Exploratory prototypes for video: interpreting PD for a complexly disabled participant

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ABSTRACT

Participatory Design (PD) seeks to involve the end users in all aspects of the design process. However, when working with participants with severe disabilities, communication problems can make it difficult to involve the user. In this paper we discuss an attempt to adapt PD approaches to design video tools for a man with severe physical and speech disabilities. To help us understand his requirements, we built simple exploratory prototypes that would allow him to explore the possibilities of video, and allow us to understand what his requirements are. We discuss how successfully we believe the use of these prototypes address the challenges of using a PD philosophy with James, the methodological challenges that we discovered working with James and discuss future methodological improvements.

Author Keywords

Disability, Participatory Design, Artistic Expression, Exploratory Prototyping

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

INTRODUCTION

Participatory Design (PD) is a widely accepted approach for engaging people directly in design of systems that will affect them. However, when working with participants with severe disabilities, communication difficulties mean that many PD methodologies are inappropriate and so new ways of engaging with participants must be found, particularly if researchers want to move beyond looking at Assistive Technology. In this paper we discuss how we approached this problem when we attempted to design a video editor for James, who has severe physical and speech disabilities. As James is unable to speak, and had no prior experience of video editing, we were unable to ask him directly about his requirements. Instead we designed and built exploratory prototypes that would enable him to explore ways in which he could make use of video and so allow us to understand his requirements through observation.

While the work described in this paper was limited to a single evaluation with a single user and was not as successful as we would have liked, it uncovered a number of methodological issues that we believe are relevant for researchers who wish to use PD approaches when working with similarly disabled participants. In particular we would highlight the problem of communication which not only makes eliciting requirements directly from the participant extremely difficult, but also makes it almost impossible to explain the purpose of a tool, or task, to the participant. To address these problems, we argue that successful exploratory prototypes need to be conceptually simple, provide clear and immediate feedback, while the purpose for which they are designed should be comprehensible by the user within what can be assumed of their current experiences.

Introducing James

James[1] is in his late 20s and lives in an assistive care residential centre in London. Due to cerebral palsy, he has very limited control over his limbs and is confined to a wheelchair, though he has good control over his neck and facial muscles. He is physically unable to speak, though he can make noises and signals 'yes' and 'no' by using his head. He does not appear to have any learning disabilities.

To start a conversation with James it is necessary to pose a question that can be answered with a 'yes', or a 'no'. As this is not always possible, it can be impossible to converse on certain topics. For example, it is hard to ask James about

[1] Because our research depended so heavily on James' cooperation, we have chosen, with the permission of both him and his carers, to acknowledge his contribution by making him a co-author on this paper.

his weekend, as the possibilities are too vast ("Did you go to the park?" "Did you go to a festival?"). James' disability places him in a passive position where he is unable to initiate activities or conversations, and is fully dependent upon others to assist with everyday activities.

For the past five years, James has been working with an arts group called Entelechy Arts through a structured program of artistic activities (e.g. disability dance). The founding purpose of this group was to provide marginalized groups with the means for self-expression. Three years ago they commissioned Malcolm to build a mechanism that would enable James to control a video camera as they believed this might be one mechanism for James to express himself.

The video camera is attached to James' wheelchair and through buttons attached to his head he can make the camera pan from left to right, as well as zoom in and out. Using a button placed by his right hand, he can stop and start the camera recording. A display is also attached to his chair so that he can see what he is recording. James has no control over his wheelchair, so a third party must maneuver him into a position of interest when he is using the camera.

James enjoys using the video camera and has shot a wide range of footage with it (ranging from footage shot at a local market to capturing Entelechy dance performances), but this footage is inaccessible to him, as even a task as simple as watching the footage at a later date is out of his control. If video is to play a meaningful role in his life, James requires tools that will allow him to use and manipulate the footage once it has been shot.

Ideally we would start with existing tools, such as video editors, but these have complex interfaces and therefore can be inaccessible for James. However, even if these tools could be adapted for James' physical capabilities they may be inappropriate for his needs. Before we can build video tools for James, we need to know what his requirements are; what he wants to do with video, and how he wants to use any resulting tools.

Given James' limited communications capabilities, he is unable to tell us directly what these requirements might be. If the right question is posed, he can answer with yes, or no; but this greatly limits the kinds of conversation and topics possible. To complicate things further, James has a very different set of life experiences to the designers. He is dependent upon carers for everyday tasks, and has limited experience of direct social and physical interaction with the world. Given that conversation is dependent upon presuppositions of shared knowledge, the paucity of shared knowledge between James and the designers will make communication very difficult. Furthermore, James' default mode of social and physical interaction is very different from the norm, and consequently interfaces designed for able-bodied users (which perhaps assume these norms), might not be appropriate.

One solution would be to bypass James entirely and to instead work with the professionals who know and work with James (an approach used by [4, 9]). However many inappropriate systems have been designed (with the input of experts) because disabled users were not consulted in the design process [7], and so researchers have adopted UCD techniques that enable them to draw upon the situated expertise of these users [17]. There is a further political consideration – upon whose behalf as designers we should be designing. Given that this technology has the potential to affect James' life, and for artistic tools the only true criteria for success is whether they are used by the end user, James' involvement in the design process is critical. As a result, we have adopted a PD approach to design.

To address the challenges of communication, we have used exploratory prototypes [3]. These are fully functional tools that allow James to explore a novel space that would otherwise be inaccessible; enabling us to better understand what James' requirements are and for James to also learn about the possibilities of this space. In contrast with iterative prototypes, these prototypes are not intended as a step towards a final product.

In this paper we describe the design, construction and evaluation of two such prototypes built for James: a video trimmer and a video assembly tool. We discuss how successfully we believe the use of these prototypes address the challenges of using a PD philosophy with James, the methodological challenges that we discovered working with James and methodological improvements for the future.

DISABILITY AND TOOLS FOR SELF EXPRESSION

While there has been considerable work within the HCI community looking at disability (e.g. see the ACM conferences CUU and ASSETS), we have found very little research that examines how to help disabled people express themselves. The exceptions either have a different focus (e.g., Hine & Arnott [13], who looked at multimedia storytelling for people with communications difficulties), or their users have had a different suite of disabilities (e.g. [16]). One exception is the work of Anderson & Smith [1] who provided access to musical composition software (both preexisting and custom made) to disabled users of varying abilities, but their focus is on the system they built, rather than appropriate methodologies for design.

In designing for disability, there are two broad methodological approaches: Alternative Access Devices (AAD) and Universal/Inclusive design[2]. AADs provide alternative ways of accessing computers [18] (e.g. head operated mice), while Universal/Inclusive Designers seek to widen access to existing computer systems (e.g. [15, 20]). However, a key finding of the work of Anderson & Smith

[2] While there is a distinction between Universal and Inclusive Design [12, 16], we will treat them as equivalent for the purposes of this paper.

[1] was that users with complex disabilities tend to require different things from their tools, both in terms of the interface and also functionality. This is partly due to physical differences (interfaces that require a mouse and a hierarchy of menus will be inappropriate for many disabled users, who lack the speed and precision to use them efficiently), but also many of the more critically disabled users had different experiences from able-bodied users, and so wanted different things from the software. This suggests that it is not enough to simply make existing computer tools accessible through AADs, as the underlying interface may still not be usable. However a simplified interface would be too simple, unusable, or inefficient for able-bodied users [7, 12]. Instead we will have to treat it as a new problem space, with a different set of requirements. This leads us back to the methodological challenge of how we engage someone like James in the design process.

THE METHODOLOGICAL CHALLENGE

If we wish to engage James directly in design activities there are number of methodological challenges to be addressed. We shall discuss these in turn. As James can only communicate by answering 'yes' and 'no' to questions posed by the designers, he is unable to give rich answers, or provide original insights to the researchers. Any methodology which depends upon the user being able to *verbally articulate* their views and thought processes (e.g. storyboard prototyping, card games, 'envisioning future solutions', together with other techniques such as post-evaluation interviews and 'talk aloud' protocols) will not work with James. The ability to engage in verbal communication is a necessary but not sufficient condition.

Typically when working with able-bodied users, we can also assume certain *life experiences, or shared concepts* (e.g. knowing what a website is, or having experienced an interview). In contrast, James' disability – where he has lived in care homes and is dependent on carers for every need – has limited the set of experiences that he has had. Unfortunately because of James' communications problems we have no way of assessing which experiences we can, and cannot, assume. In the absence of evidence to the contrary, we have to assume that James has very few experiences that we can take for granted.

In PD and User Centered Design (UCD) we typically work with people with a high level of *agency*. However James is dependent upon other people to carry out even basic activities, and it is almost impossible for him to take the initiative in everyday life. This may affect how James interacts with the researchers in a number of ways. He may lack initiative, or be unused to exercising meaningful choices. When asking James questions, we cannot be certain if James says he likes something because he does, or because he thinks that's the answer we want to hear.

When working with James we are not just working with an individual, but with a *network of people* whose centre of concern is James. We are reliant upon other people to transport him to evaluations, to take care of him in evaluations and to give consent upon his behalf. We will also be reliant upon the professional expertise of people who work with James, such as speech therapists, or physiotherapists to help interpret his responses. This means that when organizing any kind of work with James we are not just arranging it with James, but with at least part of the group that surround him. Not only does this mean that evaluations will take longer to organize, but also that there will be a number of competing agendas and interpretations that we need to deal with.

A further challenge is that James has a unique set of disabilities and so is not representative of the user base as a whole. A reasonable assumption when conducting design sessions with able-bodied users is that the user is (within certain parameters) representative of some user base and is therefore relatively interchangeable, as indicated by use of 'audience segmentations', personas and so on. However when we are working with severely disabled users, there may be *significant differences in ability*, even between two people with superficially similar impairments. For this reason researchers typically choose to work with a single disabled participant to create a prototype [21]. However, not only does this mean that we are dependent upon the availability of a single user, but also that the result of our work may not be generalizable to wider user base.

Given these challenges, it might seem as if it is impossible for us to work directly with James. However, we shall argue in the next section, for a design to be successful for a severely disabled user like James, then the user must be involved in as much of the design process as possible.

Participatory Design

Participatory Design's (PD) origins lie in Scandinavian attempts to democratize the workplace. As part of this work, researchers developed methodologies that allowed workers to actively engage in designing workplace computer systems [8]. Since then, PD approaches have been used outside the workplace and have been used to design technologies for the home [14], children [6] and disability [4, 5, 9, 16, 21].

Given that disability is a very different problem domain from that which concerned the originators of PD, we need to reconsider both what a PD approach in this domain is, and why it is justified. Greenbaum defined three perspectives on PD: pragmatic, theoretical and political [11]. We will use these perspectives as a framework to recontextualize PD for our problem space, designing video tools for severely disabled users.

Pragmatically, as designers we want to build the most effective tools that we can. Particularly when designing artistic tools, the only meaningful criterion of success is whether the users *use* the system. In the field of disability, there is a long history of devices being designed by able-bodied users which either solve non-existent problems, or

are unusable by disabled people [7]. This is because there are aspects of design which will only be apparent to disabled users [7]. Even if as designers we could experience disability, we will always understand that experience by comparing it to our able-bodied experience [10] – making it impossible for us to understand the experience of having been disabled from birth. So we are ignorant about both how James experiences the world, and what he knows about it and can assume nothing about either of these two things.

As an example, consider that James' sole experience of social interaction is passive. Consequently an interface which requires him to take the initiative may be inappropriate. On the other hand just because James does not have the opportunity to take the initiative does not mean he is incapable of it. Without James' input we cannot know the right answer; so we can see there is a strong, pragmatic, need to involve James early on in the design process.

We would argue that design is always a *political* act; that choosing on whose behalf we are acting as designers (e.g. management, or the workforce) we are making a political decision. When we build systems for disabled users, we make a choice between designing on behalf of the disabled user, or the various carers and disability professionals who work with them. When working with severely disabled users like James it is easier to design on behalf of the professionals given that they have specialized knowledge and experience of the user that we as designers lack, while the disabled user is unable to verbally articulate their wants and desires. This approach has been used by a couple of research teams building assistive/rehabilitative technology [4, 9]. Cole et al [4] designed a rehabilitation system for users with cognitive disabilities using PD – but the end user's participation was limited to commentating on and testing the resulting prototypes. Arguably, the primary participants were the professionals, while the research problem became the work done by the professionals in handling their clients.

The danger with such an approach is that the resulting design will reflect the professional's concerns. While those concerns may be valid ones, they could also involve making their job easier (rather than enhancing the quality of life of the disabled person), or reflect professional prejudices about what the disabled person needs, or is capable of (in contrast to what they actually need, or are capable of) [10]. Consequently we need to privilege as much as is feasible the views of disabled users, by involving them, as much as is possible, in the design process.

Theoretically, there is also a problem of communication around common ground understandings between designers and end users, as both parties have different sets of experiences and skills. It would, for example, be extremely difficult to discuss painting with somebody who had never even seen a painting or quantum mechanics with somebody who never studied Physics. However the experiential gap with James is far greater and more fundamental, as he has no experience of things that most of us would take for granted (e.g. starting a conversation), while as designers we cannot share his lived experience of disability. Given that conversation relies upon shared knowledge and experiences, this will limit what we can discuss with James.

PD methodologies seek to address this problem to some extent by grounding all discussions in the lived experience of the user [2]. Such techniques range from understanding the user's lived experience from their own perspective (through techniques such as ethnography), to providing the users with hands on experience of technology so that they can bring their tacit knowledge to bear on the design. So for example, McGrenere et al [5, 16] used ethnography to understand the strategies used by their participants to communicate, and cooperative prototyping to help design an appropriate communication aid for people with aphasia (a cognitive disorder that affects speech). However, strategies used by James to cope with his everyday life are largely irrelevant to us; we are interested in the strategies he would use to work with video and given that this is a radically different scenario to any experienced by James today, such knowledge is unlikely to be useful.

In the following discussions we will describe our use of exploratory prototypes as a means to engage with James directly. Our aim is that if we provide James with tools to engage with this space so that he can gain hands on experience with video, we will be able to observe how James uses, and adapts, the technology and so begin to understand his needs and capabilities. Furthermore, we will be able to ask James simple questions about his experiences with the tools, thus grounding them in a common experience. The tools therefore will act as a boundary object [19] – a shared experience that can be used as a resource for communication about James' requirements.

THE DESIGN OF THE EXPLORATORY PROTOTYPES

Requirements

The first set of exploratory prototypes that we built needed to test our initial assumptions about James' capabilities and experiences. These tools must be sufficiently sophisticated such that James can use them to do something meaningful with video. However, they must also be simple, as if James failed to use a complicated tool, then we would not know whether this was because it was unusable, or inappropriate. It must also have a single function, as if James rejected a prototype with multiple functionalities, then we could not be certain which function was being rejected. However we also wanted the tool to be sufficiently flexible, so that it could be put to multiple purposes. So for example, a video editor should not force a particular style of editing upon him, but would instead allow him to find his own style.

The only experiences that James has with video that we could rely upon, were the practical experiences of shooting video, together with the passive experience of watching films made from video he has shot (this includes art

installations and theatre projects). Given that he had reacted positively to the ways in which footage he had shot had been used, we hypothesized that James would be interested in creating his own films and understood the relationship between a film and the source footage, but did not understand how a film is assembled.

While James ultimately needed to be able to review his footage and make decisions about which pieces of footage he wanted to use, we did not know if James was intrinsically interested in reviewing his footage. Consequently, we thought it important to first test how *capable* James was at defining shots, before exploring his motivation to do so.

This meant that we needed two prototypes: a Video Assembly Prototype and a Video Trimmer prototype. The Video Assembly prototype would allow James to assemble a film from predefined shots. If James was motivated to use this tool, we believed that this would provide him with the motivation to define his own shots, which he could then use to make his own films in the Video Assembly prototype.

The Design Process

Due to the difficulties of arranging and running an evaluation with James, we wished to make our prototypes as usable as possible, before James used them. To enable us to explore design ideas with people who understood James, we constructed lo-fidelity prototypes, which enabled us to find problems early in the design process. We then built both prototypes and evaluated these using adapted usability heuristics and cognitive walkthroughs, based upon what we knew of James' capabilities. Based upon our findings we constructed a second set of prototypes.

We chose to use the same controls that James successfully used to control the video camera with. However we knew that there could be problems with the way that we had designed the interface due to physical problems, or aspects of the controls being obscure to James. As the prototypes were speculative, we did not want to waste time in an evaluation getting the controls to work, only to discover that the prototype itself was inappropriate. So we chose to use a 'Wizard of Oz' protocol, so that we could modify the control mechanisms on the fly during an evaluation.

Macromedia Director[tm] was used to develop the Video Assembly and Video Trimmer prototypes. Both prototypes were deployed on a laptop running WindowsXP[tm], and were controlled through the keyboard.

Video Assembly Prototype

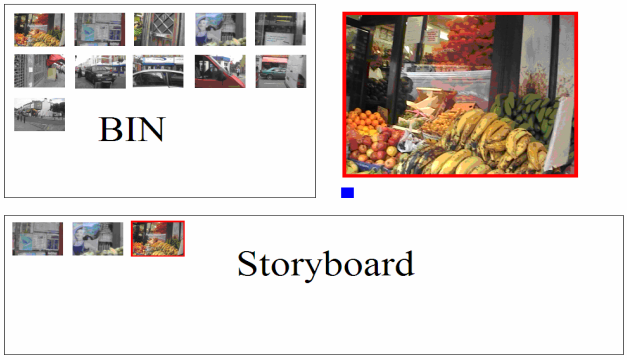
Our minimal requirements for the Video Assembly prototype were that James should be able to assemble and edit a film, using a collection of predefined shots. We hoped to find out using this prototype if he was able to, and interested in, creating his own films.

The Video Assembler used a storyboard interface similar to that used by products like Apple's iMovie[tm]. It enables the user to assemble a movie in a nonlinear fashion; allowing him to move shots around the storyboard, delete shots from it and insert shots from the bin. The shots that comprise the film are laid out from left to right on the storyboard. The shots in the bin were pre-selected by the researchers.

There were two modes: the 'bin mode' and the 'storyboard mode'. The 'bin mode' allowed the user to select a shot from the bin to be inserted onto the storyboard. The 'storyboard mode' allowed the user to move shots around the storyboard, delete shots from it, or change into the 'bin mode'. Depending upon the mode, the cursor would either be in the storyboard, or the bin. The cursor highlighted the currently selected shot. James could control the cursor by moving his head left and right (an evaluator would then press the corresponding button on the laptop keyboard when he did this). From the 'bin mode', James could insert a selected shot onto the storyboard by pressing his 'action' button (placed by his right elbow.

> Would you like to insert a new shot in the video? <pause>
>
> Would you like to delete the shot you have selected from the video? <pause>
>
> Would you like to move the shot you have selected to somewhere else in the video? <pause>

In the storyboard mode, there were three things that James could do. He could move, or delete, the currently selected shot; or he could change to the bin mode and insert a shot where the cursor was currently placed on the storyboard. To initiate one of these actions, he would press his 'Action' button, and would then be presented with a series of spoken choices (see box above). He could assent to any of these by pressing the 'Action' button a second time – or he could wait for the next choice to be presented.

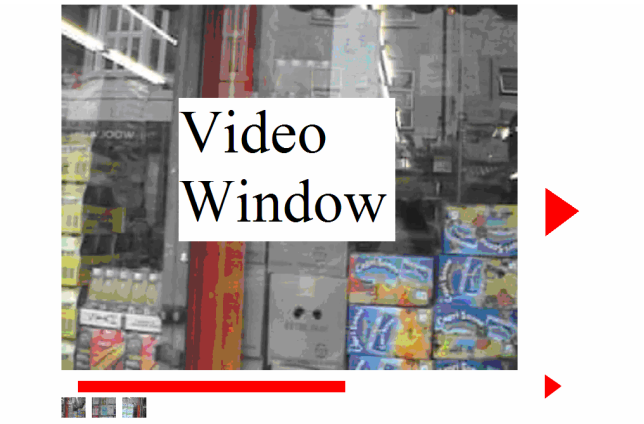


For the first evaluation this would be simulated also by using a 'Wizard of Oz' protocol, as we thought it would take some adjustment of both the language and mode of interaction before this worked properly. This mode of interaction is similar to the way that that James interacts with the world. James is presented with choices by the people around him, to which he responds 'yes', or 'no'. By following a similar protocol, we hoped that this method of choosing would be familiar to him.

Video Trimmer Prototype

Our minimal requirement for the Video Trimmer prototype was that it should allow James to define the start and end points of a shot while watching a clip. We hoped to find through this prototype how accurately James could define a shot.

The Video Trimmer could play backwards and forwards and at normal and twice normal speeds – which was controlled by James moving his head in the direction that he wished the video to play in (so for example, if the video was clip was playing back at normal speed, then James would speed it up by pointing his head to the right a second time). When a point in the video was found where James wanted to start defining the shot he pressed his 'action' button, when the video reached the end of the shot that James wanted he pressed his 'action' button a second time. He would then be shown a preview of the shot he defined. Feedback was provided under the video window. When James had started defining a shot, the red line showed what proportion of the video had been defined, whilst below that stills from the shot being defined were laid out.



METHOD

Prior to the evaluation, the author who attended the evaluation had spent time with James at three artistic events organized by Entelechy Arts, getting to know him. In addition he interviewed James' speech therapist and two members of Entelechy Arts who had been working with James over a period of five years.

For the evaluation there were five other people present: James, James' speech therapist (to help communicate with him), the arts director of Entelechy Arts, a dancer who had worked with James previously and James' care assistant (to look after James during the evaluation). These people were chosen because they knew James well, James likes them and so we believed that they would help us to interpret James' behavior. Written consent was sought from all those present, and in addition the residential home. James' speech therapist explained the purpose of the session to him, what would happen and made sure that he understood what would happen, and consented to it.

The session took place in James' room, within the residential centre where he lives, and lasted for two hours. One of the authors was present to run, and evaluate, the session. A laptop, placed in close proximity to James, was used to run both prototypes. The session was designed as a structured series of tasks, but due to problems with the first task, we were forced to improvise a new series of tasks (this improvisation will be discussed in the section below). The evaluation was videotaped. We subsequently analyzed this tape through repeated viewings, identifying aspects of communication, interaction, how James used the tool and how he responded to it.

The evaluation was intended to consist of a structured series of tasks. First of all we would show James an animation demonstrating how a film decomposed into a series of shots (the film was constructed from footage that James had enjoyed shooting, with a simulated Video Assembler). We would then demonstrate the functionality of the Video Assembler to James, before asking him to construct a simple film. Depending upon the outcome of this, we planned to either continue exploring the functionality offered by the Video Assembler, or asking to James to define a shot using the Video Trimmer. We will now describe what happened in the evaluation.

THE EVALUATION SESSION

After the purpose of the evaluation had been explained to James by his speech therapist, the animation was shown to him. James nodded as if he understood throughout this demonstration. The Video Assembler prototype was then demonstrated to James, to show how it could be used to construct the film that he had just seen.

We then attempted to evaluate the video assembler, but unfortunately we were unable to interpret James' head movements, because we were unable to determine whether they were meant to control the Video Assembler prototype, or an attempt at communication. As we were unable to find a solution to this problem, we reconfigured the Video Assembler on the fly so that it could be used as a tool through which James could select the clips that he liked.

This 'new' prototype played the clips sequentially. As each clip was played, James would press his 'Action' button with his elbow if he liked it. The clips that were selected went onto the 'storyboard' of the Video Assembler. To provide stronger feedback, so both we and James understood that he had pressed the button, a button which played back a recording of somebody saying 'like it' was used.

This 'new' prototype proved to be very successful, as it was clear to everyone in the room from James' facial expressions that he was selecting clips that he liked (e.g. while watching one clip he laughed), and that he was generally interested in reviewing this footage. After watching him make his selections, his speech therapist believed that some of his selections were because he liked a particular image, rather than the video sequence. She asked

him if this was the case, and he responded that it was. Prior to this evaluation it had not occurred to us that James might be more interested in still images than video.

Through watching James' facial expressions as he selected clips, we realized that James appeared to be interested in particular sections of footage. This provided a clear motivation for him to then use the Video Trimmer. So we tested this using a couple of the clips that he had selected and had particularly strong responses to.

The Video Trimmer was demonstrated to James, with the researcher explaining why he was carrying out particular actions (e.g. "I don't like the footage of the fruit because it is too colorful, but I like the meat, so I'll have this bit here."), so that James saw the tool in use. For the purposes of the evaluation we simplified the interaction so that James did not have any control over the playback of the video. Instead the video was started for him, and he defined the start and end of each shot using his 'Action' button. Before each shot played, James was given a count down so that he knew the clip was about to start playing.

Although James had a few initial problems understanding the exact mechanism of control, he was able to rapidly grasp the purpose of this prototype. He defined shots from the clips using this tool, and the choices he made appeared to be purposeful. From his response to the playback of the shots he had defined, it was clear that he was selecting the parts that he liked. This concluded the evaluation.

Requirements Gathered

The evaluation described above was intended as a means for us to test the effectiveness of particular video editing interfaces for James. Instead, it became a means for us to better understand James' relationship to video, and so understand better his requirements.

James appeared to be very interested in the footage that he had shot, and enjoyed making selections about which pieces of footage he liked. He seemed capable of making precise decisions about the start and end points of shot. Both the Arts group person and his speech therapist found this very exciting, as James has so few opportunities to express choice in his everyday life. Something that seems trivial from our privileged, able-bodied, stance can be a far more significant advance for James. A further and surprising discovery is that James is interested in defining stills from existing video footage, a possibility that we had not hitherto considered. We were unable to evaluate the Video Assembly (we will return to discuss possible reasons why in the Discussion), and so we do not know whether there is a requirement for making films in this fashion.

DISCUSSION

Our solution to the problem of maintaining a Participatory Design (PD) stance, when working with individuals with severe communication problems, was to build them tools which would allow them to *do things*, rather than talk about things. Although our initial prototypes were not as successful as we hoped, we believe our general approach is the right one; the problem was with the complexity of the prototypes, rather than methodology, while additional problems arose from us not having a sufficient understanding of the challenges of working in this space. In the next section we will first discuss the practical problems of working with complex disabilities, before discussing the complexities of working with communication impaired individuals. We then discuss ways in which we believe exploratory prototypes can be designed to both address these needs and uncover requirements in partnership with the participants.

Practical Issues

The timescales when working with disabled participants are longer than they would be with able-bodied participants [17], and this project was no different. Unlike conventional UCD work, we are not working with individuals, but a complex social network. We had to coordinate with the manager of James care home and his care assistant so that the evaluation occurred at a time convenient for them and James. In addition as we relying on experts who knew James (such as James' speech therapist), we had to arrange a time suitable for them also. During the evaluation considerable time was taken up by mundane activities like getting James physically comfortable, while explaining even simple concepts to James took far longer than we expected. These are not solvable problems, so designers working in this space should be aware that working with severely disabled participants is a slower process than they may be used to and plan accordingly.

Due to the time taken to organize this evaluation, we were concerned that we might discover an intractable problem with the usability of our video tools early into an evaluation, causing the evaluation to end prematurely. One of the ways we chose to minimize this risk was by using a 'Wizard of Oz' protocol, but this was unsuccessful. Given that James had no problem using the 'action' control, we believe that there was a problem with clarity. If James had to press a button with his head, then it would have been clear to both James, and the evaluators, that an action had taken place. Without that, it proved impossible to distinguish control movements from a general background of everyday movements. However, the value of a flexible control mechanism was demonstrated by the speed with which we were able to adapt the tool on the fly when we had problems with its usability. This suggests that a 'Wizard of Oz' methodology is useful for early evaluations, but the mechanism through which control is expressed needs to be unambiguous to both the user and designer.

Communication Challenges

Due to James' inability to communicate beyond asserting yes and no through moving his head, we knew that we would be unable to gather requirements directly from him. The prototypes were built as means through which James

could explore the possibilities of video, allowing us to understand his requirements by observing how he used the tools we built him. Although he was unable to fully use these early prototypes, we were still able to both test our assumptions about his requirements (in particular was he interested in using this video, and making choices about the video that he liked), and to uncover surprising new requirements (we learnt that he was interested in creating stills from his video footage, as well as creating shots).

Communication is still a problem, as we need to both explain the purpose of these prototypes to James (and what we would like for him to do with them) and interpret his actions with the prototype. While we knew that interpretation would be a problem, we had not considered that explaining things to James would be equally difficult. When we explain a new concept to James, it is very difficult to be certain that he has understood it properly; not only is James unable to tell us if he has misunderstood an explanation, but even if we ask him and he assures us that he has understood, it is impossible to be certain that he truly has understood. For example, during the evaluation when we demonstrated to James how Video Assembly worked, James assured us that he understood the explanation. However, while James may have thought that he understood, we had no way of testing whether he really had as he was unable to *demonstrate* understanding. The only way for him to demonstrate understanding was through using the Video Assembler correctly, but as he was unable to do this, we cannot be certain if James' problem with the Video Assembler was with the 'Wizard of Oz' protocol (as we believe), or understanding our explanation.

Similarly, when we try to understand *why* James carried out an action, the only thing that we can be certain of is that James did it; our interpretation of that action may be flawed, and we cannot always clarify that interpretation with James. To pick an example from the evaluation: we assumed that James was using the Video Trimmer to define shots that he liked. However he may have been doing so for other reasons that we do not understand, or seem implausible from our perspective, but perfectly plausible for James. Sometimes, as we did with our interpretation about James' interest in defining stills, we are able to test our interpretations by asking James if they are correct. Even then we cannot be certain that 'yes' means 'yes'. James might feel that he is giving us the answer that we want, or he may simply misunderstand the question that we ask him – and it is very difficult for us to pose a question so as to exclude those possibilities. We drew upon the expertise of those who work with James to help us interpret his actions, but this returns us to our original problem of how we privilege James' voice and whether we can rely upon those interpretations. Consequently we need to maintain a skeptical stance to any interpretation of James' actions. One possible approach is to test interpretations with further prototypes, taking a skeptical stance to all "findings".

An additional communication challenge that we had not considered was inter-group communication; a problem common to multidisciplinary groups. Each discipline had different understandings as to the purpose and outcomes of the work we were undertaking. So for example the speech therapist saw outcomes as being about James communicating and engaging with the world, while the designers obviously were interested in what James did with the prototypes. While these differences in perspectives caused problems when we were trying to interpret James' actions, the prototypes helped reduce this problem. Though different disciplines may interpret actions differently, all disciplines are concentrating on *what* the user did and so discussions were grounded in the context of the same boundary object [19]. Even if we were not always speaking the same language when discussing something James had done, we were able to ground discussions in terms of James' physical actions.

Using Exploratory prototypes for Participatory Design

Given the problems that we have discussed in the previous section, how successful was the use of these prototypes. One concern that we had in advance was that given few opportunities James has to exercise control over his life, he would be unable to make meaningful choices about how he used the prototypes. However, James made what appeared to be definitive choices about the footage that he liked, something that both Entelechy Arts and his speech therapist found very exciting as he has so few opportunities to exercise choice in everyday life. While we cannot be certain that James was engaging with the prototypes because he wanted to, rather than because we wanted him to, he seemed to enjoy the process and when asked later if he enjoyed it, he responded with a 'yes'. At the moment we see no reason to assume that James is not interested in doing something with the video he has shot. While it is possible that when we work with other complexly disabled participants they may fail to make meaningful choices, our work with James gives us confidence that prototypes are appropriate for a subset of this user group. Nonetheless, the prototypes as designed were unsuccessful and it was only when we simplified them in the evaluation that James was able to use them. Reflecting on our experience of working with James, we believe that there are two important issues to be addressed with any exploratory prototype: the complexity of prototype's interface, and the complexity of the task for which it is designed.

A good exploratory prototype needs to be designed so that it is immediately obvious how to interact with it. It should provide clear feedback so the user can quickly learn what effect their actions have. Our simplified Video Trimmer was a good example of this. It required only one button, making it reasonably obvious to James how he should interact with it. As the Video Trimmer played back the newly defined shot, it provided clear feedback as to what task has been achieved. Consequently, we believe that James was able to understand the purpose of the prototype

through use. In contrast, the Video Assembly had a very complex set of interactions, making it hard for any new user to understand (without considerable assistance) how they were supposed to control it. The only feedback provided after a change was made to the composition of the film was to modify the storyboard on the bottom. Given that this is an abstract representation, this feedback is essentially meaningless to anyone who has not already learned what this metaphor represents. The appropriate feedback would have been to play back the entire assembled film after a change had been made to it. However, this film might be several minutes long. While this would be a problem for a finished video editor, this is not necessarily a problem for our purposes. In hindsight, our mistake was to conceive of the Video Assembler within the framework of *a finished product*, rather than as a way of exploring opportunities and bootstrapping James' set of experiences.

Secondly, the task for which the prototype is designed should be comprehensible within the participant's experiences to date. In the case of the Video Assembler, the complexity of the task (assembling *and* editing the subsequent movie) was too far removed from what we could safely assume about James' understanding about the space. If instead we had provided him with a tool that only allowed him to assemble a movie, then this would have been more appropriate for James' current level of experience. The problem with editing as an additional task is that the necessity of this only becomes apparent *after* one has experience of assembling a movie and so understands why one would want to change it.

The prototypes were designed both to gather requirements, and to allow us to test our assumptions about James' requirements and capabilities. So for example, we had assumed that James would not be interested in doing anything with the footage without some prior purpose, and purposefully designed the evaluation so that James would first explore assembling a film, and only then would we move onto defining shots from clips. Our reasoning for this was that without this prior motivation of assembling a film, James would not see the point of defining shots. However this assumption proved incorrect, as James appeared to be very interested in both watching and creating shots from footage. This demonstrates the danger of making assumptions from an able-bodied stance. From our perspective this seemed quite a boring activity, because it is very easy for us to do. In contrast, for James this is something novel; by giving James the opportunity to find this activity boring, we learnt that for him it was interesting.

If we had successfully evaluated the Video Assembler, then we would not have realized that James required no intrinsic motivation for defining shots, and thus would have missed the opportunity space that this discovery opens up (e.g. the opportunity to explore the purposes to which James could put an accessible library of shots). We made this assumption as we wanted to maximize the use that we made of the time we had with James, and we did not want to waste time evaluating a tool that we thought James was not ready for. While this was a reasonable assumption given our knowledge of James, we need to be very careful about acting upon untested assumptions, so that we do not miss possible user requirements.

This illustrates a tradeoff that must be made by designers of exploratory prototypes for severely disabled users, such as James. Due to the timescales involved we want our prototypes to be as sophisticated as possible, so that if the opportunity presents itself in an evaluation we can explore the widest space possible. On the other hand, as we have seen, too much functionality may distract from the task and confuse the user. In our case much of the Video Trimmer's functionality remained unused (such as the ability to play back video) and was too complex for James, but we were able to hide these controls from him so that he was not distracted by them. This suggests that one solution to this problem is to build tiered tools, so that extra functionality can be made available if appropriate, or hidden when not.

Conclusion

Our initial work with James supports our initial assumption that exploratory prototypes support Participatory Design approaches when working with participants with severe disabilities and communications difficulties by using exploratory prototypes. Although our initial prototypes were not as successful as we would have liked, they allowed us to both gather new requirements, as well as testing assumptions that we had about our participant's likely requirements. Our early work suggests that successful exploratory prototypes need to be simple and provide good immediate feedback. The task for which these prototypes are designed should be comprehensible within what can be assumed of the participant's current experiences, as communication difficulties make explanation difficult.

Although our work to date is too limited for us to make definitive statements, researchers working in this space need to take account of the increased complexity that arises from both the logistics of organizing an evaluation with the a much larger social network (such as care assistants, care home managers, medical professionals, etc) and running an evaluation where time must be allocated for everything from mundane tasks like making the participant comfortable, to complex tasks such as explaining the purpose of the evaluation. Communication impairments mean that things that researchers take for granted in evaluations with able-bodied users are impossible; we cannot explain the purpose of a task to the participant, we cannot test our assumptions about why a participant carried out a particular activity by asking them. Instead evaluations need to be designed where possible so as to minimize ambiguity of interpretation.

Moving forward we plan to continue working with James using more appropriate exploratory prototypes. Currently we are using a prototype that allows James to act as a video jockey. This tool allows James to select in real time a clip

to be projected on a projection screen. This tool provides James with immediate feedback (as the selected clip is projected on the screen), while its purpose is something that he is familiar with from theatrical performances that he has participated in previously. As we predicted, James has had no problems using this exploratory prototype and we are now designing possible scenarios of use for James which range from live video editing, to providing him with a "voice" in meetings.

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