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

Amanda Hynan
Leeds Beckett University - a.hynan@leedsbeckett.ac.uk

Janice Murray & Juliet Goldbart
Manchester Metropolitan University

digitalbubbles.org.uk
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
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
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
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
Conceptual Grounded Theory

Hynan, Goldbart & Murray, 2013

**CENTRAL PHENOMENON**
Desire to use the Internet and online social media

**CAUSAL CONDITIONS/CAUSES**
- Access technology
- Mainstream technology on VOCA
- Introduction to the internet and online social media
- Support to use
- Requesting to use
- Self-reported evidence of use

**FACILITATORS**
- To use independently: literacy, symbolised vocabulary, social media tools set up on VOCA software, access technology
- If cannot use independently: working collaboratively with family, friends or personal staff
- Information about relevant access technology
- Availability of relevant access technology
- Requesting relevant technology
- Support from family/friends and educational, technical or personal staff
- Formal training (educ. settings, AAC manufacturers, AAC charity, NHS)
- Support for literacy
- Funding support

**BARRIERS**
- VOCA & mainstream computer issues (toggling, lack of cameras, VOCA browser limitations (uploading photographs), computer games, power limitations)
- Funding
- Limited evidence of mobile technology and Apps
- Limits of staff knowledge and skill
- Limits of parental knowledge or skill
- Restrictions on use
- Lack of response to requests
- Difficulty explaining problems
- Working with someone, less privacy, finding someone, waiting for help, sharing
- Individual technical knowledge and skills, e.g. literacy

**CONSEQUENCES**
**Self-determination:**
- independent access to information
- enhanced privacy
- organising own activities
- Employment and voluntary charity work
- supporting others

**Self-representation**
Online social ties
- enriching existing
- creating new
- maintaining old friendships
“Talk to everyone”
Reduced isolation
Resilience (resources)
Dating opportunities

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Antecedents for perceived community-based participation

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

Reference
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....