for families with children with autism spectrum disorders

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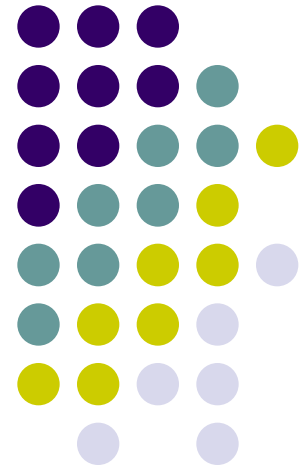


# Effective respite care for families with children with autism spectrum disorders

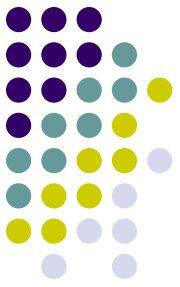


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# Value and benefits of respite care – short breaks from providing care



- Benefits to families
- Benefits to children with autism spectrum disorders (ASD)
- Benefits to service providers and the state

# Benefits to families



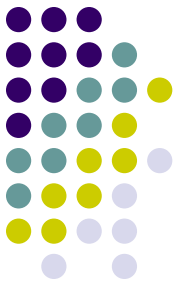
- Effective respite care reduces family stress
- Provides support – families with children with ASD at risk of limited informal social support
- Allows time for activities that cannot be undertaken with child with ASD

# Benefits to child with ASD



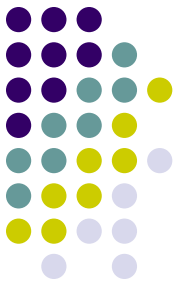
- Positive experiences
- Social and educational opportunities
- Steps towards greater independence and adulthood

# Benefits to service providers/state

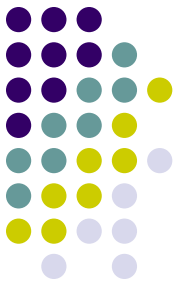


- Can help families continue caring for child with ASD
  - Reduction in family breakdowns / out-of-home placements
  - Financially, ethically & practically more effective
- When child remains in local community, easier to plan for adulthood

# However - obstacles to effective respite care



- Inappropriate services – trying to fit children with ASD into generic disability services
- Inadequate levels of service availability
- Eligibility criteria
- Understanding and attitudes of ‘gatekeepers to services’



# Impact of ASD

- Impact of the triad
  - Social interaction
  - Communication
  - Restricted interests, need for routine and sameness
- Sensory issues
- Inconsistent skill profile – splinter skills and difficulties



# Limitations of respite services regarding children with ASD



- **Children with highest levels of dependence and/or challenging behaviour:** least likely to access services
- Lack of appropriate services
- Problems with:
  - exclusion;
  - service-user mix;
  - activities;
  - staff skills and understanding;
  - ecological factors



# ASD – a separate case

- Evidence from education – children with ASD benefit from specialist adapted approaches
  - Teaching
  - Environment
  - Communication
- Norms appropriate for children with special needs – may not apply to them (R. Jordan & G. Jones, 1997)
- Equally true regarding social care provision



# The Northamptonshire approach to providing services for people with ASD

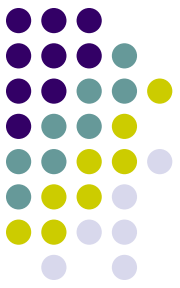
- From 1990 - multidisciplinary strategy & approach, underpinned by use of **TEACCH**
- Integrated network of services, in
  - Education
  - Children's Services
  - Adult Services
  - State and voluntary sectors

# Respite care



- Breaks in a family setting (family-based)
- 6 place autism-specific residential service

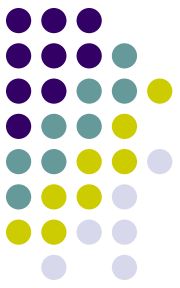




# Quality of services

- Positive external inspections
- Identified as effective by external government audit
- Cited as exemplars of good practice by UK government departments
- Consult to/provide training to other parts of UK
- Research indicates high parental satisfaction

# What helps in respite care for children with ASD?



- Attention to ecological factors – visually clear environment, low arousal, mix/number of children
- Staff attributes
- Consistency with other settings (e.g. school)
- Use of ASD-appropriate approaches (e.g. TEACCH, PECS, Social Stories™)
- Individualisation

*(D. Preece, 2000; D. Preece and R. Jordan, in preparation)*