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Exploring Multiple Factors Affecting Participation Outcomes for Children with Communication Aids

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BACKGROUND AND PROJECT AIMS

Supporting and developing participation in everyday life is an ultimate goal of augmentative and alternative communication (AAC) intervention. Participation is defined by the World Health Organisation as “a person’s involvement in a life situation” (WHO, 2001 p.213), where ‘involvement’ is characterised as “...taking part, being included or engaged in a life area, being accepted...” (WHO, 2001 p.15). While in many cases the provision of communication aids can significantly promote children’s participation in everyday life, some children apparently do not benefit fully from communication aids.

It has long been acknowledged that multiple and various factors can influence the take-up and use of communication aids and the impact of communication aids on children’s participation in everyday activities. Research in the AAC field has identified many of these factors. Arguably however, the ways in which such factors interact to influence the impact of communication aids on children’s participation is apparently less well understood.

This brief paper provides an outline of pilot research being undertaken to es-

tablish a reliable parent-response questionnaire aimed at exploring how environmental, personal and child factors interact to affect children’s communication aid use and participation. Some preliminary findings concerning children’s profiles of participation are also presented.

METHODOLOGY

Design

The project was designed as a questionnaire study, with responses being collected from the parents of children and young people who use communication aids.

Participants / Respondents

Participants for the study were identified as parents and carers of children assessed for communication aids at either the Augmentative Communication Service at Great Ormond Street Hospital or the ACE Centre in Oxford between March 2006 and March 2008. Because we aimed to investigate within-group variation across the whole population of children assessed for communication aids, we approached all families of children who had been recommended a communication aid incorporating the

symbolic representations of language (e.g. photographs, pictures, graphic symbols, words). We did not approach families of children with progressive

(Intrinsic) Child related factors

- Disability
- Personality
- Preferences

Communication aid related factors

- Amount of use
- Type of use
- Usability

Support services

- Amount
- Type
- Perceived effectiveness

Family support & demands

- Stress and Coping
- Socio-economic Category
- Personality
- Attitudes towards communication aids

Table 1 Variables identified for analysis

Mean Age	10.6 years
Age Range	1.08 - 21.07 years
Gender	67.1% male, 32.9% female
Child's speech reported as "Not understood by strangers or familiar people, or unable to speak at all"	48.8%
Child reported to have difficulties with vision	48.8%
Child reported to have difficulties with manual dexterity	86.4%
Child reported to have difficulties with mobility	76.8%
Communication Aid Type:	
Complex VOCA and Communication Book	23%
Communication Book only	16%
Complex VOCA only	12%
Simple electronic aid only	5%
Literacy Levels:	
Early (using symbols / pictures)	50%
Emergent (basic sight vocabulary, some spelling skills)	38.2%
Fluent literacy	11.8%

Table 2 Summary of children in study

conditions or profound and multiple learning disabilities, or those known to have suffered bereavement or who presented with especially sensitive personal circumstances.

To date, 97 questionnaires have been returned. An early analysis of 82 responses is provided here to complement the very preliminary data (n=23) presented at the Communication Matters National Symposium in September 2009.

Some details of the children reported on are summarised in the table above.

Procedures

Based on the World Health Organisation's (WHO) International Classification of Functioning, Disability and Health (ICF), and the version for children and youth (ICF-CY), a conceptual model was designed to illustrate hypothesised relationships between a range of key factors that potentially affect the take-up of communication aids and children's participation.

The factors were identified from the research literature, the clinical experience of the research team, and a motivation to examine variables that are likely to be sensitive to intervention.

The key factors identified in this model are represented by four domains:

1. Professional services used by families.
2. Internal family characteristics and demands.
3. Communication aid technology.
4. Child's abilities.

The outcome measure for the study was children's participation in social activities.

The conceptual model provided a clear framework for the development of the questionnaire, which was constructed from a combination of scales designed specifically by the research team for the purpose of the study and, where appropriate, the use of existing measures.

For example, in the domain of professional services used by families, no appropriate measure existed to capture key issues relevant to our study (e.g., perceived effectiveness of services, perceived knowledge and skills of professionals). Therefore we designed a number of scales that explored these key issues. Each scale incorporated a number of statements relating to that particular issue, each of which is rated

by parents on a five-point Likert scale: strongly agree, agree, don't know, disagree and strongly disagree. An example of an existing measure used for the study is the Children's Assessment of Participation and Enjoyment (King et al. 2004), which is designed, in part, to measure the diversity and intensity of children's participation.

The questionnaire underwent review by clinical teams at both the Augmentative Communication Service and the ACE Centre, and by a focus group of parents of children attending these centres. Written feedback was also received from two parents unable to attend the focus group. Parents and professionals were invited to comment on the questionnaire content, structure and layout. Their comments led to careful refinement of the questionnaire in a number of specific areas including for example, question wording and the ordering of questions.

Following the period of development the final draft was mailed to prospective participants. An online version was also offered. The initial mail-out was followed up by two reminders; the first of which included a second paper copy and the second a link to the online questionnaire.

ANALYSIS

The reliability of scales designed specifically for the study was assessed using Cronbach's Alpha internal consistency estimate of reliability. This measure tests whether statements in a single scale measure a single construct. For example the degree to which all the statements in the scale relating to 'perceived knowledge and skills of professionals' tended to measure the same thing.

Alpha coefficients normally range between 0 and 1. A high alpha coefficient suggests high reliability. Cronbach's Alpha coefficient threshold of 0.6 was considered suitable for our measure given the relatively small number of items per scale. Descriptive statistics were used to explore profiles of participation

RESULTS

Questionnaire reliability

We were pleased to observe that 23 out of the 27 scales designed specifically for the project attained acceptable to excellent levels of internal consistency with alphas ranging from 0.673 to 0.934. Exceptions that did not meet the required levels of internal consistency will require further development if they are to be employed in any further study.

Participation

The diversity and intensity of children's participation, as derived from parents' ratings of subscales of the CAPE measure, varied considerably between families but mirrored findings from studies of participation in children with disabilities, although not necessarily communication difficulties (Imms et al. 2009; Law et al. 2006).

It is notable that the spread of scores from our study was fairly large compared with other studies suggesting greater variation in diversity of participation in the group of children with complex communication needs than those included in the previous studies.

It has been noted that the amount and type of children's participation is likely to change as children mature (e.g. McConachie et al. 2006) so that older children may show more restricted profiles of participation diversity and

intensity. In our sample, mean participation intensity scores are seen to differ significantly between children aged over and under 12 years. Parents of children under 12 years of age gave significantly higher participation intensity scores ($z = -3.695$, $p < 0.01$) than parents of children aged 12 and over.

SUMMARY

The primary aim of the study was to produce a reliable questionnaire instrument, and to this end the study has been successful.

It has also been possible to make some interesting preliminary analyses of the data collected, and some interesting observations have been made that would benefit from further analysis with a larger sample. *

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