

“Dominating Interactions”- Identity and AAC- A Review of the Literature

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Background

“An identity is a set of meanings that define who one is when one is an occupant of a particular role in society, a member of a particular group, or claims particular characteristics that identify him or her as a unique person.” (Burke & Stets, 2009, p. 3) This presentation will review the literature that focuses on people who use AAC and identity.

Identity theory is a complicated area of study, involving how an individual understands themselves and an understanding of who they are and who they want others to see them as; this means understanding the individual’s interactions within a group and the need to feel they belong. Through conversations and narratives we express our personhood, or how we want to be seen to others.

Research into the Disability Identity suggests that the disability identity can act as a dominant stigmatising identifier for people with disabilities, overriding other characteristics including gender, sexuality and ethnicity.

People who use AAC are often restricted by physical movement and time pressure.(Dattilo et al., 2008; Smith & Connolly, 2008; Wickenden, 2011b), and sometimes by the AAC system or technology. Teenagers who use AAC and identity found that they just wanted to be “viewed for who they are”(Wickenden, 2011a, p. 26), but may be reliant on a patient and skilled communication partner to realise this wish. Indeed, according to Wickenden, teenagers who use AAC perceive that their identity is misunderstood and that they are viewed by others as different. It is difficult to determine an identity orientation for people who use AAC with life-long disabilities as there is very little research on the topic.

It is important for people who use AAC to know their identity, not only for their own well-being, but also to be able to express themselves as who they are and to have a sense of belonging to a community.

Method

Data bases chosen were eBook Collection (EBSCOhost);Academic Search Complete; AgeLine; CINAHL Complete; Communication & Mass Media Complete; Global Health; Health Source - Consumer Edition; Health Source: Nursing/Academic Edition; MEDLINE Complete; Psychology and Behavioral Sciences Collection; PsycINFO; Social Work Abstracts; SocINDEX with Full Text. The database was expanded in EBSCO to include Applied Science & Technology and Business Source Complete in the hope of picking up some computing sources.

We used the terms “augmentative and alternative communication” OR “alternative and augmentative communication” OR “assistive communication” OR “augmentative

communication" OR "alternative communication" OR "AAC"AND (identity OR self) AND cultur*. "disability AND "identity", "AAC" AND "stigma", "disability" AND "stigma", "assistive technology" OR "computer synthesized voice".

Searches were limited to the English language, published and grey literature.

Results

Currently we are analysing 83 articles, the outcome of the analysis will be presented at the conference. Preliminary analysis indicated that adults with a disability may be categorised into two major groups; those with life-long disabilities and those with acquired disabilities. Those with life-long disabilities are more likely to have disability embedded in their identity along with their knowledge of the Disability Rights Movement, whether as an activist or observer, and have a positive view of selfhood. (Darling, 2013) Those who acquire a disability later in life or with ageing, may find it difficult to adapt to the new perception of themselves (Darling, 2013), as they may have spent the majority of their lives with an embedded negative stigma towards people with disability(Wang & Dovidio, 2011) and the feeling of loss is so great.

Conclusion

Understanding how people who use AAC negotiate and enact their identity, requires research about both disability identity and the identity of the person who uses AAC. There has been a revolutionary change in language and perceptions about disability over the past three decades that underpins any research about the way disability exists in society and how important issues like identity and stigma are understood and experienced by people with disability.

Research into the AAC identity is vital if we are to understand the steps that must be taken for people who use AAC so that they can manage a positive self-identity to maintain a healthy outlook on life and to be included in communities of their choice.

Burke, P. J., & Stets, J. E. (2009). *Identity theory*. New York: Oxford University Press.

Darling, R. B. (2013). *Disability and Identity : Negotiating Self in a Changing Society*. Boulder, Colorado: Lynne Rienner Publishers.

Dattilo, J., Estrella, G., Estrella, L. J., Light, J., McNaughton, D., & Seabury, M. (2008). "I have chosen to live life abundantly": perceptions of leisure by adults who use Augmentative and Alternative Communication. *AAC: Augmentative & Alternative Communication*, 24(1), 16-28.

Smith, M. M., & Connolly, I. (2008). Roles of aided communication: perspectives of adults who use AAC. *Disability & Rehabilitation: Assistive Technology*, 3(5), 260-273.

Wang, K., & Dovidio, J. F. (2011). Disability and autonomy: priming alternative identities. *Rehabilitation psychology*, 56(2), 123.

Wickenden, M. (2011a). Talking to Teenagers: Using Anthropological Methods to Explore Identity and the Lifeworlds of Young People Who Use AAC. *Communication Disorders Quarterly*, 32(3), 151-163. doi: 10.1177/1525740109348792

Wickenden, M. (2011b). Whose voice is that?: Issues of identity, voice and representation arising in an ethnographic study of the lives of disabled teenagers who use Augmentative and Alternative Communication (AAC). *Disability Studies Quarterly*, 31(4).

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Signature Date Meredith Allan

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Other activities (please describe):

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