

"Happy and excited": The role of social media in the lives of young adults with cerebral palsy who use AAC.

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Background

- Online social media is being used by young people to negotiate and support friendships
- Peer relationships are a significant factor for adolescents' perceived quality of life
- Reduced social networks can increase the risk of adolescent depression

References

Livingstone, S., Haddon, L., Gorzig, A. and Olafsson, K. (2011). Final report, EU kids online II. The London school of economics and political science.

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Brage, D. and Meredith, W. (1994). A causal model of adolescent depression. *The journal of psychology*, 128 (4), 455-468



Background

- Physical disability and complex communication needs can affect social participation opportunities
- Being online may help overcome challenges of face-to-face communication for people who use Augmentative and Alternative Communication (AAC)

References

Parkes, J., McCullough, N. and Madden, A. (2010). To what extent do children with cerebral palsy participate in everyday life situations? *Health and social care in the community*, 18 (3), 304-315

Smith, M.M. (2005). The dual challenges of aided communication and adolescence. *Augmentative and alternative communication*, 21 (1), 67-79

Gandell, T. and Sutton, A. (1998). Comparison of AAC interaction patterns in face-to-face and telecommunications conversations. *Augmentative and alternative communication*, Vol. 14, pp. 4-10

Hyatt, G.W. (2011). The iPad: a cool communicator on the go. *Perspectives on augmentative and alternative communication*, 20 (1), 24-27



Background

- Literacy and language challenges are barriers for text-based Internet sites. People who use AAC often use symbol-based vocabularies
- AAC devices (inc. symbol-based) have social media tools/mainstream devices have voice output so increased opportunities to go online
- Research gap for Internet use by young people who use AAC in the UK

References

Browning N. (2002). Literacy of children with physical disabilities: A literature review. *Canadian Journal of Occupational Therapy* 69, 176-82

Sturm J, & Clendon S. (2004). Augmentative and alternative communication, language and literacy: Fostering the relationship. *Topics in Language Disorders* ,24, 76-91

McNaughton, D. and Light, J. (2013). Editorial. The iPad and mobile technology revolution: Benefits and challenges for individuals who require augmentative and alternative communication. *Augmentative and alternative communication*, Vol. 29 (2), pp. 107-116



Research Objectives

- To investigate the self-reported experiences of the accessibility of the Internet and social media by people who use AAC
- To investigate the self-reported use of the Internet and social media by people who use AAC
- To explore the perceived role and importance of the Internet and social media for self-determination and self-representation
- To establish how social media is perceived in terms of social ties for people who use AAC



Methodology

- Grounded Theory (Charmaz, 2006)
- Concurrent data collection and analysis
- 25 participants who used AAC (Voice Output Communication Aids, alphabet board, Makaton signing)
- Age 14-24 (13 male, mean 20.4 years)
- 24 interviews and a blog
- Range of ability and AAC devices used with different access methods and support
- 3 interviews with educational staff

Results – Nine Themes

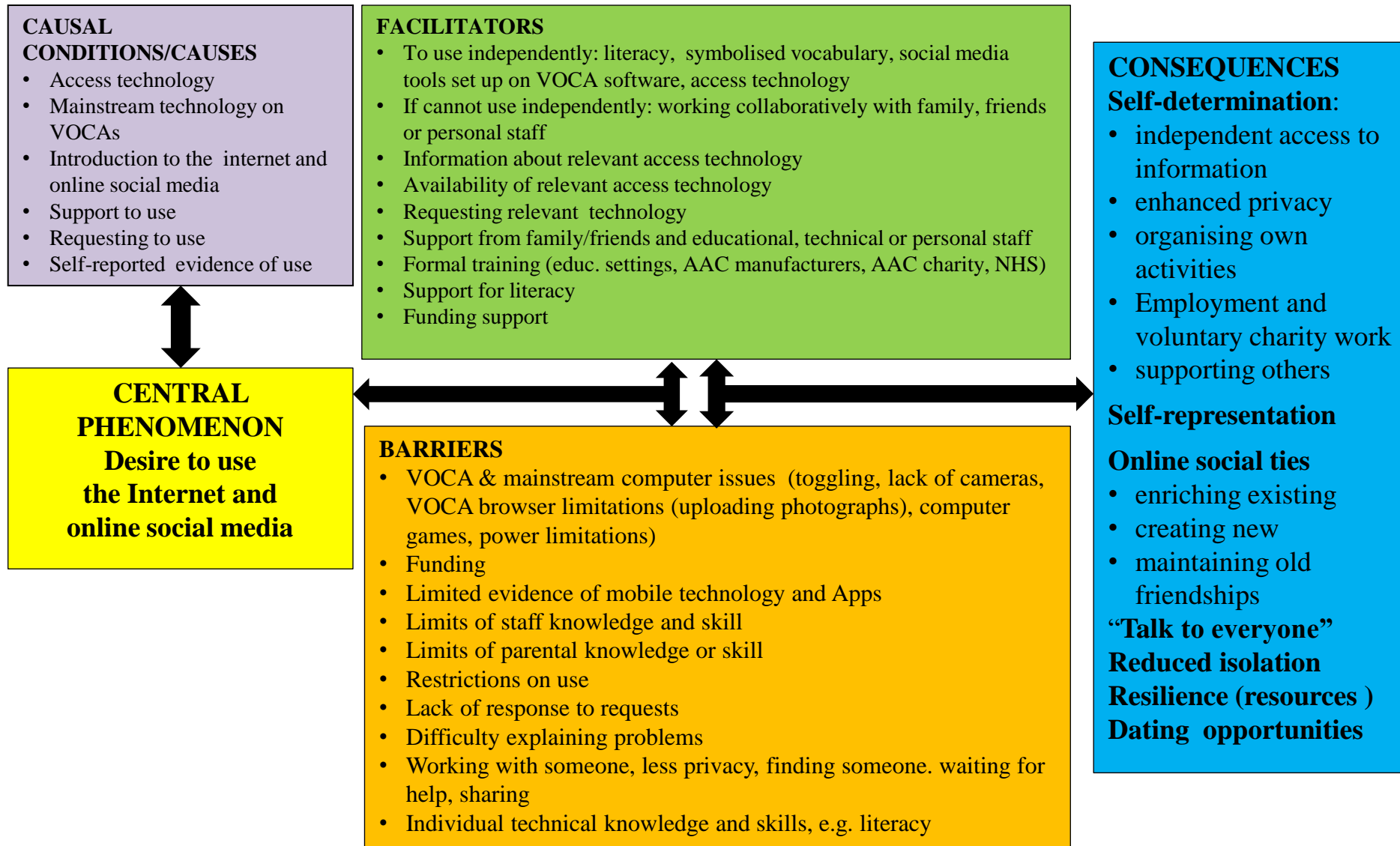
- Desire to use the Internet and social media
- Reported use of the Internet and social media
- Describing support
- Online challenges
- Access technology
- VOCA issues
- Self-determination
- Self-representation
- Online social ties

References

- Hynan, A., Goldbart, J. & Murray, J. (2015). *A grounded theory of Internet and social media use by young people who use augmentative and alternative communication (AAC)*. *Disability and Rehabilitation*, Vol. 37:17, 1559-1575
- Hynan, A., Murray, J. & Goldbart, J. (2014). *'Happy and excited': Perceptions of using digital technology and social media by young people who use augmentative and alternative communication*. *Child Language Teaching and Therapy*, Vol. 30:2, 175-186
- Hynan, A. (2013). *How I use the internet and social media: Experiences of young people who use AAC*. *Communication Matters*, Vol. 27:2,10-12

Conceptual Grounded Theory

Hynan, Goldbart & Murray, 2013






Antecedents for perceived community-based participation

- Self-determination
- Social identity
- Reciprocity and valued contribution
- Participatory expectations
- Psychological safety

Reference

Milner, P. and Kelly, B. (2009). Community participation and inclusion: People with disabilities defining their place. *Disability and society*, 24 (1), 47-62



Collaborative use and possible implications

- Orthographic literacy
 - Observing and co-creating content
- Social care workforce implications
 - Training
 - Professional boundaries
 - Entering into private relationships
 - Knowing how to deal with problematic issues
 - Demographic profile



Discuss...

- How does this research into social media use by people with cerebral palsy cross over into autism research?
- How can social media be used to involve people with complex communication needs in research, what do we need to consider?
- Where next? Future research directions....