Chapter 7

Participatory Design: The Story of Jayne and Other Complex Cases

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ABSTRACT
The ACE Centre user trials have involved over a hundred people who have severe and complex physical, cognitive and visual difficulties. Participatory Design methodology underpinned the approach that was adopted, which involved being led by the requirements of the most complex users. Jayne was one of many users through whom we not only developed more effective ways of using the technology, but also more innovative strategies to support its implementation. In this chapter, we describe the process, and outcome of our participatory design approach, through the cases of Jayne and other users.

INTRODUCTION
“...I had an email yesterday from one of the tutors who was saying that you were being disruptive in class and talking too much on your gaze control system... and I thought ‘Fantastic!’ You haven’t had a voice for twenty years and you’ve suddenly got one and people start complaining that you’re speaking too much!...”

DOI: 10.4018/978-1-61350-098-9.ch007

CASE STUDIES
The above comment was made by Tom, a specialist speech and language therapist who works in a college for students who have disabilities. Tom was referring to a student who had started to use a gaze control system, as a result of the COGAIN project. The user was called Jayne. Jayne was one of numerous users involved in the ACE Centre user trials, spanning five years.
The COGAIN project has involved young people and adults who have a wide range of complex physical, cognitive and visual difficulties (Donegan et al., 2005, 2006a, 2006b, 2009). Our approach relied heavily upon Participatory Design methodology, an approach which involved being led by the users (Bødker et al., 1993; Bødker, 1996). In participatory design, users (putative, potential or future) are invited to cooperate with researchers and developers during an innovation process. Potentially, they participate during several stages of an innovation process ie., during the initial exploration and problem definition both to help define the problem and to focus ideas for solution; and during development by evaluating proposed solutions. By adopting this approach, we decided to be led by the requirements of the most complex users. It was felt that, if we could modify the technology to meet the needs of this group, then the scope of our work could benefit many equally (and less) complex users worldwide. Aspects of this work have been conducted in collaboration with other specialist centres of assistive technology.

During the COGAIN user trials, a range of gaze control systems were trialled by the ACE Centre. Whilst many users and those supporting them were keen to know which system was best, this question was, and always will be, impossible to answer. Each of the systems performed in different ways in terms of size, power, how well they dealt with involuntary movement and the user interface, etc. However, whilst it is not possible to answer the question of which is the best system, our users were able to inform us about their requirements. By listening to them, and being led by user requirements, we were able to collaborate with hardware and software developers, other professionals, carers and, of course, the users themselves to proceed through an iterative process that led to more and more of their requirements being met. Jayne was one amid many unique users though whom we not only discovered more effective ways of using the technology, but also more innovative strategies to support its implementation. Below, we describe the process and outcome of participatory design with Jayne and other complex users.

**CASE STUDIES**

Jayne has embraced gaze control through the encouragement of family, friends and college staff. During a recent visit, the college server had become jammed by a flurry of emails; “I get emails now” her mother says, pausing to reflect; “endless emails, but I’m sure this will calm down”. Jayne had previously refused to use all other high-tech methods of computer control. “I think it’s the technology itself” says her mother, “she so hated switches and I think felt they were unreliable”.

Jayne had made it perfectly clear, for her switch control was simply too erratic. However, this is a successful access method for many other people. For further detailed information, Donegan et al. (2005, Chapter 5) discuss alternative access methods including special switches, mice and keyboards. Tom sees such devices being set up and successfully used by students on a daily basis. It seems that some users associate certain activities with specific methods of computer control. Their choice needs to be knowledge based – guided by what is known of the user’s physical and cognitive abilities (Donegan & Oosthuizen, 2006). For example, Michael uses a head switch to control his environment including the television, but, chooses to email and listen to music with his gaze control system. Meanwhile, Jonathan (Brough, 2009) uses a switch to control a camcorder on a pan and tilt base, but, chooses to write; Skype; play games; make PowerPoint presentations; and to visit the MyTobii Community (2011) with his gaze control system.

As far as Russell is concerned, his wife says that he is able to converse with his daughter by adopting the voice within his gaze-controlled software. Independently reading and writing emails...