**Listening to adolescents who use augmentative and alternative communication**

**Background**
Cerebral palsy is a non progressive collection of motor disorders caused by neurological damage either before, during or soon after birth. The type of motor difficulty and level of impairment depends on the site of neurological damage and there may be additional medical problems (Miller and Bachrach, 1995). It is not uncommon for speech, language and gesture to be affected and this can limit a person’s ability to communicate effectively with other people (Pennington et al. 2003). As Light said “communicative competence allows individuals ... to realize the very essence of their humanity” (1997:61).

The field of augmentative and alternative communication (AAC) has developed to assist individuals who have little or no functional speech. Since the 1980’s rapid technological advances have taken place with computer based communication devices and many can produce analogue or synthesized speech and are referred to as either Voice Output Communication Aids (VOCAs) or Speech Generating Devices (SGDs) (Zangari et al. 1994, Schlosser, 2003).

Research within this rapidly moving field has traditionally focussed on measuring successful intervention in quantitative terms but people who use AAC have expressed the view that functional measures of communicative success are more relevant to them and there has been a move towards qualitative research to explore their experiences (O’Keefe et al. 2007). Light states “attaining social closeness with others is frequently the priority for many individuals who use AAC” (1997:64).

Leisure activities offer opportunities to make friends and reduce isolation whilst promoting positive self-image (Cavet, 1999). This can be instrumental for developing social skills and relationships which has implications for long term mental and physical health (Law et al. 2006). Wickenden (2009) reported teenagers who used AAC had expressed they wanted more friendships and independence and much of their spare time was spent in activities chosen by parents or siblings. She said they strongly identified themselves as teenagers rather than as disabled. Smith (2005) discusses the implications of adolescence for those who use AAC and says future research should explore maintenance of social networks. Children with cerebral palsy are increasingly being included in mainstream society, many with growing expectations about how they will contribute as adults, research must explore how social participation promotes this (Imms 2008).

The benefits of using VOCAs to increase leisure participation have been reported by users (Wickenden, 2009) but there is evidence some VOCA devices are bought with high expectations and either rejected or not used to their full potential (Stancliffe et al. 2010, Stoner et al. 2010). Accessing the world wide web has the potential to increase societal participation for those affected by disabilities (Bryen et al. 2010) but Vicente and Lopez (2010) identified people with disabilities are less likely to use the internet. McNaughton & Bryen (2007) when reviewing how AAC increases societal participation found users have expressed interest in distance communication technologies. Cooper et al. (2009) explored the loneliness experienced by young adults with cerebral palsy who use AAC and found support networks, use of AAC devices, access to the internet and having good technical advice were all important factors in mitigating feelings of loneliness.

Johnstone (2001) discusses the growing recognition that the lives of disabled people have traditionally been interpreted by researchers. He says disabled people have “had very little opportunity to tell their own stories within the political and cultural contexts of their personal circumstances” (2001:116). Research exploring the views of disabled children is limited and is often conducted through family members or health professionals (Morris 2003, Wickenden, 2009).

Social closeness is a desired outcome for people who use AAC and participation in leisure can help achieve this by supporting social skills development and friendships. It is important that barriers and supports for inclusion are explored from the viewpoint of people affected by physical disability and as adolescence is where many interpersonal skills and social networks are formed outside the family it is pertinent to focus on their perceptions and experiences.

**The Study**

**Aim**
This study seeks to explore the perceptions and experiences of adolescents who use AAC, due to a diagnosis of cerebral palsy, about their social participation.

**Objectives**
- To explore how social interaction contributes to the ways in which AAC devices are used by adolescents?
Methodology and Procedure
A constructivist approach (Bryman, 2008) is believed to best fit the aspirations of the research as it is felt social participation is constructed through interaction. A qualitative methodology will provide the rich contextual data needed to explore the participants' experiences and perceptions. Data collection is planned through asynchronous email focus groups to identify issues related to social participation and technology and semi-structured interviews (Bryman, 2008) will seek to explore the issues in more depth. It is hoped to gather data from a sample of 20-30 participants aged 13-19 years from a range of geographical locations. Inclusion criteria will require a diagnosis of cerebral palsy, use of aVOCA as part of total communication, spelling and written skills that allow functional use of email, and computer access to the internet. The interviews will take a narrative approach (Bryman, 2008) to encourage the participants to recount their experiences in their own words. Data analysis at this stage is planned by thematic analyses to create a network which allows rich exploration of the underlying patterns (Attride-Stirling, 2001).

Ethics
Participants are to be recruited through personal contacts with schools, charities, and NHS staff. This study will require approval from NHS Ethics of Research Committee (IRAS) from one, possibly two, regional centres and ethical approval from Manchester Metropolitan University. To ensure informed consent is gained, information and consent forms will be adapted appropriately for participants. All data used will be anonymous to prevent identification of participants and stored securely.

REFERENCES
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