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Conference or Workshop Item

Title: Ascertaining the views of individuals with ASD using structure and visual supports

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Version: Presented version

http://nectar.northampton.ac.uk/5821/
Ascertaining the views of individuals with ASD using structure and visual supports

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Content of this workshop

- Look at some of the problems in getting the views of children on the autism spectrum
- Talk about two in-depth research studies carried out
- Identify what helps
- Give you the chance to think about how you can use this information in your work
Ascertaining views of disabled children and adults

- Required across educational and social care settings, e.g.
  - Code of Practice on the Identification + Assessment of Special Educational Needs 2002
  - Valuing People (2001)
Growing body of literature on consultation

But...

- emphasis largely upon values + principles
- tendency to consider ‘disabled children’ as homogeneous group.

As a result:

- bias towards those with whom consultation easiest...not those with ASD
Tools for consultation

- Off-the-shelf resources and toolkits are available.
- But they may be inappropriate/will almost certainly need to be adapted and individualised.
Number of helpful studies

- Germain – ‘Talking Mats’ approach
- Taylor – Involving children with MSI in person-centred planning
- Ware - PMLD
What about ASD?

Autistic spectrum disorders - 3 main features

- impaired **social** interaction
- **communication** impairments
- **restricted** range of interests + activities

These impairments inevitably affect our ability to effectively ascertain their views.
The research

2 studies

a) Classroom-based consultation study (Preece, 2002)
b) Consultation in family home (Preece and Jordan, 2010)

Research carried out with children and young people, but applicable across children and adults
Classroom-based study - focus

- Child’s experience of short breaks (respite care)
  - child’s level of consultation + involvement
  - activities available
  - quality of care
  - enjoyment
Classroom-based study - data collection: multiple methods

- Semi-structured interviews (parents + teachers) pre-consultation
- Field notes of observation (short breaks unit + school)
- Results of consultation sessions (notes, tape)
- Teacher’s field notes from short breaks unit
- Semi-structured interviews (with teachers) post-consultation + residential workers
- Documentary evidence: daily notes, files
Classroom-based study

- Consultation carried out by class teachers
- Research sample – 3 children, all of whom attended short breaks
  - A (12) Attends ASD unit in SLD school
  - B (7) ASD unit in Lower School
  - C (14) ASD unit in MLD school
Classroom-based study - How did the teachers carry out the consultation?

- A: observation visits to short breaks provider
- B: ‘consultation’ as part of schedule: visually organised tasks (at 1:1) structured conversation with visual prompts (quiet area)
- C: structured conversation at question time (-/+ photos)
Home-based study - focus

- Factors associated with why families used or didn’t use short breaks (respite care)
- Consultation undertaken with mothers, fathers, siblings and children with ASD (14 families, 44 interviews) – users and non-users of short breaks
- Children with ASD –
  - Family life
  - Likes and dislikes
  - ‘Respite care’ / professionals
  - Wishes
Home-based study - data collection: multiple methods

- Semi-structured interviews with mothers, fathers, siblings and children with ASD
- Field notes of observation (short breaks providers and in the child’s home)
- Semi-structured interviews with short breaks providers
- Documentary evidence: daily notes, files, social workers’ assessments
Home-based study

- Consultation carried out by researcher
- Research sample - 14 children, aged 7-18
  - 2 x Asperger Syndrome
  - 1 x Semantic Pragmatic Disorder
  - 6 x ASD
  - 2 x Autism
  - 3 x SLD/ASD
- Education settings - schools for children with moderate>severe learning difficulties (10); FE college (1); mainstream (2); special unit in mainstream secondary school (1)
Home-based study - How did I carry out the consultation?

- 2 children with SLD/ASD – could not give consent therefore observed only (in family home & short breaks setting)
- the remaining 12 children – in family home
  - Initial visit – whole family together (meeting + planning session)
  - Second visit: 5 children interviewed alone, 7 with at least one parent present
- 3 children – no visual supports (parental decision)
How did characteristics of ASD impact on consultation process? (1)

Major issues:

- Problems regarding social interaction
  - Social anxiety
  - Aloofness
  - Problems concerning emotional responses to situations/using these to evaluate events
  - Problems concerning contexts
How did characteristics of ASD impact on consultation process? (2)

- Problems regarding communication
  - Limited / idiosyncratic language use
  - Poor initiation skills
  - Cue-dependence
  - Extended processing time
  - Distress at communicating
  - Phenomenon of recency
  - Echolalia
How did characteristics of ASD impact on consultation process? (3)

- Impairments of imagination/need for routine / resistance to change
  - Poor autobiographical episodic memory
- Overselectivity
- Dislike of change
- Need for concreteness
Other factors impacting on the process

- Parents/carers butting in – due to processing issues / habit
- Interviewer rephrasing
- Acquiescence to adults/carers
  - Agreeing with carers
  - Trying to give the ‘right’ answer
What was helpful?

1. Presenting information visually

- Letting the children know, in advance, who I was what I wanted to know, and why
- All children in home-based study had letter with my photo, explaining the research
- Letters differentiated for younger/older children
What was helpful?

1. Presenting information visually

- This photo was e.g. put on children’s schedules
- If child could not read, parents asked to communicate information to child

NB. Meant I had to keep same haircut etc. for period of interviews!
What was helpful?

2. Spending time together before consultation

- In classroom study, teachers already knew children.
- Home-based study: initial visit – researcher spent time with child, in place interview would occur, engaging with child (e.g. playing a game, building a Lego tower, talking about child’s interests)
What was helpful?

3. Giving questions visually in advance

- At first visit, left parents, siblings and children with ASD with list of questions I’d be asking. For children with ASD, this was:
  - My family
  - Things I like
  - Things I don’t like
  - ‘Respite care’ and social workers
  - Wishes

- Some children brought their own list (of issues + answers) to the interview
What was helpful?

4. Keep timescales short

- In both studies, timescales were kept short
- In the home-based study, second interviews were carried out within 2 weeks of the initial visit
- Use e.g. visual calendars to maintain child’s awareness + interest
What was helpful?

5. Using photos as supports

- At first visit, identified (with parent(s) + child) the places, people and activities I’d need to photograph

- For 11 interviews with visual supports, used over 200 photos
  - NB Issues about male researcher taking photos of children’s play areas, etc

- BUT…Be aware of potentially limiting impact of visual supports
Photographs to support interview process
What was helpful?
6. Asking questions visually

- Individualised tasks
- Used to identify preferred (and disliked) activities
- Child physically manipulated the photos
- Repeating task enabled verification
What was helpful?

7. Using work systems

- Enabled the children to keep track of the process
- Let them know a preferred activity would follow
- The children manipulated the work system
- Easy questions first, finished on preferred activity
What was helpful?

8. Addressing child’s experience

- Schedule cards helped **some** children discuss associated activities
- Visual supports helped them remember what they have done
- Can’t make assumptions about what child views as important
9. Tape recording interviews

- Enabled interviewers in both studies to ‘listen on all channels’
- Taping child’s responses meant they could have a hard copy of what they said
- Letting children manipulate tape recorder made them active participants in process
- Go with the child’s interests - I recorded children singing, playing instruments, talking to rabbits + and doing their fitness regimes
What was helpful?

10. Use of proxies

- Observation
  - by or checked out with someone who knows the individual with
  - to a structured checklist (answering the questions)

- Parental/carer support
  - Positives – support, comfort, translation
  - Negatives – acquiescence, control

- NB Triangulation essential
What was helpful?

11. Triangulating data

- Using multiple sources of information

- ‘Triangulating’ responses with people who knew the children helped clarify, e.g.
  - when individual's response was factually correct or incorrect

- Also helpful in trying to identify reason for factually incorrect responses
What was helpful?

12. Individualisation

- In both studies, no two interviews with children with ASD were the same.

- But... time- and resource-consuming: home-based study took:
  - 4 months to complete consultation process.
  - Over 80,000 words of transcript, 3 months to transcribe.
  - 5 months to code before analysis.

- No ‘one size fits all approach’
Five Outcomes Files

- Used in residential services for children
- Portfolio of evidence based on Every Child Matter Five Outcomes
- Evidences likes, dislikes, activities, key issues – positive and negative
- Can act as proxy for child in review
Five Outcomes File
The child’s words

Harry could not cope with attending his reviews, but wrote down his likes and positive + negative feelings/behaviours
Ascertaining the views of these children

- Time-consuming
- Challenging
- Thought-provoking
- Important
- Valuable
- Potentially life-changing