Enhancing social participation in young people with disabilities: Evidence based strategies for supporting access to online social networking

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Overview

• Activity – exploring our experiences of social networking
• Benefits and Barriers (background)
• Overview of Research Project
• Case Study Activities
  – Goals
• Strategies
  – handout
• Results

Learning Objectives

• To describe potential benefits and barriers in supporting young people with disabilities to get started with or increase their use of online social networking and social media.
• To identify social media goals relevant to young people with disabilities, including those with complex communication needs
• To obtain knowledge around evidence based strategies for addressing physical, literacy, language, age or cyber-safety related barriers to social media use.

Activity 1

• Introduce yourself
• How do you use Social Media and mobile technologies
  – Who with (friends of friends, family, etc)?
  – How often?
• What are the requirements for you to be able to use social media successfully?

Activity 2

1. What do you know about young people using social media and mobile technologies?
2. What do you know about young people with disabilities using social media and mobile technologies?

Adolescence and Social Participation

• Some authors have suggested given the impact on healthy development health based interventions should focus on improving social relations (Erickson, et al., 2012, O’Connor, et al., 2011).
Social Networks of children with disabilities

- Reduced social networks in children and adolescents with disabilities (Raghavendra et al., 2011a, 2012; Thirumanickam et al., 2011)
- Children and young people with disabilities have fewer friendships, are more socially isolated, and at increased risk of social impairment (McMaugh & Debus, 1999; Nadeau & Tesser, 2006)

Internet Use and Young People

- “Digital native” generation or “Net Generation”
- 79% of Australian children (2.2 million) access the Internet during or outside school hours (ABS 2010 – data for 12 months to April 2009)
- 90% of 12-17% year olds and 97% of 16-17 year olds regularly used social networking services (ACMA, 2009a, 2009b)

Internet Use and Young people with disabilities

- Survey of Internet Use (Newman et al., 2010; Raghavendra et al., 2011b; Raghavendra et al., 2012)
- Online social networking use (Lewis, 2010)
- Bridging disability divide? (Tsaliki & Kontogianni, 2013)
- Online peer support intervention (Barnfather et al., 2011; Stewart et al., 2011)

Aim

To determine whether strategies to support using the Internet for social networking could facilitate the social participation of children with physical disability or acquired brain injury (ABI)

Inclusion criteria for Participants

- Children with ABI or PD between 10-18 yrs
- Child, parent and/or therapist thinks that child might benefit
- Not at pre-intentional level of communication, No severe cognitive difficulties

Participants

- 18 Participants
  - Physical disability (13)
  - ABI (5)
- Mean age: 13;7
- Gender: 12 Males, 6 Females
Participants

<table>
<thead>
<tr>
<th>Level</th>
<th>GMFCS</th>
<th>MACS</th>
<th>CFCS</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>1</td>
<td>1</td>
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<td>5</td>
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<td>III</td>
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<td>IV</td>
<td>3</td>
<td>1</td>
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</tr>
<tr>
<td>V</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

Pre-Post intervention assessments

- Problem areas identified using the COPM (Law et al., 1990)
- Goal Attainment Scale (GAS) - (Kiresuk & Sherman, 1968)
- Social Networks- Circles of Communication partners (Backstone & Hunt Berg, 2005)
- Asher Loneliness and Social Dissatisfaction Questionnaire for Children (Asher et al., 1985)
- Beck Self Concept Inventory for Youth (SCI - BYI-II) (Beck et al., 2005)
- Participants and parents interviewed (post)

Intervention

- Cyber Safety – house rules
- Home Visit support to family and young person
- Software & Equipment
- Setup support for software, equipment or social networking
- Strategies to support use (e.g. visual supports, prompts)

Examples of Goals

- Emails, Games Online, Blogs
- Skype Calls (Number of peers connected, Circles of communication partners connected to, support required)
- Social Networking (e.g. Facebook, Twitter, LiveWire)
  - Number of peers connected,
  - Amount of support required to send 1 message,
  - maintain turns/ topic & confidence to start chat,
- Functions used on Facebook
  - Comments on others posts,
  - adds photos, status updates, sharing links, sharing favourites, adding favourites, looking at news feed etc)

Examples of Goals

Case Study Tony

- Tony is 14 years old. He lives at home with his mum and attends mainstream secondary classes (Grade 9).
- He has a congenital upper limb malformation affecting both arms. GMFCS level 1, MACS level 3 and CFCS level 1.
- Tony plays golf competitively and has responsibilities in his golf club so sends a lot of emails and messages for this. He has a large network of golf friends online. Tony’s mum helps him with his computer use including all social networking. His mum feels that with more computer skills Tony could learn to manage this independently. Tony would also be keen to learn to do this.
Case Study Tony - Goals

1. Behavioural Goal:

<table>
<thead>
<tr>
<th>Predicted Level of attainment</th>
<th>+2</th>
<th>+1</th>
<th>0</th>
<th>-1</th>
<th>-2</th>
</tr>
</thead>
</table>

Case Study Tony - Intervention

- Installation
- Voice Training
- Array microphone vs Headset microphone
- Hints and Support for using Dragon
  - Turning the microphone on and off – hot key 0 on number pad
  - Also learnt to use Livewire as heard about this through the project.

Case Study Tony - Intervention

- Other similar cases
  - Voice Training – 1 participant was unable to train voice at all
  - Installation problems - Cost
  - Learning the prompts and commands
  - Dragon Dictation at this time couldn’t read text from the Internet browser. We used a separate Word Read program where this was required.

Case Study Peter

- Peter is 12 years old and lives with his mum & dad. He loves his dog. He enjoys watching ‘browsing the web’ by watching his mum bring up some of his favourite surfing websites on the family computer.
- He has a diagnosis of CP, GMFCS level V, MACS level V and CFCS level V.
- Seizures are uncontrolled and his skills are therefore variable.
- Peter has complex communication needs and uses two switch step scanning to access a Word Power grid on grid 2.

II Case Study Peter

- He blinks his eye for yes and at times shakes his head for No but is still learning to respond consistently for No.
- His mum wants him to write grammatically correct sentences by email and browse the web.
- At this stage Peter’s communication device does not connect to the Internet.
- Peter doesn’t like direct instruction techniques and often is given 1:1 support to complete a task that he can complete independently at other times (e.g. to say something or to open a page on his communication device).
- Also for Peter to be able to look up his favourite web
Case Study Peter - Goals

1. Behavioural Goal:

<table>
<thead>
<tr>
<th>Predicted Level of attainment</th>
<th>+2</th>
<th>+1</th>
<th>0</th>
<th>-1</th>
<th>-2</th>
</tr>
</thead>
</table>

- **Behavioural Goal:**

  - **Predicted Level of attainment:**
    - +2
    - +1
    - 0
    - -1
    - -2

Case Study Peter - Goals

- **Set up incoming and outgoing mail server on device**
- **User Name:** username@isp.com.au
- **Password:** myfavouritedog

My incoming mail server is a POP3 server

**Incoming mail:** pop.isp.com.au, PORT - number, No SSL

**Outgoing mail:** mail.isp.com.au, PORT - number, with SSL

- **ISP** – it's the communication device
- **Supplier** – it's the ISP

Together with the IT consultant: Over 3 hours of support and trouble shooting we finally got the email set up correctly.

Case Study Peter - Intervention

**Programing & Email functions.**

<table>
<thead>
<tr>
<th>Navigation</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 7</td>
<td>Move x 6</td>
</tr>
<tr>
<td>“please” row (group 7, row 4)</td>
<td>Choose x 1</td>
</tr>
<tr>
<td>Special Functions button (group 7, row 4)</td>
<td>Move x 2</td>
</tr>
<tr>
<td>Group 6 on the Special Functions page</td>
<td>Choose x 1</td>
</tr>
<tr>
<td>Email inbox button (in group 6):</td>
<td>Move x 2</td>
</tr>
<tr>
<td>Block 1 on the Email inbox page</td>
<td>Move x 2</td>
</tr>
<tr>
<td>Open Email button (in block 1):</td>
<td>Move x 1</td>
</tr>
<tr>
<td>Email workspace (block 2) – Reads Email</td>
<td>Move x 1</td>
</tr>
<tr>
<td>Total Time</td>
<td>27 switch presses</td>
</tr>
</tbody>
</table>

Strategies & Resources

- **Devices used to access Internet**
- **Intervention Tool Kit**

- **Software Purchased and Installed on Participant devices**
- **Free downloads Installed on Participant devices**
Strategies & Resources

- Websites

Examples of tools developed

Common Barriers

- Access to Internet account (e.g. account blocked)
- Home computer breakdown / slowness
- Equipment not charged
- Family’s home Internet connection
- Forgot password
- Family or participant personal choices

Common Barriers

- Difficulties scheduling appointments
- Time to travel to appointments.
- Successful voice training on Dragon
- Participant/ Family fears around SNS’s
- Behaviour difficulties
- Needing a second person
- Programming needs & troubleshooting complex communication devices.
Facilitators

- Support team
- Participant and Family motivation
- Participant and Family experiences of success
- Quick resolutions and simple presentation of solutions to technical problems

RESULTS

COPM Scores

GAS T Scores

Online Partners

Loneliness

d = 0.34
Summary

- Support and training were effective
- Shows improvement in performance, satisfaction with that performance, and confidence in using the Internet for a variety of social networking purposes
- Reduction in mean loneliness, that was not statistically significant.

Key messages

- Importance of Digital inclusion and Digital independence
- Community participation includes online communities as well
- Importance of individualised training and support provided at home

References

- Australian Communications & Media Authority (2009a). Click and Connect: Young Australians’ Use of Online Social Media, 01: Qualitative Research Report. Australian Communications and Media Authority, Canberra, Australia. Available from: http://www.acma.gov.au
- Barnfather, A; Stewart, M; Magill-Evans J; Ray, L; Letourneau, N. 2011. 'Computer-mediated support for adolescents with cerebral palsy or spina bifida'. doi:10.1145/1950163.1950165

References