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

Conference or Workshop Item

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

Creators: Preece, D.


Version: Presented version

http://nectar.northampton.ac.uk/5818/
Effective respite care for families with children with autism spectrum disorders

David Preece MEd CSS
Northamptonshire County Council / University of Birmingham
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)