

# Cerebral Palsy and Online Social Networks

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## ABSTRACT

This study qualitatively explores the experiences and challenges faced when people with cerebral palsy use online social networks. Fourteen interviews were carried out consisting of participants with different types of cerebral palsy. The study identified the reasons for use and non-use and also discovered key themes together with challenges that affected their experiences. For example abrupt and frequently changing online social networks were reported to slow down or prevent use. In spite of this, the study recognized the technology is a vital way for these people to communicate and would continue to play a crucial role within their lives.

## Categories and Subject Descriptors

H5.m. [Information Interfaces and Presentation (e.g. HCI)]: Miscellaneous, K4.2. [Computers and society]: Social Issues

**General Terms:** Human Factors

## Keywords

Cerebral palsy, online social networks, online social network use

## 1. INTRODUCTION

Since the first online social network (OSN) launched in 1997 the growth in OSN recognition and use has been significant. Today, OSNs like Facebook, MySpace and Bebo have emerged as service leaders and draw in hundreds of millions of international users. In the United Kingdom 49% (of 16.6 million) Internet users are using OSNs and are making over 24 million visits a month [1, 2]. However, such OSNs are often directed at persons without disabilities. Existing HCI literature suggests that OSNs have the potential to help people with cerebral palsy (CP) to overcome their mobility, access and communication limitations to enable communication independence [3]. In spite of this, there have been no studies that focus solely on OSN experiences and challenges faced among users with CP. Existing studies like [4] have looked at OSN use and barriers among people with disabilities, therefore making their findings open to interpretation when considering the requirements of OSN users with CP. The goal of this work is to address this gap in research to make this community visible.

## 2. METHOD

In order to examine OSN experiences and the challenges faced by these under represented users, an exploratory interview study was

carried out. Fourteen interviews were carried out with participants who have different types of CP. Participants were predominately female ( $n=10$ ), all aged over 18 years and had diverse backgrounds. The following questions were addressed: Where and when do they use OSNs? What is their purpose for using OSNs? Do they require assistive technologies and or support to use OSNs? Do they experience any problems when using OSNs? What are the advantages and disadvantages of using OSNs? What are their reasons for not using OSNs?

The interviews were audio and video recorded. The raw data was transcribed verbatim and user profiles were developed to support data familiarization. The data was then coded using the general inductive approach [5] and a model based on the most important codes answering the study questions was developed and used to report the findings. However, only the key themes and challenges will be summarized here.

## 3. FINDINGS

### 3.1 Summary

Thirteen of the 14 participants reported using OSNs, primarily Facebook, for up to 6 hours a day at home or at their place of work or education. Participant's family members and friends introduced them to OSNs, and they were the people the participants often communicated with. This communication involved sending public and private messages to find out what their online network of friends was doing and to organize face-to-face communication. Participants also reported using comments and within-website applications, for example poking to encourage communication from their online network of friends. Further to this, participants also reported requiring assistive technologies to use OSNs. The most commonly used were large print keyboards and sticky keys, but other devices like trackball, screen readers and word prediction software were also reported (see figure 1a). On the other hand, a participant reported not using OSNs due to a lack of access and training in conjunction with a reduced confidence to ask for help. The participant interviewed reported: "*I do not have a computer at home and I don't go out much ... they have this Internet thing around the corner at the centre but I don't know how to use one and I don't want to be a annoying?*" Further to this, the rich qualitative data also identified four key themes that affect OSN experiences that have not been previously reported:

#### 3.1.1 Independence

Participants reported OSNs were a vital, often the only, way to reduce their isolation and carryout independent communication. Two participants interviewed reported: "*I can't socialize without it ... it is like food*", "*I think from a wider disability perspective they enable people that are isolated to have a life*". However, this

independence is often reduced by change (see section 3.1.2) and the challenges the technology creates (see section 3.1.5), as support individuals are often required to resolve problems or assist use (see figure 1b). However, this support is often felt inappropriate. One participant interviewed reported: "...you are phoning everyone to come and help and I think that is wrong".



**Figure 1: a) interview subject using large print keyboard and screen reader software; b) interview subject requiring an alternative and augmentative device and a support individual**

### 3.1.2 Change

Abrupt and frequently changing OSNs often slowed down or prevented use. Participants indicated changes to OSN layouts were the most challenging. One participant interviewed reported: *"I don't like how they forced it onto people you must change to this because we can do this ... when you used to have the wall the old interface was clearly defined, you used to have the barriers this was your wall this was your profile"*. Additionally, these changes often affected assistive technology in conjunction with communication quickness. This meant participants are required to re-learn the number of clicks when using switches, often making interacting with OSNs time-consuming. One participant interviewed reported: *"personal assistant: the switch she knows how many times she is going to click and press there and there ... they are changing she has to learn new ... it makes time slow because they keep changing. Interviewee: yes"*.

### 3.1.3 Privacy

Participants indicated that using OSNs offered greater privacy than conventional communication such as telephone, text message and face-to-face. They were concerned about being observed. One of the participants interviewed reported: *"... at home it is more personal so I can go on Facebook, outside my home environment it is not personal enough"*. Contradictory to this, participants were also concerned about the privacy of the information they shared. One of the participants interviewed reported: *"I don't want people to see all my pictures because it is private to me"*. This meant participants were only taking partial advantage of the OSN services provided.

### 3.1.4 Trust

Participants reported a lack of trust among their online network of friends. They were concerned about the legitimacy of the users they were communicating with. This meant they trusted very few of the people they talked to. One of the participants interviewed reported: *"... because of the way my life is I find it hard to let people in and trust people ... I may have 561 friends on Facebook*

*but I have one close friend"*. Further to this, participants reported feeling displeased with some of their 'friendships' as they felt it affected their privacy. One participant interviewed reported: *"my supervisor is on my friend list but I rather she wasn't...because it is an invasion of my space ... Facebook is my personal space"*.

### 3.1.5 Challenges the technology creates for this population

In addition to the key themes, participants also reported challenges that affected their experiences with OSNs. These included: 1) slow text input, 2) poor interface features e.g. small target areas, 3) lengthy and complicated tasks especially when sending messages to friends, 4) lack of user interface personalization e.g. hard-coded text size and colour, and 5) unavailable or inappropriate within-OSN help. All of which, created confusion and slowed down or prevented use.

## 4. SUMMARY

This study explored the experiences and challenges faced when people with CP use OSNs. The study identified the reasons for use and non-use, and discovered key themes together with challenges that affected their experiences with OSNs. The findings from the study indicated that the participants use OSNs for similar reasons while taking partial advantage of the services provided. They reported 4 key themes and 5 challenges that often slowed down or prevented OSN use. In spite of this, participants reported that OSNs were a vital way to communicate, and even though these themes and challenges are occurring, they indicated the technology would continue to play a vital role within their lives. The findings from this study will act as a starting point to be built on in later research.

## 5. ACKNOWLEDGMENTS

Thanks to Stephanie Wilson for providing advice and support; Action Disability Kensington and Chelsea, Scope charity and City University London Learning Success for helping to elicit participants and EPSRC for funding the research.

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