

PARTICIPATION, COMMUNICATION AND AGE

An examination of relations between participation, communication and age in children with complex communication needs

Keywords: Augmentative and alternative communication, Children, Complex communication needs, Communication aids, Speech, Participation

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Abstract

The aim of this study was to examine variation in the frequency of children's participation in out-of-school activities as a function of speech intelligibility, perceived effectiveness of the child's communication aid, and child age. Sixty nine caregivers of children with complex communication needs provided with communication aids completed a questionnaire survey. Younger children showed higher rates of participation than older children particularly in recreational activities. Evidence also suggests that those younger children with partial intelligibility participated more frequently in recreational and social activities than [both](#) younger children without speech and older children. Results and limitations are discussed within the context of participation research in childhood disability, highlighting the impact of communicative resources and maturation on everyday participation.

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Introduction

In the field of augmentative and alternative communication (AAC), the International Classification of Functioning, Disability and Health (ICF; World Health Org, 2001) and the later version for children and youth (ICF-CY; World Health Org, 2007) have become increasingly influential in shaping the landscape of intervention practices. The ICF provides a framework for documenting sociological, psychological and biological aspects of health and health-related functioning. It also promotes a hypothetical system of bi-directional relationships between personal factors (e.g. age, gender), body structures and functions (e.g. mobility, sensory abilities, ~~and~~ personality), environmental factors (e.g. attitudinal environment, provision of assistive technology) and activity/participation (e.g. communication, interpersonal interactions and relationships). Although not designed specifically as a predictive system, the ICF has also informed the development of conceptual models of outcome in the assistive technology field generally (e.g. Fuhrer, Jutai, Scherer, & DeRuyter, 2003), and provides a principled standpoint from which to examine a spectrum of outcomes for children with complex communication needs (CCN).

Advancing opportunities for children and young people to participate in society in ways that match their own motivations and aspirations is a cornerstone of intervention philosophy. Enhanced participation is also likely to nourish children's social abilities and psychological health (Bottcher, 2010; Raghavendra, Virgo, Olsson, Connell, & Lane, 2011). In the ICF and ICF-CY, participation is presented as a linked but ultimately separate concept from activity. Participation is described as "involvement in a life situation" (p.12), while activity is the "execution of a task or action by the individual" (p.12). However, these concepts are not differentiated in the ~~life~~ domains of the activity/participation taxonomy, fuelling considerable debate about how they can be distinguished and measured (e.g. McConachie, Colver, Forsyth, Jarvis, & Parkinson, 2006; Coster & Khetani, 2008; Perenboom & Chorus, 2003). The ICF does provide some potential strategies for marking a

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distinction between activity and participation, including the use of two qualifiers: capacity and performance. In brief, *capacity* refers to the best possible level of functioning achievable by an individual without particular reference to context, and *performance* is concerned with what the individual actually does in everyday life situations. It has been suggested that because capacity does not reflect context it is perhaps most closely linked to the concept of activity, while performance reflects contextual influences and may therefore conceivably be related to both activity and participation (Granlund et al. in press). As such, when construed within the notion of performance, participation may, in part at least, be assessed in terms of the frequency of involvement in everyday activities (Adolfsson, Malmqvist, Pless, & Granlund, 2011; Granlund et al., 2011).

Participation research in childhood disability has primarily been concerned with children with a clinical description of cerebral palsy (Fauconnier et al., 2009; Forsyth, Colver, Alvanides, Woolley, & Lowe, 2007; Hammal, Jarvis, & Colver, 2004; Imms, Reilly, Carlin, & Dodd, 2009; Law et al., 2006; Orlin et al., 2010; Palisano et al., 2009; Voorman, Dallmeijer, Van Eck, Schuengel, & Becher, 2010), although children with other primary disabilities [have also been the subject of enquiry. These includesuch as](#) children with spinal injury, attention deficit hyperactivity disorder, autism spectrum disorders, learning disabilities and complex communication needs [have also been the subject of enquiry](#) (Clarke, Newton, Griffiths, Price, Lysley, & Petrides, 2011; Klaas, Kelly, Gorzkowski, Homko, & Vogel, 2010; Raghavendra et al., 2011; Shimoni, Engel-Yeger, & Tirosh, 2010; Solish, Perry, & Minnes, 2010; Thirumanickam, Raghavendra, & Olsson 2011). While some studies have examined aspects of the subjective experience of participation (Clarke, Newton, Cherguit, Donlon, & Wright, 2011; King, Petrenchik, Law, & Hurley, 2009; Klaas et al., 2010; Raghavendra et al., 2011; Shimoni, Engel-Yeger, & Tirosh, 2010; Solish, Perry, & Minnes, 2010; Thirumanickam, Raghavendra, & Olsson 2011) in press), research has most typically framed participation as the range and frequency of everyday activities in which children partake. Factors largely intrinsic to the child such as age, level of motor ability, learning disability, personality traits

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(especially trait emotional self-efficacy; see Petrides, Pita, & Kokkinaki, 2007), pain, and communication abilities emerge as salient predictors of participation for children with developmental disabilities (Beckung & Hagberg, 2002; Clarke et al., 2011; Donkervoort, Roebroek, Wiegerink, Heijden-Maessen, & Stam, 2007; Fauconnier et al., 2009; Forsyth et al., 2007; Hammal et al., 2004; Imms et al., 2009; King, Law, Hurley, Petrenchik, & Schwellnus, 2010; Orlin et al., 2010; Voorman et al., 2010). The relationship between level of severity of communication disability and level of participation restriction varies across differing participation contexts. For instance, increase in communication disabilities has been shown to be unrelated to increasing participation restriction in social and recreational activities (Fauconnier et al., 2009; Hammal et al., 2004). Although proportions of children in these studies had no functional speech, the impact of AAC tools was not specifically modelled, and the degree to which communication aids may have accounted for the mixed findings has not been established.

For the developing child, expectations and opportunities for participation change over time. For example, in a detailed examination of out-of-school participation in 422 children with physical disabilities (cerebral palsy or musculoskeletal limitations) and 354 non-disabled children, King and colleagues (2010) observed differences in participation in recreational (e.g. playing computer games, watching television) and social activities (e.g. hanging out, visiting ~~with~~ others) with age. In that study, younger children (six to eight years) with and without disabilities participated more often and in a more diverse range of recreational activities than older children (aged nine to 14). However, while children without disabilities were seen to experience an expanding profile of social participation with age, that change was not matched by children with disabilities. For instance, older non-disabled children were more likely than children with disabilities to engage in social participation with peers than family members.

While there is a relative scarcity of research examining participation specifically in children with CCN provided with communication aids (Clarke et al., 2011; Raghavendra et al., 2011;

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Thirumanickam et al., 2011), emerging evidence suggests that they experience relatively restricted out-of-school participation compared with non-disabled children (Thirumanickam et al., 2011), and even greater restrictions in social participation and interaction with peer networks than children with physical disability ~~but~~ without CCN (Raghavendra et al., 2011). For example, Thirumanickam and colleagues (in press) compared extracurricular participation in a group of five children, aged 6;00 to 9;5, with physical disabilities and CCN using communication aids, ~~aged 6;00 to 9;05~~, with an age matched group of non-disabled children. The range of activities pursued by children ~~that with~~ complex communication needs, the frequency of engagement in those activities, and the contexts of participation (range of locations and co-participants in attendance) were limited compared with the non-disabled group. However, the authors note that children with CCN reported higher levels of enjoyment in activities than their peers.

A core principle underpinning AAC intervention concerns supporting and developing the child's ability to utilise total communication strategies to the best of their ability, including the integrated use of speech and communication aids. The ways in which communicative resources such as speech and the use of communication aids are incorporated into human interactions are intricate and nuanced, and are affected by numerous factors including, for example, the influence of the communication partner, the broader communicative demands of the situation, and the shifting expectations for what might be relevantly said next in the interaction (e.g. Clarke & Wilkinson, 2008). Notwithstanding the multimodal complexity of these children's interactions, significant scope exists for examining the ways in which participation may vary as a function of communication resources, given the theoretical and practical significance of participation as an outcome of intervention, and the substantial investment by professionals and families in supporting effective AAC tool use. The aim of this study was, therefore, to undertake an initial exploration of variation in the frequency of children's participation as a function of child age and two factors

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relating to communication resources: level of speech intelligibility and perceived effectiveness of the communication aid.

Method

Participants

The sample consisted of 69 children and young people with CCN in two age groups: (i) 3;00 to 11;00 (n= 40; Median age = 7.9; SD=2.0 years), and (ii) 11;00 to 21.07 (n=29; median age=15.06; SD=3.0). Table 1 presents selected child and family characteristics.

Insert table 1 about here

Measures

Speech Intelligibility

Caregivers' perceptions of their children's level of speech intelligibility were measured using the speech subscale of the Health Utilities Index (HUI; Feeny, Furlong, & Torrance, 1995). The HUI speech subscale assesses whether or not family or unfamiliar listeners are able to understand the child's speech. The five-point scale provides descriptions ranging from full intelligibility to being unintelligible with both family members and strangers. In this study children were grouped according to whether they presented with some degree of useful speech (fully or partly intelligible to family and/or unfamiliar listeners), or no functional speech (not intelligible to family members or strangers).

Perceived effectiveness of the aid

A scale was developed for the study to establish caregivers' views concerning the perceived effectiveness of their child's communication aid. In this study effectiveness of the aid related to

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caregivers' perceptions of its ability to support and promote children's interaction with others. Six statements were presented (e.g. much of the time communication aids just don't help communication), and parents were asked to rate their level of agreement with each statement using a five point rating scale (strongly agree to strongly disagree). This scale formed part of a broader set of measures, not included in the current analysis, aimed at determining parents' views on a range of issues related to communication aid provision including their perceptions of impact on their children's self-perceptions (e.g. self-esteem, self-efficacy). Scale items were developed on the basis of clinical and research peer consultation, and through focus group discussion and written correspondence with caregivers of children provided with communication aids. The scale's internal consistency was good, achieving a Cronbach's alpha coefficient of 0.73.

Participation

This study used a questionnaire survey approach to establish patterns of child participation via parental report. As no suitable proxy measure of participation was available for children in this study, our measure of participation was adapted from the Children's Assessment of Participation and Enjoyment (CAPE; King et al., 2004). The CAPE assesses the diversity, intensity, context (e.g. with friends, at home), and level of enjoyment in 55 participation activities, comprising five formal and informal activity domains: recreational (e.g. playing computer or video games, collecting things), social (hanging out, visiting with others), self-improvement (e.g. doing homework, shopping, doing a chore), active physical (e.g., water sports, team sports, racing or track and field) and skill-based (e.g., dancing, learning to sing, doing gymnastics, playing a musical instrument). The CAPE is intended to be used as a child self-report measure: however CAPE instructions allow for adult support for children in recalling past events; it has been completed by caregivers where children have been unable to themselves (Imms et al., 2009), and more generally, it is proposed that

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participation may be measured via others' reports rather than self-reports where participation is realised as frequency of engagement in activities (Granlund et al., in press).

Frequency of children's participation in three CAPE domains was assessed: recreational, social, and self-improvement domains. Although all domains of participation represented by the CAPE are of significance for children, the recreational, social, and self-improvement domains were considered the most relevant in which to examine variation in participation as a function of communication skills, and in particular the use of communication aids. The ICF-CY life areas represented by the individual items in the selected CAPE activity domains are presented in Table 2 (M. Granlund personal communication 7 June 2011; see also Adolfsson et al., 2010). Although CAPE items do not map directly to the ICF-CY life domains, the measure does allow for a relatively straightforward appraisal of the frequency of participation across a range of participation domains. In the current study caregivers were asked to rate how frequently their child participated in activities in the previous four months using a percentage score between 0% and 100%, rather than the 1-7 Likert rating scale provided by the CAPE. Percentage-based response scales have a propensity to be more intuitive for adults and also more sensitive than a Likert scale, allowing for a finer differentiation of participation levels (Masters, 1974; see also Weng, 2004).

Insert table 2 about here

Procedures

Ethical review and approval of all procedures was given by the Oxfordshire REC B NHS National Research Ethics committee. Subsequently, a questionnaire was distributed to caregivers attending two specialist AAC assessment centres in England between March 2006 and March 2008. The questionnaire addressed a range of issues concerning child and environmental factors and aspects of participation. Caregivers were able to respond using the pencil-and-paper questionnaire

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provided, or by using an online facility. The initial questionnaire was followed up by two reminders: the first enclosed a replacement questionnaire and highlighted use of the web-based questionnaire, the second only re-directed caregivers to the web-based questionnaire. The study excluded caregivers of children with progressive conditions where intervention focused on managing a decline in communication abilities and participation opportunities. Caregivers of children with profound and multiple learning disabilities were also not included in the survey because, overwhelmingly, reciprocal spoken interaction and the use of graphic symbol or orthographic communication aids are not expected to be commonplace experiences. Caregivers of 97 children returned questionnaires, and 69 complete datasets were available for the current analysis.

Statistical analysis

We conducted a 2x2x2 multivariate analysis of variance (MANOVA) with the three participation criteria (recreational participation, social participation, and self-improvement) as the dependent variables and age (younger versus older children), level of speech intelligibility (none versus partial), and perceived effectiveness of the communication aid (low versus high) as the independent variables. Summated scale scores for perceived effectiveness of the communication aid ranged from 2.17 to 5.0 (possible range 0 to 5), with higher scores indicating greater effectiveness. The median score (3.5) was used to dichotomise the variable. All dependent variables were fairly normally distributed; skewness and kurtosis values ranged between +/-1.00 in all cases. Nevertheless, in the single case of self-improvement participation, the skewness/standard error ratio exceeded |2| (3.35) indicating a somewhat asymmetric positive tail. Table 3 presents descriptive statistics for participation scores.

Insert table 3 about here

Results

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There was a significant multivariate main effect of age ($F_{(3, 59)} = 3.11, p < .05, \eta_p^2 = 0.14$), with younger children receiving higher ratings particularly on recreational participation ($F_{(1, 61)} = 9.08, p < .05, \eta_p^2 = 0.13$). There was also a statistically significant multivariate interaction between speech and age ($F_{(3, 59)} = 3.07, p < .05, \eta_p^2 = 0.14$), although none of the three follow-up univariate ANOVAs reached significance levels, perhaps due to our low sample size. The multivariate simple main effects analysis revealed that while there was a multivariate effect of speech in the younger group, the effect was absent from the older group. More specifically, children with partial speech intelligibility significantly outscored their counterparts with no speech on both recreational participation ($F_{(1, 46)} = 9.05, p < .05, \eta_p^2 = 0.16$) and social participation ($F_{(1, 46)} = 5.27, p < .05, \eta_p^2 = 0.10$), but in the younger group only.

It is worth noting that the three-way interaction between age, level of speech intelligibility, and the effectiveness of the communication aid closely approached significance levels ($F_{(3, 59)} = 2.69, p = .054, \eta_p^2 = 0.12$). However, none of the three follow-up univariate ANOVAs reached significance. Furthermore, when the two-way interactions between speech intelligibility and usefulness were examined separately in the younger and older groups, neither of them reached significance levels.

Discussion

Clinical experience and research evidence suggest that multiple individual and contextual factors, including factors related to communication aids, influence children's participation. The aim of this study therefore was to begin to illuminate the ways in which participation in recreational, social and self-improvement activities varies with [apparently-the](#) important variables of level of speech intelligibility, perceived effectiveness of the child's communication aid and child age.

The study revealed a significant multivariate main effect of age, with younger children showing higher levels of participation than older children. In particular, caregivers of younger

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children reported markedly higher rates of engagement in recreational participation compared with social and self-improvement activities, although younger children had numerically higher scores on social and self-improvement domains than older children. This finding broadly reflects a developmental trend in recreational participation observed in children with and without disabilities (e.g. King et al, 2010). Items from the CAPE's recreational domain used in the current study include, for example, watching television and films at home, playing computer and video games, playing with toys, pretend play, and collecting things etc. While older non-disabled children show a reduction in recreational participation, this appears to be offset by an increase in social participation. However, this was not observed in the children with CCN in this study.

Evidence suggests that for the group of children with CCN in this study, level of speech intelligibility influences recreational and social participation in younger children. Social participation items from the CAPE include going on a full day outing, going to a party, hanging out and visiting others. Younger children with CCN who retain some intelligible speech appear to engage more frequently in such activities than young children without functional speech and older children with CCN. It is possible that where some ability in the use of speech provides benefit for younger children in recreational and social participation contexts, this (apparent) advantage diminishes with age. Such a difference may reflect changing participation practices in families of older children and shifting societal expectations for older children's participation in society. Given the sample size, care is required in not over-interpreting the observed interaction between speech and age. Nonetheless, this preliminary observation perhaps provides a glimpse into potentially dynamic relations between the use of 'natural' speech, albeit limited in its functionality, and the communicative demands and opportunities associated with young children's social participation, and changing communicative demands and expectations linked with social interaction as children mature (Pennington & McConachie, 2001; Smith, 2005).

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The use of communication aids in interaction as part of an array of aided and unaided resources is a complex matter. In this study, caregivers were asked to evaluate the effectiveness of the communication aid in supporting interaction. Perceived effectiveness of the communication aid was not related to level of participation in recreational, social or self-improvement activities: for example, those parents who rated the communication aid as effective did not necessarily report significantly higher levels of participation. However, this study has provided some suggestion, although not quantitatively significant, of a complex interaction between age, level of speech intelligibility, and the perceived effectiveness of the communication aids. Further investigation of higher-order interactions in a considerably larger sample appears warranted.

The ICF-CY concept of activity/participation incorporates a diverse range of life situations, and there is, as yet, no unified approach to defining and measuring participation in isolation from activity. This study framed participation in relation to the ICF-CY performance qualifier, adopting a focused definition of participation as frequency of engagement in out-of-school contexts. Although no single participation domain was assessed entirely using the CAPE, partial correspondence between the CAPE items and the ICF-CY activity domains (see table 2) provides some scope for reflecting on the current findings in the context of the ICF-CY. For example, younger children, and particularly those with partially intelligible speech, appeared to engage more frequently in recreational activities related to the ICF domains: d650 caring for household objects, d880 engagement in play, and d920 recreation and leisure. However, increase in social participation with age in non-disabled children (albeit not English children), reported by King and colleagues (2010) using the CAPE, was not replicated in this cohort of children with CCN. Social participation as measured by the CAPE is associated with the following ICF-CY activity domains: d360 using communication devices and techniques, d620 acquisition of goods and services, d630 preparing meals, and d920 recreation and leisure.

Limitations

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An important limitation of the present study was the small size of the sample, which means that some design cells comprised limited numbers of participants. The main repercussion of this limitation is that the design may lack the necessary power to detect statistically significant findings. A corollary of this is that we can be particularly confident of the results that did reach significance in our analyses. A further limitation concerns the adaptation of the CAPE as a proxy measure with a modified scoring procedure.

The ICF and ICF-CY assert that the nature of children's participation may be derived from a community of inter-related factors linked to child abilities, personal factors and environmental variables. Consequently, multiple factors in addition to age, speech intelligibility and perceived effectiveness of the communication aid will be influential. For example, child emotional functioning has been identified as a predictor of out-of-school participation in children with CCN, and the family impact of raising a child with disabilities is a potentially critical factor (Clarke et al., 2011). Also, variation in ability within groups may influence individual experience of participation. For example, the group of children classified as having some level of speech intelligibility includes those who are partly intelligible to family and/or unfamiliar listeners. It is possible that level of intelligibility with unfamiliar listeners may be particularly influential in shaping profiles of out-of-school participation.

In this study, younger children were reported to engage more frequently in participation activities, particularly in recreational participation, than older children. Although children are recognised as being distinct from as well as integrated within their families, findings from participation studies involving children with motor, learning and communication needs, including the current paper, may reflect family participation as much as individual child participation (McConachie, Colver, Forsyth, Jarvis, & Parkinson, 2006). Children with CCN, like others with significant disabilities, and young typically developing children, are likely to be more dependent on family support in facilitating access to and engagement in everyday activities and events,

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particularly those taking place outside the family home. Western societal expectations for a transformation from reliance on caregivers to independence from caregivers as children get older may be influential here. For example, reduced participation in older children may reflect underlying family expectations for increased independence that may not be achievable by young people with CCN. Equally, divergence of child chronological and developmental age as children mature may limit opportunities for independent participation that match children's motivations. For such young people, the context of the family (however that may be defined), rather than the individual child, as the likely primary agent in participation is emphasised.

Summary

The current study suggests that young children with CCN show perceptible quantitative difference in participation compared with older children with CCN. Equally, those younger children who have ~~it~~ some intelligible speech display a higher frequency of participation than young children without speech and older children. This was particularly evident in social and recreational participation. Caution is needed to avoid the supposition that high frequencies of participation are most desirable by default. For some children, extension of participation quantity may be less important than qualitative improvement in current participation. As such, establishing subjective experiences of participation, including in-the-moment or posteriori reflections, are also important aspects of the ecology of children's participation. Children's subjective insights can shed light on the importance attributed to activity and participation experiences, and hence what matters most for them (Clarke et al., in press). Children with CCN are prone to social isolation, which is realised, in part, through limitations in everyday participation. Determining relations between child factors, communication aid characteristics, together with other pertinent environmental variables, and qualitative features of children's participation across a diverse range of circumstances will inform

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theoretical developments in childhood disability and intervention strategy, including, for example, the design and development of more cognitively and socially inclusive technologies.

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Table 1

Participant characteristics

		Frequency	%
Gender	Male	46	67
	Female	23	33
Communication aid*	Electronic communication aid	58	84
	Paper based communication aid only	11	16
Child Primary Reported Condition			
	Cerebral Palsy	43	62.5
	Autism / ASD	6	8.7
	Dyspraxia	3	4.3
	Learning Disabilities (not associated with CP or Downs Syndrome)	6	8.7
	Cerebral Palsy & Autism	3	4.3
	Other	7	10.1
	Unknown	1	1.4
	Total	69	100
Child's ethnicity			
	White - UK heritage	56	81.2
	White - other	5	7.2
	Bangladeshi	1	1.4
	Black – African Heritage	1	1.4
	Black – Caribbean Heritage	1	1.4
	Other	3	4.3
	Unknown	2	2.9
	Total	69	100
Family Socio-economic classification			
	Managerial and professional occupations	43	62.3
	Intermediate occupations	4	5.8
	Small employers and own account workers	4	5.8
	Lower supervisory and technical occupations	8	11.6
	Semi-routine and routine occupations	2	2.9
	Never employed	2	2.9
	Unknown	6	8.7
	Total	69	100

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Languages spoken at home		
English only	94	92.8
English + 1 other	3	4.3
English + 2 other	1	1.4
Unknown	1	1.4
Total	69	100

* children with electronic aids may also be provided with paper-based systems. In these instances, caregivers responded to the questionnaire in relation to the electronic aid only.

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Table 2

*ICF-CY life areas represented by the chosen CAPE activity domains***

CAPE activity domain	ICF-CY chapter	ICF- CY life domain
Recreational participation	d6 Domestic life d8 Major life areas d9 Community social and civic life	d650 caring for household objects d880 engagement in play d920 recreation and leisure
Social participation	d3Communication d6 Domestic life d9 Community social and civic life	d 360 using communication devices and techniques d 620 acquisition of goods and services d 630 preparing meals d920 recreation and leisure
Self-improvement	d3Communication d8 Major life areas	d 345 writing messages d 820school education d 855 non-remunerative employment d 920 recreation and leisure

** the links between the CAPE and ICF-CY provided by Granlund (personal communication 7 June 2011)

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Table 3

Participation scores

	Age				Speech intelligibility				Effectiveness of the communication aid			
	Younger children (n= 40)		Older children (n= 29)		No intelligible speech (n= 32)		Partial intelligibility (n= 37)		Low effectiveness (n= 27)		High effectiveness (n= 42)	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Recreational	49.94	20.20	34.86	19.43	38.44	19.60	48.06	21.61	40.63	20.29	48.21	21.91
Social	38.69	19.92	35.92	19.16	33.73	18.62	40.81	19.93	35.36	20.30	40.90	18.08
Self-improvement	25.29	17.05	18.28	16.59	19.48	16.40	24.82	17.51	20.53	16.40	25.17	18.06