Conference or Workshop Item

Title: Respite care (‘short breaks’) for families that include young people on the autism spectrum

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Respite care (‘short breaks’) for families that include young people on the autism spectrum

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Focus of presentation

- Overview of respite care (‘short breaks’)
- Why specialist services for autism?
- What works in respite care for families that include young people on the autism spectrum?
Northamptonshire

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

- 1978 – present
- Hospital, social care settings with adults and children
- Manage autism social care services in Northamptonshire
- Part-time lecturer at ACER, University of Birmingham
- Work with Division TEACCH, UNC-Chapel Hill
What is respite care?

- Service that provides positive, enjoyable opportunities to the disabled young person and their family
- Gives the family a break from caring, chance to relax
- Gives young person time away from family
Historical perspective

- C19 – early C20: institutions and long-stay hospitals
- Post-1945: mostly hospital-based support
- 1970s: beginning of ‘social services’ support. First respite care services in community
- 1979: First family-based services
- 1993: First autism-specific respite care service (Northamptonshire)
Respite care – short breaks from providing care

- Benefits to families
- Benefits to children on the autism spectrum
- Benefits to local government and the state
Benefits to families

- Effective respite care reduces family stress and help families stay together

- Provides support – families that include young people on the autism spectrum are at risk of limited support from family, friends and neighbours

- Allows time for activities that cannot be undertaken when the young person on the autism spectrum is at home

- Benefits for siblings – parental attention and time, chance for social life, break from caring role
Benefits to the young person on the autism spectrum

- Positive experiences
- Social and socio-educational opportunities
- Steps towards greater independence and adulthood
Benefits to local government and the state

- Can help families continue caring for child on the autism spectrum
  - Reduction in family breakdowns / out-of-home placements
  - Financially, ethically & practically more effective

- When child remains in local community, easier to plan for adulthood

- Financial saving: current UK services save govt £35.5m per year across social care, health and education budgets (*Action for Children 2009*)
Problems in respite care services regarding young people on the autism spectrum

- Young people with highest levels of dependence / challenging behaviour: least likely to access services
- Lack of ‘autism-friendly’ services
- Problems with:
  - exclusion
  - service-user mix
  - activities
  - staff skills and understanding
  - environmental factors
Autism – a separate case?

- Evidence from education – young people on the autism spectrum benefit from specialist adapted approaches
  - teaching
  - environment
  - communication

- Norms appropriate for children with special needs – may not apply to them (Jordan & Jones, 1997)

- Equally valid regarding social care provision
What did we do in Northamptonshire?

- Worked together – local government, NGOs, families, teachers, social workers, speech therapists
- Consistent use of evidence-based approaches across settings – TEACCH, PECS, Social Stories
- Continuum of support
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
Continuum of support

- Autism Family Advisory Team – empowering families, teaching skills
- 82 Northampton Road – providing breaks from caring
- Arnold House – home while it is needed
Autism Family Advisory Team

- Empower families to understand autism and use effective approaches
- Range of interventions – surgeries > direct work in real time
- Assess > develop resources > model > teach family > support
Intermediate stay home – Arnold House

- 6-bed home for young people aged 8-18
- Home while needed (1 month – indefinite stay)
- Focus of work –
  - development of independent living skills
  - positive behavioural support
  - positive family relationships
Residential respite care – 82 Northampton Road

- 6-bed home, providing residential breaks to over 40 young people (5-18 yrs), open 360 nights per year
- Breaks pre-booked – level of care dependent on family’s assessed level of need, young person’s age/needs/wishes & bed availability
Making respite care work: factors associated positively with high quality respite services

- Physical environment
- Consistency
- Use of ASD-appropriate approaches
- Staff attributes + understanding of autism
- Individualisation
- Activities available/accessing the community
- Grouping of children

(Precece 2009)
1. Physical environment

- Strengthened glass
- External security
- Lighting and water
- Flooring and walls
- Space – clear purpose, labelled
- Transition area
- Gardens + activities
- Storage
- Furniture
2. Consistency

- Consistent use of same structure, approaches + positive routines between school, respite and home settings
- Identified ‘key worker’
- Regular liaison and meetings
3. Use of ASD-appropriate approaches

- TEACCH
- PECS (Picture Exchange Communication System)
- Social Stories
4. Staff attributes and understanding of autism

- Imaginative, flexible
- Able to adapt communicative style
- Able to adapt social interactive style
- Good team-workers
- Humility
- Training in autism, TEACCH, PECS, Social Stories, low arousal, behavioural intervention
5. Individualisation

- Initial assessment
- Risk assessments / placement plan / care guidelines (key worker, family, school)
- Sensory perceptual assessment
- Ongoing assessment and review
Individualised supports

- All young people have individualised programmes & schedules to meet their individual needs

- Individualised communication systems – from objects to written
6. Activities and accessing the community

- Wide range of activities available
  - in the respite home
  - in the community
Individualised activities

- Ensure young people’s activities are built around their interests, strengths and sensory profile
Structuring activities

- Structure up activities to provide:
  - organisation
  - instruction
  - clarity
Taking structure into the community

- Ensuring that appropriate structure is taken out and about
- Minimises children’s anxieties in a confusing world
- Clarify finish

Going out - Thursday Evening
Shoes and coat on
Minibus
Hollywood Bowl
One game of bowling
One drink
Minibus
82 Northampton Road
Check schedule in hall
7. Grouping the young people

- Young people use the service with
  - others they can tolerate
  - common interests + skills
- Enables group activities to occur
- Fun