

The Ethnographically Informed Participatory Design of a  
PDA Application to Support Communication

by

Rhian Davies

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Department of Computer Science

The University Of British Columbia  
Vancouver, Canada

Date \_\_\_\_\_

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# Abstract

Computer technology has been used successfully to assist people with severe physical deficits meet their communication needs. However, this success has not been met for people with cognitive deficits, such as aphasia. Aphasia is a language deficit resulting from trauma to the language centres of the brain. Aphasia can impact reading, writing, speaking, and/or the comprehension of spoken language.

PDA's have a form factor and feature set that would appear to make them ideal communication devices. The first goal of this research was to address the communication needs of people with aphasia through exploring how a PDA could be used as a communication tool. The second goal was to adapt participatory design methodologies to better accommodate the needs of participants with aphasia.

This research was conducted in three phases. In phase one, a researcher and participant with aphasia spent over 70 hours together, during which they: (1) gained a shared understanding of the communication strategies used by the participant, and (2) developed an understanding both of how a PDA could be incorporated into those strategies, and of the usability problems limiting the use of the PDA as a communication device. Through the field study, a shared context developed, and the researcher gained communication skills necessary to communicate successfully with the participant. In phase 2, an application to support the participant's communication strategies was designed using an ethnographically informed participatory design methodology, which leveraged the communication skills and shared context that had developed through the field study. In phase 3, the prototype application was evaluated in an experimental study, and in an informal field study based on the participant's use of the prototype in his daily life.

This research was successful in adapting a PDA to better support the communication strategies of someone with aphasia. The evaluation of the prototype suggests many directions where future work would further increase the usability and usefulness of such an application. In addition, the field study highlighted other potential areas where computer technology could support the communication strategies of people with aphasia.

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# Chapter 1

## Introduction

The high-level goal of this thesis has been to discover how a personal digital assistant (PDA) could be used to support the communication strategies of people with aphasia.

### 1.1 Background

In this section the context within which this research occurred is described, and the people who contributed are identified.

#### 1.1.1 The Aphasia Project

This research was undertaken within the Aphasia Project. Aphasia is an acquired language deficit that affects an individual's ability to communicate using language. The Aphasia Project is a multi-disciplinary project spanning two universities, the University of British Columbia and Princeton University, and three disciplines, computer science, psychology, and audiology and speech sciences. The research focus of the Aphasia Project is to design high-level applications to support people with aphasia in their daily lives, and through the development of these applications, explore and adapt design methodologies that are appropriate for diverse populations of users.

The members of the Aphasia Project contributed to the research described in this thesis. Throughout the thesis, the pronoun “we” is used to acknowledge that contribution. Members of the Aphasia Project who directly contributed throughout the research are Joanna McGrenere, a computer scientist and the author's supervisor, Barbara Purves, a speech-language pathologist and aphasia researcher, Peter Graf, a cognitive psychologist, and Karyn Moffatt, a graduate student whose thesis [56] describes the initial research of the Aphasia Project. The experimental evaluation, discussed in Chapter 5, was done in collaboration with Shirley Gaw, a graduate student from Princeton University and a member of the Aphasia Project. “We” is used either to refer to all members of the project, or a subset of members. Specifically, when referring to *our* lack of ability to communicate with

people with aphasia, I am excluding Purves, who continuously advised and supported other members of the project in this area.

### 1.1.2 Participant and Collaborator

The research reported here was done in collaboration with Skip Marcella. Marcella had lived with aphasia for two years when the collaboration began, and his deep understanding of living with aphasia, together with his interest in technology, has brought an invaluable perspective to the Aphasia Project and made him an ideal collaborator in this research.

A tension exists between maintaining the confidentiality and acknowledging the contribution of participants [43]; in our research this balance was achieved through fully acknowledging the contribution of the participant, Skip Marcella, while obtaining his permission to include each reference to him reported in this thesis. When the name of someone else appears in the field note excerpts, it is replaced in this thesis with “xxx”.

### 1.1.3 Aphasia and Apraxia

Aphasia is an acquired communication deficit [17]. Aphasia can impact any or all of the language modalities, both receptive, the understanding of spoken and written language, and expressive, the ability to speak and write. Aphasia is the result of a brain trauma to the language centers of the brain, which are commonly situated in the left hemisphere [2]. The most common cause of this trauma is a stroke, but it can have a number of other causes, including brain tumors, infections, or injuries. Although aphasia can occur with no accompanying physical disability, if the trauma that resulted in aphasia extends beyond the language centres of the brain, other abilities will be impacted. Because of the contra-lateral relationship that exists between the brain and the body, motor and visual deficits that co-occur with aphasia are seen on the right side of the body.

Aphasia is acquired; it occurs after a lifetime of competent language use [17]. Communication is a collaborative effort in which communicators modify the delivery, style, and content of their communications to accommodate their speaking partners [70]. The ability to participate in the *collaborative achievement of communication*, gained through a lifetime as competent communicators, remains in people with aphasia.

People with apraxia of speech have difficulty coordinating the small motor movements required to form words and phrases [4]. Caused by damage to the nervous system [4], it is unclear if apraxia is the result of problems

with phonetic-motoric or phonological processing, or in buffer capacity limitations [49]. Apraxia can occur with aphasia or dysarthria, a weakness in the muscles that affects speech [4].

## 1.2 Research Motivation

This research was motivated both by *universal usability*, with its agenda of making technology accessible and beneficial to many, and by a desire to explore *participatory design*, adapting its methodologies, which include future users in the design of technology, to special populations.

### 1.2.1 Universal Usability

Ben Shneiderman has identified three challenges in achieving universal usability: technology variety, user diversity, and gaps in user knowledge [69]. In the field of Human Computer Interaction (HCI), there has been much discussion on addressing the needs of people with disabilities [8, 60, 63, 78]. Given these discussions, surprisingly little research has been done in the area of cognitive disabilities.

This lack of research can have profound consequences. Augmentative alternative communication (AAC) devices are underutilized in the population of people with acquired communication deficits. One explanation for this, suggested by Mollica, is that AAC devices *have not been designed to meet the needs of these users* [58]. Acquired communication deficits are not rare. Aphasia alone is more common than Parkinson's Disease, cerebral palsy, or muscular dystrophy [61]. In Canada, about 100,000 people are living with aphasia [5], and in the United States about 1,000,000 people, or 1 in 250, are affected [61].

There is little research being done in designing technology for people with aphasia, and a demonstrable need exists. The Aphasia Project, using a multi-disciplinary approach and participatory design methodologies, is addressing this gap. This area has its challenges. Aphasia manifests itself in many ways. One individual may have perfect syntax, but the words selected have little connection with what he is trying to say, and he only vaguely comprehends what is said to him. Someone else may be unable to formulate sentences, but have little difficulty comprehending what is said to her. This range of deficits precludes a one size fits all solution; rather, we are designing for "*a universe of one*", a phrase used by the Cognitive Levers research group, in reference to their research on developing technology for

people with developmental cognitive disabilities [19]. Their approach has been to research personalization, user modeling, and adaptation.

To better understand the needs of the users, the Aphasia Project is taking a participatory design approach. Initially, we are limiting the inclusion of people with aphasia on our design teams to those whose deficits have left their comprehension of spoken language relatively intact. However, the challenge of communication remains. The population we are working with has communication deficits, yet communication is at the core of participatory design methodologies.

### 1.2.2 Exploring Methodologies

Communication breakdowns between designers and potential users of technology has been identified as one of the challenges of *participatory design* [41]. This challenge is obviously exacerbated when working with a population of people with communication deficits. As part of our research agenda, we are exploring ways participatory design can be adapted to better accommodate people with communication deficits. We believe this is one of the challenges of working with this population that can be viewed as an opportunity, rather than a barrier [29]. The design solutions that arise when working with a population who cannot tolerate sub-optimal compromises in existing technology can often generalize beyond those for whom the solutions were initially intended, an effect that has come to be known as the *electronic curb cut* [39].

## 1.3 Research Objectives and Overview

The objective of this research was to contribute to the agenda of the Aphasia Project through: (1) gaining a shared understanding of the communication strategies used by someone with aphasia, grounding future work of the Aphasia Project in situated practice; (2) developing an understanding of the ways a PDA can be incorporated into the communication strategies of someone with aphasia, and the usability issues that hinder that effort; and (3) designing and evaluating a PDA application to better support its use as a communication device. Woven throughout the research is an exploration of an ethnographically informed approach to participatory design, and the documentation of how well this process meets the challenges of working with a population of people with communication deficits.

Our research fulfilled these three goals in three phases. A field study was conducted in which Marcella and the author spent over 70 hours together.

Immediately prior to the start of this field study, Marcella began using a PDA supplied by the Aphasia Project. During the field study, documented in Chapter 3, a shared understanding of Marcella's communication strategies emerged. Also documented is how Marcella incorporated the PDA into those strategies, and the usability issues that made that process difficult. This first phase addressed the first two goals of our research.

The last goal was addressed in phases two and three. In phase two, documented in Chapter 4, Marcella and the author, using an ethnographically informed participatory design methodology, designed a PDA application to support the communication strategies Marcella employed in his daily life; we called this application the *File Facility*. The design of this application was grounded in Marcella's attempts to use the native PDA interface to support his communication.

In phase three, the *File Facility* was evaluated. An experimental evaluation was conducted with six participants with aphasia, and six without. The goals of this study were to (1) compare the usability of the *File Facility* to the *File Explorer* for users with aphasia; and (2) compare the patterns of performance and preference of people with aphasia to those of the general user population. Results obtained from this study suggest that performance differences were dependent on which application was seen first. As expected, people without aphasia outperformed people with aphasia; however, the patterns of performance were very similar between the two groups. After this study, Marcella began using the *File Facility* in his daily life, and continues to use it today. An informal field evaluation was based on interviews in which Marcella gave feedback on his use of the *File Facility* in his daily life.

Following this introduction (Chapter 1), Chapter 2 reviews work related to this thesis. After presenting the chapters that document our research, the field study (Chapter 3), the design process and implementation of the *File Facility* (Chapter 4), and the evaluation of the *File Facility* (Chapter 5), we discuss the lessons learned in Chapter 6. In the final chapter, Chapter 7, we offer a conclusion and discuss potential areas of future work that came to light through this research.

Phase one and two of this thesis has been published in the 2004 proceedings of the ACM conference on assistive technologies [23].

## 1.4 A Note On Technology

The PDA used in this study was an HP iPAQ running Pocket PC 2002. The attachable camera was a Nexicam, a Nexian digital camera expansion pack

for the iPAQ.

## Chapter 2

# Related Work

In this chapter we offer an overview of methodologies and highlight research relevant to designing technology to support the communication strategies of people with aphasia. We begin with an overview of participatory design methodologies, highlighting literature done outside the context of a Western work setting. We then discuss ethnographically influenced methodologies. Finally, we offer an overview of the area of assistive technology and augmentative assistive communication devices and discuss the research done as it pertains to our research.

### 2.1 Participatory Design

Practitioners of participatory design (PD) actively include intended users of technology in the design team at all stages of the design cycle. PD refers to theories and practices used by designers to ensure that future users of their systems are included, as full participants, in the design of those systems [59]. PD is informed by the philosophy that expertise in design is not enough when designing. The users themselves must be included in the design process to ensure technology adequately meets their needs. PD is diverse both in the number of fields that have influenced it, including anthropology, psychology, and software engineering, and in the techniques used, including *prototyping* and *think-aloud* [59]. The technique of *prototyping* involves creating concrete representations of a system under development and using these to elicit feedback, identify usability problems, and assist both intended users and designers to envision the final system [6, 79]. Designers ask users to *think-aloud* while interacting with a system (i.e. speak their thoughts), thus gaining insight into what users are thinking [46, 64]. This technique identifies areas where users experience confusion or frustration, indicating design flaws. These two examples indicate how some PD techniques, such as prototyping, are appropriate for users with aphasia, while others, such as think-aloud, with its requirement that users articulate their thoughts, would not be appropriate.



PD originated in Scandinavia in an attempt to increase workplace democracy by involving unionized workers in the design of the technology with which they were destined to work [74]. The emphasis of PD in the USA shifted from being on democratic control with the focus on empowering the worker, to functional control by the workers of their tools, with the focus on increasing efficiency and meeting the needs of management [74]. The different philosophies behind both versions of PD can be seen in the methodologies that emerged from Scandinavia and the US after the introduction of PD. *Contextual design*, developed in the US, focuses on understanding how the *customer* works through intensive field studies and minimal user involvement in the actual design of the system [10]. *Cooperative design*, developed in Scandinavia, emphasizes *mutual learning*, with both users and designers learning from each other [45]. Both the Scandinavian and US approach to PD include future users and emphasize future possibilities when envisioning solutions. As well, they both are grounded in the workplace of a developed country<sup>1</sup>.

More recently, PD has been applied to the design of technology in a range of settings, including designing technology in developing countries [13, 65, 67], designing in community groups and organizations [48, 53, 54], and designing for people with disabilities [3, 20, 33, 40, 83]. Our work has more in common with research taking place within these contexts than in the Western work place context within which PD was first developed, and we share many of the challenges faced by these researchers. We will briefly review some examples of these shared challenges.

The assumptions that hold within a Western work place context cannot always be assumed in other contexts. As noted by Puri, Byrne, Nhampossa, and Quaraishi [67],

From the literature on participation in ISD [Information System Design] from a Western perspective (barring some exceptions, for example [Beck, Madon, and Sahay (2004)]), the underlying assumptions of the democratization of the workplace, high literacy rates, and a reasonable infrastructure are present. Though these assumptions can also be questioned in a Western context, it is unrealistic to assume that any of these assumptions can be made in a developing country context. [p. 49]

At times, this poses a challenge for implementing a PD process. PD offers

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<sup>1</sup>In a retrospective of PD done in 1993, all 10 countries represented were, as member countries of the Organization for Economic Cooperation and Development (OECD), developed countries [18].

a range of techniques, however, and working with participants allows local solutions that have succeeded within a local context to be shared, increasing the potential for creative solutions to emerge. Parikh, Ghosh, and Chavan, working with rural communities in India, found the PD process useful in bridging the gap between an educated group of researchers and a community of users with low literacy rates [65]. The PD process opened dialogue between researchers and participants, allowing the researchers to explore with participants the solutions and resources they used in their daily lives.

Community organizations have cultures and access to resources that differ from cultures within, and resources found in, a work place setting. Luke et al. [48], in reporting on a PD process being used by practitioners in a community organization, pointed out the synergy between the philosophy of PD and that of community based organizations. Challenges arose, however, in using PD to address the digital divide in an empowering way:

Stakeholders' ability to make informed decisions about technology enabling their work requires an understanding of their work and a basic understanding of the technology, and how it can help. The attention to digital divides tells us that participants cannot be expected to have that technical understanding, and that the knowledge gap may be fairly wide.[p. 18]

Luke et al. [48] pointed out that the designers did not adhere to a PD process throughout the design cycle, due to cost overruns. Including mock-ups and prototypes at earlier stages of the process may have helped alleviate the problems they faced. McPhail, Costantino, Bruckmann, Barclay, and Clement also noted the challenges of working with a more diverse group [53]. This diversity entailed that the design of their application needed to accommodate a range of users; the diversity of users was identified by these researchers as being an application design challenge, not a PD process challenge.

That technology is being designed for a diversity of users is assumed when designing for people with disabilities. Jorge has noted that this necessitates adapting user-centred design methodologies [40].

It is not clear that the current generation of user-centered design methods will be enough to tackle these problems. To solve the conflict between flexibility and ease-of-use in the context of unforeseen interactions difficult to foretell at design stage, new methodologies may be needed. This is worsened by the need to provide degrees of customizability for people with different and special needs. [p. 69]

Cole, Dehdashti, Petti, and Angert overcame the need for flexibility through a participatory design approach to one-of-a-kind systems for brain injury patients [20]. Their approach was to first design the interface components with clinical input, and then through an iterative approach with each end-user, refine the system. Sutcliffe, Fickas, Sohlberg, and Ehlhardt proposed a more generalized approach, suggesting the creation of reusable profiles of cognitively disabled users that can be referenced by designers of assistive technology [77].

In designing for a diversity of users, researchers need to be sensitive to the perception they are testing users, as opposed to testing their designs with a range of users. This is particularly true when working with people with cognitive disabilities. Gowans et al. in their research with participants with dementia reflect on this concern [33].

One small difficulty which we had not anticipated was the need to allay the suspicion of some individuals within care institution and to assure them that we would not be evaluating their performance or drawing comparisons with other practitioners. [p.829]

Although many of the challenges in designing technology for people with communication deficits are shared by others designing in a range of contexts, our unique challenge is overcoming the communication barrier between ourselves and the participants with aphasia. Communication between designers and users has been noted as being one of the challenges of PD [41]. Adapting PD to overcome this challenge is one of the goals of this research.

## 2.2 Ethnographically Informed Design

The research described in this thesis takes an ethnographically informed approach to PD to meet the challenge of designing with a population of users with a communication deficit.

Missing from PD is an in-depth analysis of current work practices, a problem that has led to the adoption of ethnographic techniques [21]. We have adopted this approach in seeking an in-depth analysis of the current communication strategies employed by Marcella in his daily life. Envisioning future solutions requires that current solutions can be articulated, a task that is fraught with difficulty even when the ability to communicate through language is assumed [76]. Ethnography, with its emphasis on understanding activities where they occur, and its use of qualitative data gathering

techniques rich in description [11], has the potential to ground participatory design in current practice. In the past few decades, ethnographic techniques have been increasingly adopted by practitioners in the area of Computer Supported Cooperative Work (CSCW) [34, 38] and HCI [11].

Ethnography, defined as the study of people in their natural setting, is the primary method used in qualitative research [14]. Observing a group of people with the intention of producing a rich description of their social behaviour is the essence of this methodology. Ethnomethodology, developed by Garfinkel, is a perspective on social structure [31]. Rather than being the underlying schema we follow, social structure must be observed in action as it is constantly being re-created [68]. Ethnography, therefore, is a methodology used by practitioners from a variety of disciplines, and requires no commitment to a sociological perspective; ethnomethodology *is* a sociological perspective. Ethnography is a popular methodology chosen by ethnomethodologists, who make the observational data the driving force in their research. Ethnomethodological ethnography has been popularized in HCI by Lucy Suchman in her book *Plans and Situated Action* [75]; given this popularity, the differences between ethnography and ethnomethodology are often blurred in HCI, with ethnography being equated with ethnomethodological ethnography in this field.

An ethnographic field study has as its focus the participant's experience, rather than only the participant's observable action [24]. For example, Brown and Chalmers [15] combined observational data, video, and interviews of tourists to better understand the problems tourists faced, and the solutions they employed. Bentley, Hughes, Randall, Rodden, and Sawyer [7] describe a project that used ethnographic methods in the design of an air traffic control system through the concurrent process of ethnography and systems development.

Ethnography has recently been adopted by those studying communicative disorders, including aphasia, as a way to study and understand the behaviour, strategies, and perspectives of people with aphasia [71]. The ethnographically informed study by Parr, Byng, Gilpin, and Ireland [66] presented a broad based account from the perspective of those living with aphasia, and was written with Chris Ireland, who has aphasia. The data for the project came from interviews with 50 people living with aphasia.

An ethnographically informed approach has been used in both HCI and aphasiology. We believe that this approach can be used to adapt PD to better accommodate working with participants with aphasia, in developing technology to support their communication strategies.

## 2.3 Assistive Technology and Augmentative and Alternative Communication Devices

Assistive technology includes tools, both low and high tech, that are used by people with disabilities to assist them in their daily lives [47]. Assistive technologies include mobility devices such as wheelchairs, perceptual devices such as hearing aids, and augmentative and alternative communication (AAC) devices, such as communication boards<sup>2</sup>.

### 2.3.1 AAC and AAC Devices

AAC is a process: it has been defined as any non-linguistic communicative process, such as gesturing or drawing [47]. AAC devices are a subset of assistive technology that assists users with their communication needs. These devices can be dedicated communication devices, but they can also include devices that are used for other purposes, for example a day planner, when used to assist communication.

Few AAC devices have been developed to meet the needs of people with aphasia [58, 80]. Mollica suggests that one reason such devices have been under-utilized is that they are seen as a communication prosthesis, rather than as aids that can scaffold communication skills. Unlike people with cerebral palsy and other physical impairments that intrude on the *use* of language, aphasia intrudes on language processing itself, and therefore people with aphasia develop alternative communication strategies. These new strategies need to be supported, and the solutions would be different than those for users with physical disabilities. AAC devices may also be abandoned when they intrude in the interaction between the person using the device and their communicative partner [9].

Communication is motivated by different needs, and plays different roles depending on those needs. Light proposed four categories to encompass these different motivations: expression of needs and wants, information transfer, social closeness, and social etiquette (as cited in [9]). AAC devices primarily address the communicative purpose of expressing needs and wants, but the motivation behind most interactions is the need for social closeness [9].

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<sup>2</sup>Communication boards are typically made out of laminated cardboard and are covered with visual-graphic symbols that represent words. Users point to the different symbols to communicate.

### 2.3.2 Relevant AAC Research

AAC research targets both the needs of people with physical disabilities ([16, 50, 73]), and the needs of people with cognitive disabilities ([3, 22, 33, 52, 56, 57]), including the needs of people with aphasia ([1, 80]). In this section we briefly review selected research within the field of AAC that is relevant to our research.

Simmons-Mackie, Kingston, and Schultz conducted a sociolinguistic analysis of an interaction between someone with aphasia and her communication partner [72]. In this analysis a description of the communication strategies used by the person with aphasia was provided. These strategies included enlisting her partner as her *spokesperson*, or *animator*. The authors describe in detail the subtle cues used to construct a conversation when one participant has aphasia.

Hine, Arnott, and Smith discuss the issues involved when migrating a AAC system from the desktop to a PDA [35]. A multi-media application was first developed on a desktop for the purpose of supporting story-telling during communication for non-speaking people. The storage demands required of the multi-media content was supported through networking, which allowed a server to provide the storage for the PDA. Interesting findings of this research include the results of a study done on optimal PDA display size for thumbnail images; story-telling support was achieved through the display of a number of images, and the optimal number that could be displayed changed when migrating the application from the desktop to the PDA. Although low-level findings such as these were useful to us in our research, it is unclear how the technique of story-telling used in this research can be adapted to users with aphasia. The user population for this application, defined as non-speaking people and users of AAC systems, is broader than the population with whom we are working. Further research would be required to determine whether the findings Hine et al. reported can generalize to people with aphasia, a group who typically does not use AAC devices [58, 80].

Waller, Dennis, Brodie, and Cairns [80] describe the design and evaluation of *TalksBac*, an AAC system for nonfluent adults with aphasia [80]. This system supports communication through the provision of prestored sentences and stories. These sentences and stories are entered into the system by someone acting in a supportive role to the person with aphasia. One problem identified with this system is that those in the supportive role did not always enter into the system events that the person with aphasia wished to share during an interaction. One of the four people with apha-

sia who evaluated the system had developed his own, nonverbal, strategies for communicating which he found to be more effective than the *TalksBac* system.

Mäkalä, Giller, Tscheligi, and Sefelin [51] conducted a field study to explore how digital images are used in leisure related communication. A prototype was developed based on findings from a user study and evaluation, followed by a field study which was conducted for four weeks and involved two groups in two different locations. The participants used the prototype application during this time, and were interviewed once a week. In addition, a log was kept of all the images that were sent between participants. The authors noted that the range of ways the prototype was used were discovered during the field study, and these uses did not surface during the initial user study. This finding also emerged in our research; not only do researchers not anticipate ways users will apply the technology, but the users themselves do not foresee the range of uses to which they will eventually put the technology.

Moffatt, McGrenere, Purves and Klawe designed an image and sound enhanced daily planner using participatory design methodologies [57]. Results from this research motivated a set of guidelines for working with special populations, including using standardized tests to assess the language deficits of participants, gaining experience working with the target population, and connecting with existing groups and organizations. Ensuring sufficient inactive space surrounds targets was suggested when designing for handheld devices.

## Chapter 3

# Phase I: The Field Study

This chapter reports on the ethnographically informed field study conducted in the first phase of our research. The three goals of this phase include the following. First, to develop a shared understanding of the communication strategies used by someone with aphasia. Second, to explore the possibility of a handheld computer, or personal digital assistant (PDA), being incorporated into those strategies. Third, to increase the ability of the author to successfully communicate with Marcella, and develop skills to communicate with other people with aphasia.

We use the term *shared* in the context of the first goal to emphasize that we are not *discovering* communication strategies. However, an expert communicator may not be conscious of all the strategies he or she is employing. Identifying these strategies is a cooperative process, with researchers and participant discussing the observed strategies and coming to a mutual understanding of their role in communication.

### 3.1 The Field Notes: Transparency and Privacy

Due to aphasia, Marcella has limited ability to produce both verbal and written language, and therefore the process by which he communicates, described later, does not allow for direct quotes. Field notes, blocked off by italics and set off from the text, serve the same role as participant quotes, allowing Marcella's voice to come through more clearly, and to militate against the loss of the contextual grounding from which the conclusions have been drawn. In the interest of clarity, field note summaries are sometimes used; these will be indicated by italics, but will not be set apart from the text. Both the field notes and field note summaries ground our work. As suggested by Lucy Suchman [75], the situated nature of interactions is fundamental to their meaning, and therefore it is important to include the field notes from which we have derived our recommendations and conclusions in order for those recommendations and conclusions to be verified by the reader. Including excerpts from the field notes has the added advantage of making transparent the process by which communication occurred between the



author and Marcella.

### 3.1.1 The Validation Process

The field notes were written by the author from her perspective. These notes describe the conversations and interactions that took place between Marcella and the author during the field study, often with Marcella as the subject. To ensure Marcella is given a voice and his perspective is heard, and to respect his privacy, the author obtained both Marcella's agreement on the events described and his permission to describe those events. All sections that refer to Marcella were read to him and his permission to include the reference was requested. If Marcella did not agree with the author's description of an event, they would discuss the description until they both agreed that the events were portrayed accurately. Although Marcella usually granted permission to include the reference, on occasion wording was changed and descriptions of events were omitted.

## 3.2 Background and Pilot Study

We include the background details here for two reasons. The first is that this is an ethnographically informed study. Our claim is that an ethnographically informed participatory design methodology has benefits beyond that of a traditional participatory design approach. An ethnographically informed participatory design process begins with the researcher spending time with the participant, observing the current context within which the application will be used. The design process, therefore, starts with a shared context, and a shared understanding of current practice. The major drawback is the time investment required. In assessing whether this approach is viable, then, it is necessary to delineate the total time that Marcella and the author spent together. The second reason the background is included is that events leading up to our decision to take an ethnographic approach were themselves motivating factors in that decision.

Marcella and the author met on January 21, 2003, four months prior to the start of the field study. During those four months, Marcella and the author met once a week for one hour to conduct a study on AphasiaMate, a computer-based aphasia treatment program. This study was being conducted by Purves for a colleague not associated with the Aphasia Project. The author's involvement came about through a directed studies course on aphasia that was supervised by Purves.

In the AphasiaMate sessions Marcella did set exercises. These exercises ranged from matching an environmental sound, such as a phone ringing, to its object, a phone, to correctly selecting a picture that represented a spoken sentence. For example, to correctly respond to the sentence “Select the box that has one small triangle between two large rectangles”, the user selects the one image that portrays that configuration, among several that do not. During these sessions the author recorded the time it took Marcella to complete an exercise and made notes on patterns and interesting observations seen in his responses to the exercises. Although little conversation could take place in each session, over the course of the four months the author grew more comfortable in her ability to communicate with Marcella, and he shared stories of his life with her.

In February, Marcella began participating in a study conducted by Moffatt. The focus of Moffatt’s project was on developing an aphasia friendly day planner for a PDA, using text, images, and sound [56, 57]. In the first session, Moffatt spent half an hour with Marcella in order to observe any difficulties someone with aphasia might experience when interacting with the native interface of the PDA. No obvious usability issues were noted.

The following week Marcella expressed a great interest in the PDA, particularly the use of the *Notes* application. As part of its core package the Pocket PC includes a *Notes* application, similar to the *Notepad* application available on *MS Windows* desktop computers. Input to Pocket PC *Notes* is done either through soft keyboard entry or through freeform entry via the stylus. *Notes* appeared to offer a natural electronic replacement for paper notes, which Marcella uses in communicating, as described in 3.3. He found it irritating to deal with the constant flow of paper notes that needed to be disposed of after a conversation. Our research team agreed that the *Notes* application seemed like an obvious benefit to Marcella and other potential users who use paper notes as part of their communication strategy. We decided to conduct a pilot study that focused on Marcella’s use of the PDA’s *Notes* application. To structure the data, we began with a preliminary study to establish a baseline of paper pad use prior to Marcella adopting the PDA, with the intention that we would then compare this baseline to his paper pad use after he became comfortable with the PDA. We assumed that his use of paper notes would drop once he had access to the *Notes* application on the PDA.

Marcella was given a sheet to record his paper pad use. He numbered his paper pads, and when he began using one he wrote down the pad number on the record sheet, together with the date he began using it; later, he recorded the date the pad was finished. This allowed him to continue his practice of

using several paper pads at the same time. Marcella kept track of how many paper pads he used between March 14th and April 8th inclusive. During these 26 days, he used an average of 21, 3 by 5-inch pages a day. Marcella was then given a sheet to record the times he used a small whiteboard and 8 by 11-inch paper sheets, both of which he sometimes used in place of paper pads. Between April 11th and April 19th he used the whiteboard four times, and he used four sheets of 8 by 11-inch paper. At the end of this study, we were not clear how accurate these recordings were. Our lack of experience communicating with people with aphasia left us uneasy as to how clearly our instructions had been understood, and how committed Marcella had been in conducting the study<sup>1</sup>.

After a baseline of paper pad use had been established, the pilot study moved onto the PDA phase. On April 22 Marcella was given a PDA to use; there were initial problems with the hardware, and Marcella was unable to use it. On May 4, the PDA he was using was exchanged with another, and Marcella again began using it in his daily life. Again there were technical problems; his home desktop computer required an additional USB port before it could be synchronized with a PDA. Marcella was also encountering difficulties accessing the PDA's *Notes* application.

Given our uncertainty of how strictly records were being kept in the baseline study, and the technical difficulties Marcella was encountering, we decided the best approach would be for one researcher, the author, to meet regularly with Marcella. In doing so, we would not only benefit through our ability to closely observe how Marcella communicated in his daily life and how he was incorporating the PDA into his communication strategies, but technical problems could be fixed as soon as they arose. Our choice of an ethnographic methodology was motivated by the difficulties we were encountering using other methodologies.

### 3.3 Methodology

This section describes the methodology used in the field study. Both the researcher, the author, and the participant, Marcella, are described to give context to their interactions as they are reported in the field notes. Field

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<sup>1</sup>Marcella heard of our concern during the process of validation. At that point the author asked Marcella if he had taken the request for an accurate assessment of use seriously. He said he had, and that the results were probably about 80% accurate. Our concern quite probably came out of our lack of experience communicating with someone with aphasia.

notes made during that time form the main source of data for this report, with secondary data sources being triangulated with the field notes.

### 3.3.1 Participants

The author, Rhian Davies, is a Caucasian female who, at the start of the field study, was 39, and was conducting this research as part of a Master of Science degree program. The participant, Skip Marcella, is a Caucasian male with aphasia and apraxia. When the field study commenced, he was 52 years old, and was two years post-onset. His aphasia and apraxia were the result of a stroke, precipitated by a single vehicle motorcycle accident.

*Skip acted out biking, crouching, hands on handlebars.*

*Davies: "You were riding on a motorbike?"*

*Marcella: "Yes!"*

*Skip writes girl*

*Davies: "You were riding with a girl?"*

*Marcella: "Yes"*

*Yes, but not quite right. Points behind him, with his thumb, crouching again holding handlebars.*

*Davies: "You had a passenger?"*

*Marcella: "Yes."*

*Turns the handlebars.*

*Davies: "You turned a corner?"*

*Marcella: "Yes."*

*Points back at passenger.*

*Davies: "She's not on the bike anymore?"*

*Marcella: "No"*

*Not quite what he meant. He gestures, turning again, points to the passenger, stands straight.*

*Davies: "She didn't turn with you?"*

*Marcella: No!*

*Davies: "So you lost control and crashed?"*

*Marcella: "Yes"*

*But there's more, I'm not sure. Skip does a summersault in the grass.*

*Davies: "You flipped? Head over tail?"*

*Marcella: "Yes!"*

*He gestures with his hands on the handlebars*

*Davies: "while you were on your bike?"*

*Marcella: “Yes!”*

The following description of the language ability of Marcella is based neither on a clinical evaluation, nor with the benefit of clinical experience, but rather is a description filtered from the interactions between Marcella and the author. With that caveat in mind, the impaired language modalities in Marcella are speech production, reading, and writing.

Marcella’s receptive language understanding has not been noticeably impacted, although miscommunication does happen, particularly when conversation occurs within a group, when abstract details (e.g., dates) are discussed, and when Marcella is tired. Miscommunication occurs less, and is caught and corrected or acknowledged and dropped, when communication is one-on-one.

Speech production is limited to a handful of expressions, such as *OK*, *no*, *holy cow*, and *hi*. Some words and phrases could be produced slowly and with great effort, but not all the words Marcella wants to say come to mind. Very few non-content words are said as Marcella rarely uses full sentences but rather speaks one or two words together. Words are rarely spoken to fulfill a syntactic role, but rather, to convey meaning. For example, *and* is not usually said in a conjunctive position in a phrase, but alone, to convey meaning, “*go on...*”.

Reading is difficult, although Marcella can pick out words, especially when they are seen in context.

*We stopped at the pizza place — not many tables, mainly for take out. Leaning on the counter, we both go over menus. They were colorful, with lots of pictures, the way pizza place menus often are. Skip picked a special, then said “no” pointing to the menu: “after 9:00pm only”.*

Although Marcella reads single words, phrases that rely on the syntactic positions of the words to convey meaning are difficult for Marcella to understand. Reading poses enough difficulty that he reads electronic material with the assistance of *ReadPlease*, a text-to-speech software program.

Marcella writes words on note pads to assist him in communicating, and appears to be able to write any content word, or at least enough to communicate any thought.

*The following is a description of a discussion on the controversial harm reduction program being introduced in Vancouver’s downtown eastside, a program that includes methadone treatment.*

*Davies: "xxx is on methadone?"*  
*Marcella: "Yes."*  
*Writes 10 years.*  
*Davies: "10 years?" disbelieving...*  
*Marcella: "Yes!" emphatically....*  
*Davies: "So there is no next step?"*  
*Marcella shakes his head.*  
*Davies: They just put you on methadone and that's it?"*  
*Marcella: "Yes!"*  
*I shake my head in disbelief.*  
*Marcella: "Yes!" More emphatically...*  
*Davies: "Why?"*  
*Skip writes \$ detox 30 days 40,000 meth 100 day.*  
*Davies: "100 dollars a day?"*  
*Marcella: "No."*  
*He writes mg.*  
*Davies: "100 mg. a day?"*  
*Skip nods.*  
*Davies: "How much is that?"*  
*Skip gestures that it wasn't that much.*

Spelling correctly, or writing the name of something out of context is difficult for Marcella. Sometimes, there is a disconnect between what he writes and what he says.

*Skip writes muff and says "motor...". I say "motorcycle?". Skip points to the note he's written, muff. I try again, "muffler?". Skip says, "Yes."*

The stroke left Marcella with a slight motor impairment on the right side. His right hand is his dominant hand, so this impairment does effect his dexterity.

Marcella has limited formal education and had left high school before graduation. His work background was diverse; he was a printer by trade, but had a strong entrepreneurial spirit and had successfully started several businesses, including a ski chalet. He had overcome addictions prior to his accident with the help of a strong spiritual faith, a faith he credits with giving him the power to accept his inability to use language.

Marcella lives with his partner, has two grown children, and two grandsons. Prior to the accident, Marcella was a leader in a 12-step Recovery Program, and publicly spoke at many gatherings, traveling across BC and

Canada. Marcella had taped one of those speeches; he was truly a gifted speaker and communicator who conveyed an easy sense of humour and had an ability to create a feeling of intimacy through his words.

Marcella is very comfortable with technology and enjoys learning about and using computers and electronic devices. Marcella is computer literate; he was a graphic designer and ran a desktop publishing business at the time of the accident. Since then, Marcella has taken a course in *Adobe Page Maker*, and, in his role as Public Relations Director for the BC Aphasia Centre, designed their posters and brochures using that software.

### 3.3.2 Procedure

The author and Marcella spent over 70 hours together between May 22 and August 29, 2003. They lived in the same neighbourhood and would meet at coffee shops and restaurants, at the home of Marcella or the author, or in local parks. Their neighbourhood was about a one hour bus ride from the university, and they would occasionally take the bus together to travel to UBC to attend the AphasiaMate sessions. Throughout June they met at least twice a week, with each meeting lasting between  $2\frac{1}{2}$  to 7 hours. In July less time was spent together, but at a minimum, meetings continued weekly. August included a two-week stretch where no meetings occurred, due to vacations.

Traditional ethnography attempts to record all observations free of pre-conceived ideas and judgment. A cultural interpretation of the group under study occurs after an extensive, and as comprehensive as possible, field study [28]. Observations and notes in this research attempted to follow this tradition. However, unlike a true ethnographic study, there was a pre-defined goal in this study: to learn more about how communication occurred, and how the PDA was incorporated into Marcella's daily life. This goal necessarily introduced an observer bias in that any communication, and any PDA interaction, drew more attention and observation than other events. While notes from any field study will necessarily only include a small subset of what transpired [14], the filter on the subset in this case was clearly the potential for technology to assist in an interaction in some way. The ability of such events to draw attention brings a corresponding shift of attention away from other events, eliminating them from being added to the rich description of daily life.

Very brief notes were written during the meetings; after each meeting the author wrote extensive field notes on what transpired. Marcella preferred that the author not take notes unless he was asked a direct question,

and the answer was being recorded. To communicate with someone with aphasia, one must closely attend to the person. Notes need to be verbalized, drawings interpreted, subtle facial cues observed, and gestures seen. During the interaction, the communication partner articulates what she or he thinks the person with aphasia is wanting to say. Note taking during this process is therefore intrusive and diminishes the quality of the interaction. Marcella knew that the author wrote notes after every meeting, and gave his permission for detailed notes on what transpired to be written, with the knowledge that further permission would be obtained before making public any event or story that involved him.

The data supplied by the field notes was triangulated with informal interviews that occurred throughout the study. As themes began to emerge, the author read through the field notes to identify supporting evidence, and discussed with and questioned Marcella about the accuracy of her interpretations.

During the field study, notes that Marcella had written during conversations were saved and used as a further source of data. Not all notes were saved; sometimes they were not requested, and sometimes after a request, they were not obtained, for a variety of reasons. Sometimes, the notes were tossed into a garbage can too quickly to retrieve, other times what was written was private. Marcella found it quite amusing that anyone wanted his *garbage*, and would sometimes teasingly toss the notes into a nearby garbage can, pretending not to hear the request in time. The notes that were obtained, however, were invaluable both when writing the field notes after the meetings and later when reading the field notes, as they allowed a comparison of what had been written in the field notes and what Marcella had written during the original conversation.

The email messages sent to the author by Marcella were another source of data. They not only served as a source of data on Marcella's use of written language, but on his use of email for communication.

During the field study the author had contact with a number of other people with aphasia, both in Vancouver and Victoria. This contact occurred in the context of other projects within the Aphasia Project and in interactions with people met through Marcella. Although this report is primarily a single case study, the field study did occur within a broader community of people with aphasia.

The validity of the themes identified was assessed within the context of research in the area of HCI, assistive technology, and aphasia. As well, during the process of validation, Marcella did challenge some of the author's interpretations and they were adjusted accordingly, further supporting the



validity of the themes.

### 3.4 Emerging Themes

Over the course of the study, three notable themes emerged: *accountability*, *communication strategies*, and *PDA use and usability*.

#### 3.4.1 Accountability

The term accountability has been used in a number of ways in HCI literature (see Eriksén [25] for a review). Here, the term is being used to mean *answerable*<sup>2</sup>. Accountability can be framed around issues of concern to the research community and issues of concern to the participants involved in the research. As researchers in HCI, we are accountable to the HCI community with whom we are sharing our research. When we use terms such as participatory design, we must offer assurances that we are truly including participants in the process of designing technology. As researchers exploring participatory design methodologies with people with aphasia, we are also accountable to the greater community of both people with aphasia and their families. Working with people with disabilities requires that we are vigilant in ensuring that power differentials are not exploited. Working with people with communication deficits necessitates that we pay close attention to how we communicate, more specifically, how we listen.

#### Accountability to the HCI Community

To be accountable to the HCI community, we must ensure that when we use participatory design, we are able to communicate with the participants. Inviting people with aphasia to the table is not enough to warrant the use of the term participatory design. Communicating with people with aphasia involves relaxing time constraints; communication takes longer, especially when the communication partners are inexperienced or relationships have not been established. Communicating with people with whom one does not have an established relationship means that there is less shared context, which makes coming to a shared understanding more difficult. Because the communication partner must often make guesses at what the person with aphasia is saying, mutual trust is involved. It is very difficult to circumvent an issue; an opinion cannot be alluded to as the communication partner must

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<sup>2</sup>This use of *accountable* contrasts with the way it is used in ethnomethodology literature, to mean *able to give an account* [24].

identify what topic is being discussed, and articulate what is being said in a forthright manner. Speaking directly, however, is much less common when speaking with someone with whom one is unfamiliar. This is true for both communication partners. People with aphasia must choose from the words they have access to, these words may not be the most discrete, or carry the subtlety their thoughts warrant. Rather than offend a stranger, a thought may not be expressed. An established relationship brings with it a degree of trust; the communication partners will not be as concerned with creating a wrong impression. *Skip and I met Shirley at UBC. After the meeting, the three of us sat in the foyer of the building to chat. Shirley asked Skip, several times, if he would like to leave. He shrugged, indicating that he could stay longer if needed. Finally, Skip and I left, taking the bus home together. As soon as we were on the bus, Skip looked at me and tapped his watch. I knew it was getting late, but asked why he had not responded with a "yes" when Shirley had asked if he wanted to leave. He shrugged and wrote 1 day. Staying late one day was not a problem, but he preferred to leave earlier than the current time, which was, at that point, well into rush hour. We discussed this together later. If he had known Shirley better, would he have tapped his watch at her, rather than indicating he could stay longer? He said yes, probably he would have left earlier.* It is easier to assert one's position with people one knows better. This of course is true of all of us, but because it is much harder to give subtle social cues when you have a communication deficit, it is easier to err on the side of politeness. This is exacerbated by the fact that language plays such a huge role in defining who we are, particularly when establishing relationships. Without words, gestures may be interpreted as abrupt or even rude by people unaccustomed to interacting with people with aphasia. People with aphasia are experienced at interacting in a world where people do not understand what aphasia is and are not accustomed to communicating with people with aphasia. This lays an added burden on people with aphasia when interacting with strangers that should not be underestimated by researchers in this area.

As well as a reticence to voice their needs, a lack of familiarity will limit the range of discussion topics, some of which are necessary to establish the communication needs of participants. *Skip asked if I would transcribe the story of his accident, as he relayed it to me. The story began with a brief overview of his life. During the process of writing his story, Skip indicated he wanted it to be softened, have less focus on certain aspects of his past life. He indicated this by writing "bad man", and gesturing that he did not want this portrayal of himself. Clearly, he had not been a bad man. I asked him if he would have chosen those words prior to his accident in describing himself at*

*different stages of his life. He rolled his eyes in response, and further assured me that his views were far from being that simplistic. Having established a relationship assured him that he could use these simplistic phrases, and that I would interpret them within the context of knowing who he was; I would get clarification when what he said did not fit with who I knew him to be. In a new relationship, context is lacking, and we rely more on the words that are said in our interpretation of meaning, making the range of topics people with aphasia can comfortably discuss more restrictive.*

When a relationship has not been established, people with aphasia may also question how well designers understand what aphasia is and how it is manifested. If trust has not been established, these queries may go unasked, leaving a negative impression of the design process. *Paper prototypes ensure that time is not spent on an unworkable design, and participants will not feel obligated to support a design that, although not usable, is the product of time and effort. Karyn, in designing an aphasia-friendly day planner, began the design process with a low-fidelity paper prototype. On one of the iterations, Skip was asked for feedback. After his meeting with Karyn, he met me in another lab. He asked me if the reason Karyn had used a paper prototype was because he had suffered a brain injury. During the process of understanding the question, Karyn joined us, and was able to clarify her reasons for using a paper prototype.* Given that a mastery of language is often associated with intelligence, language problems can be interpreted by the uninformed to indicate an underlying intellectual deficit. People with aphasia are naturally sensitive to signs that this interpretation has been taken. If participants interpret a design methodology, such as paper prototyping, to indicate a fundamental lack of understanding of aphasia by the researchers, this will have obvious detrimental effects on the design process and the willingness of the participants to continue to be members of the design team. Establishing a relationship with participants increases the chances that these misunderstandings will be shared, allowing for clarifications and discussions to occur.

An established relationship between participants and researchers can potentially increase the chance that a participant identifies too strongly with the final design, resulting in a less critical eye when evaluating the prototype. We believe this can be overcome by an evaluation process that includes participants that were not involved in the design process.

Using an ethnographically informed methodology ensures the Aphasia Project is accountable to the greater HCI community; although communicating with people with aphasia takes time and practice, we have been committed to this through the use of a methodology that ensures that the

necessary time has been taken. One of the benefits of an ethnographic approach is that technological solutions arise from the grounded context within which they must be used. Witnessing the context is even more crucial when designing for people with a communication deficit, as discussions can then occur within this shared context. The design process, therefore, can begin from a shared understanding of the context and problems encountered within daily life.

### Accountability to the Participants

Choosing to conduct an ethnographically informed study implies we are acknowledging we do not know what it is like to live with aphasia and therefore do not know what communication needs and strategies can best be addressed and supported by technological solutions. Ethnography supports the participatory design process in its ability to ground our work within the context of the daily lives of people with aphasia. However, the demands placed on participants, both in terms of their time and the invasion of their privacy, brings with it a resultant increase in our accountability to the community of people with aphasia. Although designing technological solutions that are usable and useful is the goal of the participatory design methodology, the emphasis when designing technology for use within a work setting is different than when designing technology to be used to support communication in daily life<sup>3</sup>. For example, one issue that plays a critical role in designing for people with aphasia but is rarely addressed in designing for the workplace is the necessity for developing a solution that is socially valid. Social validity encompasses the following three aspects: the social significance of the goals, the social appropriateness of the procedures, and the social importance of all effects [82]. Including participants as early as possible in the research effort, rather than waiting to include participants on the design team once a problem has been identified, increases the likelihood that the problem being addressed is one that is recognizable to people with aphasia (socially significant), the methodology used in designing a solution is non-coercive and empowering for all participants (socially appropriate), and finally, the solution is not only acceptable, but welcomed by members of the aphasia community (socially important).

Concern with social validity is voiced by those researchers working within the disability field, and has motivated the development of a research model, *participatory action research* (PAR), that actively includes participants in

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<sup>3</sup>We are not implying that designing for a workplace is unproblematic (see Suchman [76]).

defining research goals and procedures [81]. In collaborating with participants with aphasia, acknowledgement of those participants as experts in the area of study must be given. As Newell and Gregor [63] point out, the danger here is that researchers will be too motivated by the agenda of participants, limiting potential solutions to only those envisioned by them. However, actively including participants in defining research goals does not require that researchers are not involved in the process themselves. The strength of collaboration is in the combined contributions of people with different areas of expertise and perspectives.

We as researchers must not only learn how people with aphasia communicate in order to design effectively, but we must also attempt to learn what the underlying assumptions are that we hold about people with disabilities, assumptions that can become apparent during interactions. As researchers, we must educate ourselves to ensure that our beliefs about people with aphasia are not undermining our research. Krogh [44] discusses the range of models people work from that stem from an underlying focus on the deficit or capacity of people with disabilities. A *medical* or *charitable* model emphasizes the disability and therefore sees the disabled person as someone needing medical management or support. An *independent living* model focuses on the capabilities of people with disabilities. In researching solutions for communication needs, it is imperative that we examine our beliefs about people with disabilities if we are truly going to be working towards an empowering solution.

An ethnographically informed approach permits not only objective data gathering, but also an opportunity to learn the strategies one could employ to communicate without language. To be able to perceive the solutions used by people with aphasia requires that we see them as experts at communicating with aphasia. Similar to the filter on our observations that occurs when we define our study goal prior to conducting a field study, our assumptions about people with disabilities will filter the observations we make, focusing our attention on certain events and causing us to be blind to others. If we believe people with disabilities need our support it will be much more difficult to see the solutions they already use in daily life; our focus will be primarily on the communication difficulties they face. It is the strategies currently employed by people with aphasia that need to motivate the technological solutions we design. Such solutions have greater potential of being adopted by people who already use similar solutions in their daily lives. Observing the problems encountered is necessary, but should not be done through the filter of viewing the disability as existing as a problem in isolation. People with aphasia are interacting with the greater community, and

must deal with the reaction and responses of people who do not necessarily understand aphasia. As researchers, we need to understand these responses, and we need to address our own responses as inexperienced communicators with people with aphasia. Spending time with people with aphasia offers us the opportunity to challenge our own hidden belief systems through honest exchanges with participants. Seeing ourselves as both experts in the area of design, and learners in the area of living with aphasia, allows us to create a more collaborative research environment, and requires that we acknowledge the expertise of participants [27]. An ethnographic approach increases the opportunity for such exchanges.

*When I read the field study report to Skip during the validation process, he indicated I should stop using his initials and instead use his name. I first responded that, due to confidentiality concerns, I could not do this. This response reflects a paternalistic view of disability. I saw myself, and the Aphasia Project, as being responsible for the level of exposure Skip would have within the context of this research. Further discussion resolved this impasse.* The issue of acknowledgement, raised by Krogh [43], is critical to confront and discuss if partnerships between researchers and people with aphasia are to be mutually beneficial and productive. Marcella and the author explored the issue of confidentiality and acknowledgement further, a topic that would be much more difficult to pursue outside the context of an established relationship. As a result of this discussion, Marcella is fully acknowledged as a collaborator in this thesis and is a co-author on a paper based on this research [23].

Accountability is difficult to measure and discuss within the framework of traditional science. It is, however, a critical component of research done within the disability field. Awareness of the complex issues surrounding collaborations is essential in creating an environment where communication can flourish. This becomes even more essential when including people with communication deficits.

### 3.4.2 Communication Strategies

Marcella is a great communicator; he has an outgoing personality and enjoys social interactions. Marcella played a tape of himself speaking at a public engagement on the author's first visit to his home. Although hearing him speak was startling and unexpected, it was not surprising to hear the easy style with which he communicated verbally; he communicates with the same style using alternative communication strategies. Marcella puts his communication partners at ease, and is a great teacher in guiding communication

partners through a conversation where only a few words are being offered on his side. It is up to the communication partner to articulate the story, weaving the sentences from single words both spoken and written down, gestures, tone of voice, and pictures. Marcella makes great use of technology in his communication strategies. He often carries a camera and shares photographs, and uses word processors and email frequently.

### Non-Electronic Communication Strategies

Marcella uses a number of strategies in his day-to-day interactions. He says a few words and can write down words on pads of paper, mainly nouns and verbs. He also uses gestures, serendipitous props, and acts out events. His communication partners pay close attention to him during interactions and try to articulate his thoughts. He guides his partners to express his thoughts by indicating how close they are to correctly articulating what he is trying to say, and offers more cues to either correct them or further engage in the conversation.

Although Marcella is able to articulate only a handful of words without effort, the various tones he uses give these few words a vast range of meanings. A *yes*, said with little enthusiasm, means good enough. You are not saying what he is intending, but the thought is not important enough to be pursued. A *yes* said with great enthusiasm means you have said what he intended; this usually occurs only after several iterations. *Yes—no* means that although what you have said is true, it is only partly true, and you need to expand on the thought. An absent *yes* suggests you should change course, you are completely off the path, but he does not want to pursue that line of conversation. This can be an extremely effective way of carrying one side of a conversation. *At the end of our discussion on safe-injection sites, quoted earlier, Skip's response to one argument that I had re-phrased more than once was "Oh, OK" in a tone that clearly implied he did not agree at all.* The ability of people with aphasia to learn to communicate so effectively with only a few words, about subjects as complex and subtle as safe-injection sites, is humbling and a reminder that no technological assistive device will be a silver bullet, but rather another tool in the arsenal of people who truly know the meaning of communication.

Gestures can add another dimension to single words, expanding the potential meanings that can be assigned to them, as well as reinforcing or correcting the meaning of a word. Words that denote times, such as *yesterday* and *tomorrow*, are difficult for Marcella. He would always gesture backwards or forwards when he attempted to say either word, to ensure the

correct meaning was taken. Marcella draws letters and symbols in the air. He once picked up a stick and wrote a word in the dirt when out walking. He also re-enacts events. *After his accident, Skip had an out-of body experience. This was a particularly difficult concept to get across without words. To tell the story, Skip used re-enactments and gestures.*

Marcella carries a small pad of paper and pen with him, and writes single words on it to assist in communication. The paper pads fit easily in his hand and are 3 by 5-inches or smaller; his preference being a pad that is 3 by 4-inches. He draws rough pictures, the meaning of which is enhanced through the use of lines, arrows and pointing the pen at various parts of the pictures and words. Marcella prefers that his communication partners attempt to articulate his thoughts while he is expressing himself, so that he knows if his message is being understood and so that he can hear his thoughts being expressed. Marcella also writes on a small, 6 by 8-inch whiteboard which he uses as a substitute for the note pads. In meetings he will also use 8 inch by 11-inch paper.

Marcella utilizes various serendipitous props when available. *During a discussion about a piece of artwork that hung on his wall, Skip disappeared into his bedroom and came out with a T-shirt with a map of BC and the Yukon on it. He pointed to the location of the cabin; the home of his friend, the artist. Other props were used as well. I asked Skip if he had incurred a parking expense when we met at the university. We were walking down the street at the time and in response, he pointed to a parking sign indicting two hours of free parking.*

Marcella uses business-sized cards which he hands to strangers during interactions to explain why he cannot speak, and why the words he does say are slurred. These cards state:

*As a result of a stroke,  
I have **Aphasia**,  
this means I have no speech.  
However,  
my intelligence is intact.*

At times the cards are only glanced at, or not accepted. Marcella has experienced people assuming he is drunk because of his slurred speech, or assuming an intellectual deficit because of his inability to use language. Many times people are simply uncomfortable, not sure how to respond or react, appearing uncertain whether he could understand them. Cultural attitudes filter through in the attitudes of people. According to Marcella, men, more than



women, tend to not want to accept the cards, or any other written material, and when they do accept, rarely read more than a sentence. During the field study, it seemed people from a European background showed more discomfort compared to First Nations people, and immigrants from Asia, when interacting with Marcella. *I asked Skip about the different way people from different cultural backgrounds respond to him on first meeting him, with some being comfortable interacting with him, and others being slower to attain the same comfort level. He confirmed my perception.* When the author and Marcella were together, men were more likely to address the author even when Marcella was the one making a request, or ordering at a restaurant. By contrast, women tended to address Marcella. Of course, this is only a general pattern, with many exceptions. *Our favourite coffee shop was run by a gregarious Caucasian man who did not even notice that Skip had aphasia, until Skip handed him a card. A little embarrassed, he gruffly responded that many people have trouble asking for a coffee in the morning. He then paused and said, "Sorry buddy", and went back to asking Skip what type of coffee he wanted.*

When establishing new relationships, Marcella will introduce and situate himself through the use of short stories written on 8 by 11 inch paper. The primary story Marcella shares is the story of his motorcycle accident. One version is very short, describing the accident, the subsequent ambulance rides to two hospitals, his coma, and his acquired aphasia. The second describes these events with more personal details and includes the story of his recovering not only from the physical consequences of the accident, but his emotional recovery from the loss of his ability to use language. Marcella also uses a 3-ring binder that includes pictures and stories written by significant others who were close to him at the time of the accident. This is much bulkier and he brings it with him only with the intention of showing it to someone, rather than bringing it to share in serendipitous encounters.

Papers related to other significant events in his life are stored in boxes, much like people without aphasia might store mementos and records of events. In addition to containing memories, however, these papers facilitate Marcella in introducing topics of great interest to him. These papers allowed a conversation to progress to a much deeper and serious level on one occasion during the field study; the pictures and stories situated Marcella within the context of particular social and political events.

Marcella uses a variety of reference materials to assist him in communicating, including maps, dictionaries, photos, day planners, and wall calendars. Maps, as previously described, are used to point out the locations of places being discussed, but they are also used to indicate details of past

events. *I asked Skip if getting out at a certain bus stop and walking home would be too long a walk for him. In response, he stopped and pulled out a map from his back pack. He wrote dogs on a note, and pointed to two places on the map. The walk he had taken the dogs on the previous day was much longer than the walk I was suggesting.* He once brought a dictionary with him when the focus of our meeting was to transcribe the story of his accident. Although he did not use it on that occasion, when questioned, he said he had used it in the past when he could recall only the first few letters of a word. He uses day planners and wall calendars not only to assist in scheduling, but to easily share the details of past events: what occurred, and when and with whom it occurred.

Using a combination of communication strategies augmented with pen and paper, gestures, and artifacts, enables Marcella to communicate very effectively. Communicating something specific can be a long process, however. *Skip told me that his speech therapy program was now over, as it only extended two years post-onset. When I finally understood what he was saying, Skip wrote 10 minutes. The information contained in that one sentence had taken 10 minutes to convey and nine sides of 5 by 3-inch paper.*

### Non-PDA Electronic Communication Strategies

Marcella often carries a camera. He uses photographs as a way to share events and preserve memories, as do people without communication deficits, but he also uses photographs in more revealing ways, to share parts of himself with others. *Among the photos Skip showed me were photos of sociopolitical actions. By showing these to me he shared aspects of his political and social philosophy.* He often shows people pictures of his dogs; this not only succeeds in the usual way of showing what they look like, but also shares the information that he has dogs, how big and what breed they are, and that they are important to him. This kind of information is often shared through words, with pictures serving to reinforce the words; for Marcella, the photos play a larger role in communication.

Marcella uses his desktop computer extensively. He uses *MS Word* to read and write documents, with the assistance of *ReadPlease*, a text-to-speech software program. To write new material, Marcella uses previously written material from several sources.

Prior to his aphasia, Marcella had been an editor of a community-based magazine, and these editorials formed one source of previously written material. He also had a journal of personal stories about his life that he had written prior to his accident. He creates electronic versions of some of these

stories by typing them, word for word, with little understanding of the sentences, into a *MS Word* document. He then uses *ReadPlease* to listen to the story and make corrections. Marcella also has more recent stories that he has communicated to people and that have then been transcribed for him. Using all these previously written documents, Marcella is able to compile new documents of several pages. During the course of the field study, Marcella wrote personal life stories, acceptance speeches, and speeches for community meetings. He reads his previously written documents, using *ReadPlease*, in search of a sentence or phrase that expresses a thought he wants to insert in his new document. He then copies the phrase from the old document into the new document, and continues the process. After he is satisfied that he has expressed his thoughts, he asks his partner or a friend to edit the document. When it is returned, he once again carefully reads it, using *ReadPlease*, to ensure the meaning he intended had not been altered. This process is extremely slow. A 20-minute speech took Marcella 10 hours to edit and update after he had typed the major content from a previously written piece.

Marcella uses a scaled down version of the strategy above when writing email, using *ReadPlease* to assist in reading the email. He culls potentially useful phrases from email he receives, saving them in a *MS Word* document, and then use these phrases in his own email and, where appropriate, in other material he writes. Email is a very useful medium for him as it allows him time to translate his thoughts into language. Sometimes, when a communication partner had not understood him but they are parting ways, he says *email*, and continues with good-byes. This allows him a graceful way to end an interaction and also an alternative way to communicate a thought he wants to share.

Emails sent to him in an appropriate way, i.e., framed as clear questions, are a particularly efficient way for him to communicate. In his response, he leaves the question, typing in his response underneath or beside the question, a *yes* or *no*, or a date, or another short response to a straightforward question. This was a strategy other people with aphasia used in their email communications with the author. The following is an excerpt from an email sent to the author from another participant with aphasia. In it, the respondent has used another part of the email that was sent to him in his response to a question:

*Rhian,*  
*Shirley will be in town for the Aphasia Centre Open House - OK*  
*WE WILL MEET THEIR.*

Leveraging the content of the received email allows for the context to be supplied by the communication partner, and results in less chance that a mistake will confuse the recipient.

Marcella uses *Adobe PageMaker* to create the business-sized communication cards previously mentioned. He uses a scanner to scan in documents he wants to read and image-to-text software to translate the image into a format that can be read by *ReadPlease*.

Marcella made great use of electronic-based communication strategies prior to the field study. However, the nature of the devices he was using precluded them from being incorporated into situated interactions. He was not using a digital camera, and therefore the photos were not available until after he had processed the film. He wrote emails and stories at one time, and then either sent them via the Internet, or shared hard copies at a later time.

### 3.4.3 Incorporating the PDA into Communication Strategies

Marcella began using a PDA just prior to the start of the field study. Once Marcella was using the PDA regularly a number of issues emerged, and these can be organized into three categories. The first includes the various ways Marcella incorporated the PDA into his daily life and how it supported his communication. The second includes the problems Marcella encountered using the PDA. The third covers the unexpected benefits of using the PDA experienced by Marcella.

#### PDA use in Daily Life

The way Marcella incorporated the PDA into his daily life can be organized by the applications that he used to support his communication.

#### *Notes*

Marcella originally felt the *Notes* application would be beneficial to him, as it would save him continually using and having to dispose of paper. Although committed to using this feature, Marcella ran into several difficulties.

Given his enthusiasm for the *Notes* application, we were surprised when he continued to use paper to support his communication, rather than using the *Notes* application. We believed there were two possible reasons why adoption was not occurring. One, suggested by Marcella, was that the PDA was not as accessible as a paper pad; he kept his PDA in his backpack and

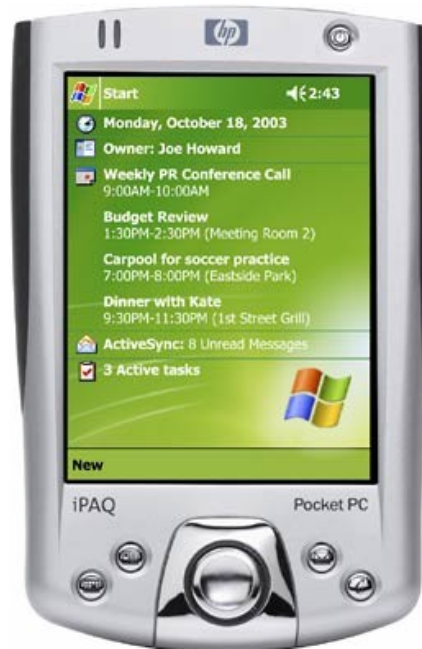


Figure 3.1: An iPAQ Pocket PC PDA. Hardware buttons can be seen at the bottom of the device [37].

the paper pad in his back pocket. It was much easier to pull a note pad out of his back pocket than take his back pack off and search through the contents looking for the PDA. Two, we believed that because Marcella was using the PDA with the understanding that it would be returned after the study, he may have been wary of developing a dependence on the PDA. To address the last concern, we made the decision to offer the PDA to Marcella on a long-term loan basis. While he was finding it useful, he could continue to use the PDA.

Both issues, accessibility and fear of dependence, were discussed with Marcella. At the end of the discussion, he decided to switch to carrying the PDA in a hip bag, and also chose to not bring a paper pad with him for a few days, to force himself to adapt to the *Notes* application. He did not believe that he had a lack of commitment to the PDA, but was happy with the terms of the long-term loan. Problems interacting with the *Notes* application were observed both in starting the application, and selecting the desired input options. A new note can be started by selecting *Notes* from

the *Start* menu on the *Today Screen*, and then selecting *New*, once the *Notes* application opens. A new note can also be started by selecting the *Notes* option from the *New* menu on the *Today Screen*. To make the process of starting a note one step shorter, we assigned one of the hardware buttons at the bottom of the PDA to the *Notes* application (Figure 3.1). After several weeks, Marcella would occasionally forget the steps required to start a new note. Mapping the hardware button to the *Notes* application had not alleviated this, as Marcella rarely used this method to access a *Note*. In fact, it seemed only to add to the confusion, it was yet another option to consider in the decision of which method to use to open a note.

The soft keyboard input mode is the default in *Notes*; Marcella preferred to use the freeform input method as this mode is faster and allows him to both write words and draw pictures. Switching from the soft keyboard to the freeform option was not straightforward and caused some delay in Marcella adopting the *Notes* application.

The assumption that the *Notes* application would offer the same functionality as the paper pads proved incorrect. The PDA's screen is not easily read when looking at it on an angle. For Marcella, writing notes is part of an interaction and it is difficult for two people to see the screen at an optimal angle at the same time. If his communication partners have difficulty reading what he writes the interaction suffers. Pausing from an interaction to write a note and then pass it to the communication partner breaks the flow of an ongoing exchange.

Although it was possible to read what Marcella was writing when sitting side by side, the PDA was not easily read in the more common face to face interaction. *Skip is seven inches taller than me; when walking, it was relatively easy for him to hold a paper pad low enough for me to see it, while he wrote on it. If Skip used the PDA while walking, we would have to stop so that we could both see it at the same time.* Given the motor deficit on his right side, his handwriting was not always firm and clear. This was barely noticeable on paper, but the screen on the PDA was less robust to uneven pressure, and therefore, in contrast to paper pads, Marcella found it more difficult to hold the PDA at different angles and heights.

Although the *Notes* application was not as successful as we had hoped, both because accessing the application was problematic, and because of the difficulties associated with the screen, unexpected benefits were also discovered and will be discussed in Section 3.4.3.

### ***Pocket Outlook***

The *Pocket Outlook* day planner application proved more useful to Marcella than the *Notes* application. Initially, Marcella used *Pocket Outlook* in conjunction with his paper day planner, entering appointments into both. Gradually, he used the paper planner less, although this was not consistent. At times, Marcella only brought the paper planner, and he would enter appointments into that. The next time we met, however, the appointment would be in the PDA.

On a few occasions prior to the field study, when we made appointments for the next AphasiaMate session, the dates or times were confused. *Skip and I were just getting to know each other and I was uncomfortable looking over his shoulder to check up on what date he had written. Sometimes this resulted in missed appointments. After we became more familiar with each other, I always looked at what he was writing down, and he would look at what I had written. When we began to beam appointments through our PDAs, though, confirming appointments became a shared moment of humour, as we both found the process fairly amusing.* The ability of the PDA to beam appointments to another PDA eliminated the chance that two people would make two separate appointments. Checking if the appointment had been registered by the PDA was also a much lighter activity, focusing on validating the technology, rather than validating Marcella.

### ***Pocket Word and iSpeak***

*The first day of the field study, Skip and I met at his home to work on his computer. I was showing him how to access files on the PDA through the desktop, and how to copy files from the desktop to the PDA. He requested that I copy the short story about his accident to his PDA. At this meeting, iSpeak, a text-to-speech software program, was also installed on his PDA.* By the middle of the summer Marcella had copied a number of other stories to the PDA. The field notes did not contain any observation of Marcella showing others the stories on the PDA, except to show people he had them there. When asked if he shared his stories on the PDA, he said he did. He would start *iSpeak* and listen as the person read the story. Marcella visited people in hospitals who had recently discovered they had aphasia. Some of these people had difficulty reading, making communication between them and Marcella difficult. Using *iSpeak* to read his stories, which were *Pocket Word* documents, or the words he typed in a note, was particularly useful in this context.

Marcella had previously told me that men tended not to read the whole story; I asked him if the reaction between the genders differed when the story was presented on the PDA. Marcella did not believe there was any difference; men were still hesitant to take and read the PDA, just as they had been hesitant to read the paper version.

After Marcella returned from a week-long stroke retreat, he reported on his use of his PDA. He shared his stories in different ways, depending on the number of people with whom he was interacting. During the group introduction, Marcella asked someone else in the group to read out his story. In smaller groups, Marcella shared his stories by playing his previously recorded stories. He recorded the stories from his desktop PC, holding the recorder close to the speaker after copying the stories into *ReadPlease*. When interacting one-on-one, Marcella would use the PDA and *iSpeak* together.

*Skip explained why he preferred the tape recorder over the PDA by very slowly going through the process of pulling out the PDA, opening the correct directory, searching for the document, opening it, copying the contents, and then clicking on the iSpeak Clipboard icon, to start the sound.* There are several issues embedded in this explanation of why *iSpeak* was not appropriate when interacting with more than a couple of people. The first is efficiency; there is a time delay between deciding to share something and being ready to actually share. This same amount of time, however, is taken during a one-on-one interaction, yet here he finds it acceptable. A possible explanation is group conversational dynamics in a Western culture. When only one member of a group cannot speak the pace of conversation increases, in much the same way it does when only one member speaks English as a second language. This was noted on several occasions, even in participatory design sessions that were conducted to elicit feedback from Marcella. In larger groups there is a tendency for speakers to speak one after the other without an intervening silence. For Marcella, this conversational style is a difficult one in which to participate. In this setting, being able to simply press a button when he has indicated to others that he has something to say makes a big difference in how smoothly he can participate in the ongoing social interaction. When interacting with only one other person, it is much easier for Marcella to set the pace of the interaction.

The second reason that the tape recording was preferred over the PDA, identified by Marcella, is the poor sound quality of the PDA. The PDA simply was not loud enough for more than two people to hear together. Attaching speakers to the PDA helped, but the sound quality was still not on par with a tape recording (Figure 3.2(a) shows the speakers attached to the PDA).





Figure 3.2: PDA peripherals used during field study.

These two issues are analogous to the problems Marcella experienced with the *Notes* application, (1) ease of use, and (2) hardware not designed to be used by more than one person.

### *Image Display and Sound Clips*

Prior to the introduction of the camera PDA attachment, Marcella copied photographs from the desktop to the PDA. Troubles with opening the photographs, described in Section 3.4.3, reduced the benefits of this functionality.

Marcella began using a Nexicam camera on August 28th. The Nexicam fits over the PDA and acts as a digital camera, using the LCD display of the PDA as the viewfinder (Figure 3.2(b)). Marcella had been introduced to the Nexicam at UBC, and was enthusiastic about using it on a daily basis. *I installed nexicam using the wizard, the instructions cannot be read by ReadPlease making it difficult for Skip. After it was installed, Skip took a few photos of his cats, to test the camera, and check out how it worked. He closed it, and we looked for the photos together. Skip wanted to go down to the parking garage — we did. I thought he just wanted a photo of his motorbike. We got there and I took a photo of him on his bike. Then he pointed to the hand brake, he wanted a close-up of that. And a close up of the foot brake. And the dent in front of the seat [...discussed accident] It turned out that he wanted to show the photos to the mechanic, get an estimate of the cost of the repair.*

This excerpt points to two other motivations for communication that can be supported by photographs, and that is expressing needs and wants and information sharing. Rather than communicating about past events for the purpose of social closeness, vital pieces of information can be communicated

through pictures that, without words, would be difficult to express.

Marcella used the ability of the PDA to record sound clips.

*Skip wrote Bowen.*

*Davies: Bowen Island?*

*Marcella: Yes.*

*Skip drew a boat.*

*Davies: You went over on the ferry?*

*Marcella: No.*

*Skip wrote private*

*Davies: A small boat?*

*Marcella: Yes and no.*

*Davies: Big for a private boat?*

*Marcella: Yes.*

*Davies: How many people were there?*

*Skip gestured a few and played a recording on his PDA.*

*I could hear a number of people singing Happy Birthday - about five people, couldn't hear any kids.*

Playing the sound clip gave a sense of the gathering and supplied a context for the conversation: no children's voices could be heard, roughly five voices were singing. Later, Marcella sent an attachment via email of a photo of the sailboat. The sound clip and photo gave an almost complete picture of where he had been and what the experience was like. Although there is only one example from the field notes of Marcella deliberately using the ability of the PDA to record sound clips, this example was compelling enough to indicate that this strategy has a great deal of potential.

Marcella knew how and where he wanted to incorporate the PDA into his communication strategies. He already used technology as part of those strategies, and with the PDA he could bring the technology with him, and use it during interactions. Although Marcella was enthusiastic about the technology and the way it could be used, incorporating it into ongoing interactions was not without its challenges.

### **PDA Usability Problems Encountered**

The biggest problem Marcella encountered when using the PDA was finding files. There is very little support for organizing files, particularly organizing files together that are associated with different applications. In addition,

the file system displays files in a different way than is done in a desktop running *MS Windows*.

Creating files in the PDA is easily accomplished through selecting *New* from the bottom toolbar in the *Today Screen*. The file is then placed in the same folder that was last open in the application currently being used. The file is given a default name based on the input method, current folder, and application. Using soft keyboard entry with *Notes* and *Pocket Word* files results in the file being given the name of the first few keyboard strokes. If a freeform *Notes* or an *Excel Workbook* file is created, the default name is the name of the folder that the file is placed in together with a number. Moving or renaming the file requires interacting with a text-based menu. To find the file created through *New* requires either noting and remembering the folder currently open, or remembering which folder had been selected *the last time* the application had been opened, prior to creating the new file.

There are two main differences in the way files are displayed in Pocket PC, compared to a desktop PC running *MS Windows*. First, when selecting a file through an application, the file window fills the screen, making it appear more like *File Explorer* is open than a similar action in a desktop PC. Second, files embedded too deep in the folder hierarchy are not accessible through applications. These differences are more fully described in Chapter 5, Section 5.2.3.

*Skip was showing someone the PDA. He was having trouble. He came up to me and handed it to me. The Pocket Word document we had copied over earlier was listed, but not the photo that had been copied with it. He gestured that he wanted to show his friend the photo, but was unable to find it. He was very frustrated — he had been excited to show her the technology, but had spent the last few minutes looking for the photo. I tried to quickly find the photo for him. Did we copy it into another folder? I looked through the other folders — all Pocket Word documents. Oops, we were in Pocket Word, not File Explorer. Finally found the photo, he took the PDA and went back to his conversation.*

The method by which the PDA supports file and folder organization caused confusion and frustration on numerous occasions.

Remembering how to open applications was also problematic. Opening an application or file while someone is watching and waiting can be stressful. Increased stress places more of a burden on the cognitive system and adversely affects memory (for example, see Eysenck and Calvo [26] for a discussion on anxiety and performance). A simple solution alleviated this problem. A folder was created, called **Skip**, that was accessible from the *Start* menu. Placed in the **Skip** folder were shortcuts to the applications

Marcella used to create new files, namely *Notes* and *Nexicam*. The shortcut to the *Notes* application opened a new note, rather than opening to a list of existing notes, reducing the steps needed to begin writing a note. Additional folders for specific events, for example the birthday party described above, were created and added to the **Skip** folder. Shortcuts to all files connected to the event were then copied to the event folders. For example, a folder named **Birthday**<sup>4</sup> was created in the **Skip** folder. Shortcuts to the photo of the boat and the Happy Birthday sound clip were copied over to **Skip\Birthday**. Another folder, named **Stories**, was created and the different stories Marcella had written were copied over to **Skip\Stories**.

Although this solved part of the initial problem, creating new folders and copying files to the new folders was not straightforward. Although Marcella created new folders, he did not consistently remember the steps to complete this task. As well, images proved difficult to manipulate. Initially, shortcuts were copied to the new folders so that if Marcella did look for a file in an old location, it would be there. When Marcella began copying the actual image files, instead of the shortcuts, they would not open when the **Skip** folder had been opened through the *Start* menu, but only when it was opened through *File Explorer*. It is unclear to us why the PDA has this behaviour, but these subtle differences caused a great deal of confusion.

The PDA file system can be viewed on a desktop PC when the PC and PDA are connected through *ActiveSync*, synchronization software that supports the PDA. The PDA sits in a cradle, a piece of hardware that is connected by either a USB or COM port to the desktop. Once *ActiveSync* recognizes a device is in the cradle, device files are accessible through the desktop's *File Explorer* application. The view is similar to that seen with other storage devices such as the floppy drive or the CD drive.

Marcella found working with the PDA's file system was annoying; the targets were small for someone working with their non-dominant hand, or with an impaired dominant hand. The larger overview seen on the desktop is more usable, and the interaction techniques available there, such as *drag and drop*, were easier to use than the menu-based options of the PDA. Marcella found it much easier to use the desktop environment, and would organize, create, and delete folders on his PDA through the desktop's *File Explorer*. A problem with this approach is that it is easy to confuse what is on the PDA with what is on the hard drive; however, the PDA files exhibit different behaviour than other files. For example, clicking on file icons that appear

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<sup>4</sup>The actual folder was named after the person who was celebrating the birthday. In the interest of clarity, this detail has been changed.

in the desktop's *File Explorer*, within the PDA's designated folder, fails to open the corresponding file.

The above issues made managing files on the PDA problematic, even though Marcella managed his desktop PC files, using *File Explorer*, without any significant problems.

Marcella found *iSpeak* very useful for reading documents, even though there were many steps to initiate this action. The *iSpeak Clipboard* application only processed text that could be selected and copied into the operating system clipboard. Therefore, file and folder names could not be read by *iSpeak*. Reducing the number of steps required to read a document through *iSpeak*, and expanding its capabilities to read file and folder names, would make this application even more useful for Marcella.

The Nexicam was very useful to Marcella, and he kept it attached to his PDA at all times. It increased its size only slightly, and Marcella was still able to carry the PDA, Nexicam attached, conveniently in his hip-bag. Image files are stored in a default folder, automatically being named `nexicami.jpg`, with `i` being the number of *Nexicam* images in the `My Documents\My Pictures` folder. Unfortunately, the *Nexicam* does not offer a simple way for renaming the photos from the default it assigns. Although thumbnails can be viewed through the Nexicam, it is not possible to rename files in this view. Thumbnails cannot be viewed through *File Explorer*, which does support the renaming of files. Opening an image, viewing it, and then going back to rename it is a cumbersome, error prone, and memory intensive operation for the user, given that file identifiers are arbitrary numbers.

The Nexicam is energy intensive. When Marcella first began using it, both the main and backup battery of his PDA died. It gave a long warning message that Marcella could not read. He tapped on the default option and the screen went black, except for vertical lines; eventually the lines disappeared and the screen went completely blank. Marcella emailed and phoned me, very concerned that he had broken the PDA. When both the main and backup battery get depleted, all files added to the PDA by the user are lost. When the PDA is recharged, the user must set up the device, going through the same process that occurs with a hard reset; for more information on this scenario, please refer to the HP web site [36]. After this episode, Marcella made sure to recharge the PDA every night, and this seemed to be sufficient to meet his needs. Loosing files when the batteries die is aggravating, particularly losing the photographs taken with the Nexicam as Marcella uses these images to help him communicate about past events.

Through the conversation that was triggered by the PDA breakdown, it became clear that Marcella had some anxiety around loosing or breaking the

PDA, which was somewhat alleviated after being given the PDA on a long-term loan. However, the concern remained, which may have exacerbated some of the previous difficulties mentioned.

Finally, the PDA's usability as a communication device is adversely affected by its poor screen visibility when viewed on an angle, and by the high-degree of dexterity required of the user as a result of the small stylus and display targets.

### Unexpected Benefits of the PDA

We hoped that the PDA would support Marcella's communication strategies and suspected that certain applications would lend themselves to this role. However, certain benefits of the PDA were unexpected. In this section we give a brief overview of these benefits.

The *Notes* application introduced some unexpected benefits that were not evident with paper notes. Occasionally, Marcella would open an old note and look at it. When he did this, if the note was salient enough, he would recall the voice of the person he had been conversing with saying the word written on the note. *The following occurred during a conversation of the pros and cons of both the PDA Notes application and paper pad notes.*

*Skip drew a line across the middle of the paper note. On the top of the page he wrote pad and pen, and under the line he wrote, iPAQ and stick. Under the pad and pen heading, he wrote important.*

*Davies: important?*

*Marcella: No.*

*He crossed out important. He could not get the word he was looking for — I began to list the pros of paper.*

*Davies: It's faster.*

*Marcella: Yes*

*Davies: you can move...*

*Marcella wrote memory under the iPAQ heading.*

*Davies: memory? How?*

*Marcella opened an old Note. On it was written 116.*

*Davies: 116? What does that mean?*

*Marcella tried to say something, and then wrote on his PDA, blood pressure*

*Davies: blood pressure.*

*Skip closed the note and we talked about his blood pressure for awhile, and then he opened up the previous note, blood pressure, and said it a few times. He could now say it better, after having heard me say it, and seeing the note again. Somehow, the note triggered the memory of hearing my voice say the word. With paper notes, he threw away the old notes, so never used them to trigger his memory in this way.*

Marcella made tape recordings of *PleaseRead* reading his stories only after using *iSpeak* to read his stories on the PDA. *Skip walked into the lab - I was there already, setting up for an AphasiaMate session. He greeted me, we chatted, he was in a great mood. Barbara joined us. He pulled out the PDA and a set of small speakers from his backpack. Skip connected the speakers to the PDA and started iSpeak reading a story. He explained how he could do this in a public speaking forum.* The limited volume available in the PDA caused him to abandon the idea in favour of recording the story with *PleaseRead*. The impetus for using text-to-speech software as a way to engage in public speaking came from using the PDA.

### 3.5 Conclusion

Challenges encountered while researching the potential for a PDA to be used as a communication device motivated the approach taken in this study. Witnessing the daily life of someone with aphasia, the wide range of responses from strangers, and the range of abilities people exhibit when communicating with someone with aphasia, gave us a deeper understanding of the context within which people with aphasia communicate. This process has succeeded in shifting our focus from the mechanics of communication to supporting the situated interaction of that communication. Together with Marcella, we have identified the wide range of strategies he successfully employs to communicate in his daily life.

Observing how Marcella integrated the PDA into daily life tested our assumptions of what we considered to be the obvious benefits of the PDA. Although this study had only one participant, having one clear picture of the problems faced and the strategies used by someone with aphasia allowed us to ground our assessment of which strategies could best be supported by technological solutions.

Becoming better communicative partners to people with aphasia is essential for nurturing a positive community-based partnership among our research team and people with aphasia. After spending an extended period of time together, Marcella and the author developed a shared context, which

succeeded in facilitating communication.



## Chapter 4

# Phase II: The Design of the File Facility Prototype

The methodology used in the design phase, described in this chapter, was informed by the field study. The design process continued to be collaborative, leveraging the relationship that had developed between Marcella and the author during the field study.

The first class status Marcella had within the field study was extended to the design process. Marcella took a lead role in defining the problem space that the application was to address. A facility to access, save, and manipulate files easily and quickly was identified as the central requirement of our application. Once the problem space was defined, Marcella collaborated on and initiated design ideas. Paper prototypes were used but rather than the researcher coming to the design sessions with prototypes in hand, these were created jointly by both the author and Marcella, with members of the Aphasia Project periodically offering feedback on the design.

The collaborative process took a hiatus during initial implementation of the design; prior to a working prototype being fully developed, collaboration resumed. The bugs in the initial prototype did not hinder Marcella from stepping through the application; rather, they encouraged him to give feedback on an obviously unfinished implementation.

### 4.1 Methodology

#### 4.1.1 Defining the Problem Space

The design process began with several informal discussions that centered on the findings of the field study: the communication strategies Marcella used, how he integrated the PDA into those strategies, and the problems he encountered using the PDA. During these discussions, the scope of the problem space that would be addressed by our application was defined.

We briefly review the usability problems Marcella identified; a more complete discussion on the problems experienced by Marcella as he used the

PDA can be found in Chapter 3, Section 3.4.3.

The difficulties associated with accessing files was identified by Marcella as the primary deterrent to incorporating the PDA into his communication strategies. A method to access files quickly and easily was considered the core feature our application would support. Accessing files had a complementary problem; Marcella found it problematic to save files in a location that could be easily remembered at a later time. Interactions with files, folders, and folder structures are not as obvious, and are more text-dependent than the equivalent actions on the desktop. For example, the technique of *drag and drop* used to move a file in *File Explorer* on the desktop is gesture based, whereas in the Pocket PC, using *File Explorer*, a file is moved to a new location by selecting options in a text-based menu. The problem of successfully completing these tasks is exacerbated by the many steps required to save and retrieve files.

Marcella uses *iSpeak*, a text-to-speech software program, on his PDA. When he shares his stories with others, he not only displays the document on his PDA, but plays the audio of *iSpeak* reading the story. Marcella identified the number of taps required to copy a document and have *iSpeak* read it as a usability issue.

At one point in the field study the backup battery in Marcella's PDA died, resulting in files on the PDA being lost. This incident served to identify the problem of relying on manually archiving files. Keeping files for future reference on the desktop, that were currently not being used on the PDA, was also desirable. This task in and of itself is not difficult. Marcella had little trouble managing files on his desktop, and transferred files between the PDA and the desktop using *ActiveSync*. Although copying files between devices using *ActiveSync* was relatively straightforward for Marcella, automating the task of backing up files would alleviate the need to remember to do this regularly, and reduce the chance of losing files. We wanted files to be archived on the desktop PC, rather than synchronized. *ActiveSync* copies files from the PDA's **My Documents** to the desktop PC, and files from the synchronized folder on the desktop to the PDA. We wanted new files on the PDA to be copied to the desktop automatically without files on the desktop being copied to the PDA. In our archiving facility, in contrast to synchronization, we wanted to keep those files on the desktop even when they are deleted from the PDA. Similar to the default synchronization software, we also wanted to maintain, and automatically create, a folder structure on the desktop that mirrored that in the PDA, to make it easier to find files on the desktop. Automatic archiving of files and folder structures was added to the list of requirements our application would address.

Our design requirements defined an application that would support file and folder management in a manner easily usable by Marcella, automate *iSpeak* to open with *Pocket Word* documents, and automate archiving. The following is a list of the requirements we identified:

- The four most frequently accessed files in each sub-folder should be accessible from the *Today Screen* in two to three taps of the stylus.
- New files should be easily placed in a folder of choice.
- Files should be automatically archived each time the PDA is connected to the desktop.
- When a *Pocket Word* document is opened, *iSpeak* should start to read the text automatically.
- There should be some simple way to accomplish folder management tasks (deleting and moving files) on the PDA; although it is assumed most folder management tasks will continue to be done when the PDA is connected to the desktop.
- There should not be multiple ways to accomplish one task, because this leads to confusion.
- A simple design, which gives the user control, is preferred over a complex design where things are done automatically.
- Scrolling through many files and folders (shallow folder hierarchy) is preferred over many selection points (deep folder hierarchy). Although there is a potential for many files and folders being added, causing an excessive amount of scrolling, Marcella's usage argued against this occurring. He believed he would delete files and folders he no longer used.

Implicit in the above requirements is that each feature should be usable by Marcella without the need of assistance.

#### 4.1.2 Paper Prototype Sessions

Once the scope of the application had been decided, we moved on to discuss the design process that would be used. Marcella agreed to play an active role; indeed, he expressed a great interest in playing a role in developing technology through designing an application. We discussed the use of paper

prototypes, and both agreed to think about designs for the application; we would *both* think about the design space, and develop the paper prototypes together and in collaboration with other members of the Aphasia Project.

The first design session took place in Marcella's home. Marcella sat down with an air of *let's get down to business*, and then looked expectantly at the author to begin the process. The author began by sketching out some ideas, and Marcella was quick to offer positive feedback but more reticent to either critique her ideas or offer suggestions of his own. This first session became more collaborative when a Likert scale was introduced to elicit feedback part way through the session. Marcella was asked to grade each design idea from one to five, with one indicating a very bad idea, and five indicating an idea that could not be improved upon. Marcella generally gave a rating of four or less to each design feature, even though he had been giving positive feedback verbally and with gestures. This is an indication of the difficulty of communicating more subtle and possibly controversial ideas when one has aphasia. A Likert scale is a useful way to draw out opinions that fall within the extremes and thus begin a dialog that engages the participant in design ideas without burdening them with the task of communicating their negative opinions. Once Marcella had rated a design idea as being four or less, the author asked him to make suggestions that would improve its rating.

It was apparent during this initial meeting that Marcella assumed that his role was to listen and critique the ideas of the researcher, rather than to actively collaborate to create the design. During another project within the Aphasia Project, Marcella had previously participated in a more traditional paper prototyping session, and this may have influenced his perception of what would occur. Although he had agreed to actively design the prototype, the leap from thinking of himself as being a user of technology to a designer of technology was bigger, and more exhausting, than we had anticipated. This first session was one and a half hours long but had been preceded by a one hour trouble shooting session on Marcella's home computer. At the end of the design session Marcella was obviously tired. In retrospect, it would have been better to slowly introduce the concept of designing alternative interaction techniques during our discussions of the different usability problems Marcella encountered. A shift in perspective is required when one goes from using technology to designing technology. This shift can be draining, and may have been less tiring for Marcella if the shift in perspective had occurred more gradually, over several sessions, rather than in a very long first session.

Although the first session was draining for Marcella, he adapted quickly to his new role and the subsequent sessions went much more smoothly. Dur-

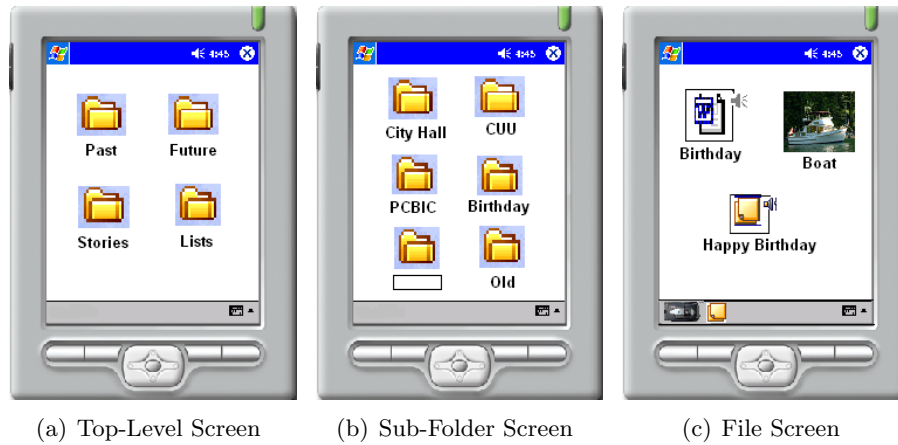


Figure 4.1: The final paper prototypes of the File Facility. Tapping on the top-level icon Past in the Top-Level Screen (a) opens the Sub-Folder Screen (b). Tapping on the icon Birthday in (b) opens the File Screen (c).

ing the months of October and November, 2003, Marcella and the author met once a week either in a local coffee shop or in one of their homes. Many of these meetings were not dedicated to discussing design ideas but rather the focus was on trouble shooting computer problems or preparing for conference and educational presentations. These regular meetings allowed for design ideas to slowly evolve, with design ideas being discussed briefly before moving on to other agenda items. Some of these meetings were dedicated to the design process, with Marcella and the author discussing design ideas and sketching rough ideas out on paper; the technique of paper prototyping was very easy for Marcella to adapt to as he already used paper notes and sketches to communicate. Marcella used the PDA to demonstrate different problems he was having with the interface and to assist in communicating difficulties and solutions during the design process. In total, approximately five hours were dedicated to the design phase. This estimate does not include time spent on other topics during the design sessions.

After the design ideas had stabilized, a final paper prototype was created based on the rough paper prototypes sketched out during the design sessions (Figure 4.1). Creating a more precise paper prototype that depicted the flow of interactions ensured all stakeholders in the design process had reached a shared understanding of the design and formalized the design requirements

for the implementation phase.

An early challenge in the design sessions was creating a way to support folder organization. Based on Marcella's use of files during the field study, and because we wanted to support recall, and therefore memory, a memory metaphor was used in the creation of a top-level folder structure. Figure 4.1(a) shows the *Top-Level Screen* in the prototype. Top-level folders are created when the application is installed. Within the top-level **Past** folder, sub-folders correspond to past events, or long-term memory. **Future** sub-folders correspond to events that have not yet happened, or prospective memory. For example, a folder **mechanic** could be created to place photos of motorcycle parts that need repair. **Stories** sub-folders correspond to autobiographical memory. Finally, in **Lists**, sub-folders correspond to semantic memory, and would contain sub-folders to hold files for various cues, lists, and communication cards. Although we were unsure how well these folders would meet Marcella's needs, we believed creating an initial structure would be helpful. A requirement of the design was to allow for quick retrieval of files. The structure supplied was intended to assist Marcella in deciding where to place files and in remembering where files were placed. It was not clear if creating a top-level structure would be successful in supplying this support.

Figure 4.1 shows the sequence of screen shots that would be displayed when accessing a file within the `My Documents\Past\Birthday` folder, starting with the *Top-Level Screen*. From the *Top-Level Screen*, all top-level folders are accessible (Figure 4.1(a)). Tapping on the *Past* icon in the top left corner would open the *Sub-Folder Screen* with icons representing all sub-folders within *Past* (Figure 4.1(b)). Tapping on the folder icon labeled *Birthday* would open the *File Screen* with icons representing all files in the *Birthday* folder (Figure 4.1(c)).

The paper prototype also shows the *Create Folder* icon, seen in the lower left of Figure 4.1(b). Tapping on the textbox underneath this icon would result in the Soft Input Panel (SIP), or soft keyboard, opening. The user could then type the name of the new folder and tap the *Create Folder* icon, resulting in a new folder and an icon representing this folder being placed on the screen. Seen in Figure 4.1(c) on the left in the lower toolbar are the *Nexicam* and *Notes* icons. When these icons are tapped, their corresponding application opens. Files created using these icons are placed in the folder from which the icons were accessed, and icons are placed on the corresponding *File Screen*.

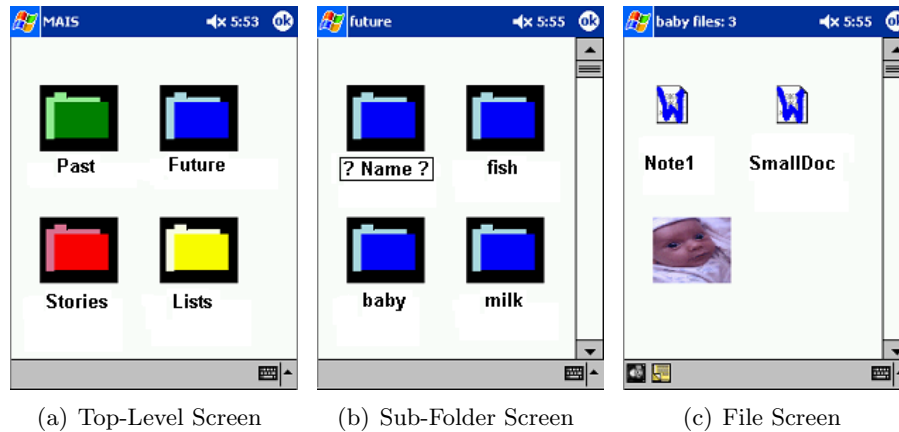


Figure 4.2: The medium fidelity prototypes of the File Facility. Tapping on the Past icon in the Top-Level Screen (a) opens the Sub-Folder Screen (b). Tapping on the baby icon in (b) opens the File Screen (c).

### 4.1.3 Medium Fidelity Prototype

With the list of design requirements finalized and the paper prototype agreed upon, Marcella and the author broke from their weekly meetings and the implementation of the design began. As implementation proceeded, design adjustments were made based on efficiency considerations, limitations of the device and its native applications, and to conform to the existing Pocket PC application model. As soon as the implementation reached a stage where basic interactions could occur, weekly meetings once again resumed. Marcella's feedback during the implementation phase was critical to ensuring that the implementation details did not supersede his design requirements. Although all practitioners of participatory methodologies consider user input necessary throughout the design cycle, input is even more crucial when designing with a population of users with communication deficits because the likelihood of miss-communication is greater.

Figure 4.2 shows the medium fidelity prototype prior to implementation of all the design requirements. The existing functionality allowed us to get feedback on target size (e.g., scrollbar width), appearance, and general interaction techniques (e.g., a request was made to add icons to every screen that would provide a shortcut to the individual top-level folders).

Figure 4.2 shows the sequence of screen shots that would be displayed

during an interaction to access a file within the folder `My Documents\Future\baby`, starting with the *Top-Level Screen* of the *File Facility* (Figure 4.2(a)). The *Create Folder* icon was re-located to the top left corner of the Sub-Folder Screen to ensure the textbox is still visible when the SIP opens, as it covers the lower third of the screen (Figure 4.2(b)).

The sequence of taps that would result in the *File Screen* (Figure 4.2(c)) begins with a tap on the *Future* icon in Figure 4.2(a), then a tap on the *baby* folder in Figure 4.2(b). Colour coding of top-level folders carries through to the *Sub-Folder Screens*. Each top-level icon is a different colour, the *Sub-Folder Screen* contains folder icons of the same colour as the top-level folder in which it is contained.

#### 4.1.4 High Fidelity Prototype

The high fidelity prototype implemented all the design requirements and the suggestions made by Marcella during earlier iterations of the design process. The *File Facility* icon is accessible from the *Today Screen*. When the *File Facility* is installed, the top-level folders, *Past*, *Future*, *Stories*, *Lists*, and *Other*, if they do not exist, are created. A fifth top-level folder, *Other*, was added as an overflow bucket. This was done to help us determine, during Marcella's use of the *File Facility*, how effective the choice of top-level folder names were for organizing files. A user can add sub-folders to any of the top-level folders through the *Create Folder* icon. The initial state of the *Sub-Folder Screens* is empty except for the *Create Folder* icon.

Figure 4.3 shows the sequence of screen shots seen when opening the *File Facility*. Figure 4.3(a) shows the *File Facility* icon on the *Today Screen*. Above the *File Facility* icon are icons associated with the individual top-level folders. Tapping on the *File Facility* icon from the *Today Screen* opens the *Top-Level Screen* (Figure 4.3(b)). The *Top-Level Screen* shows large icons representing all top-level folders. A coloured line separates the main screen from the small icon toolbar at the top of the screen; in the *Top-Level Screen* this toolbar is redundant, but exists to keep this feature consistent in all screens. This line is grey in the *Top-Level Screen*, in all other screens, it is the colour associated with the current top-level folder. Also redundant in this screen is the *File Facility* icon on the bottom toolbar. It is also there for consistency. In all other screens, tapping it would open the *Top-Level Screen*. There is a paste icon beside each large folder icon; a sub-folder can be copied and pasted into a top-level folder by tapping on the appropriate paste icon, after tapping on the sub-folders associated copy icon.

Tapping on a top-level folder icon from the *Top-Level Screen*, *Today*



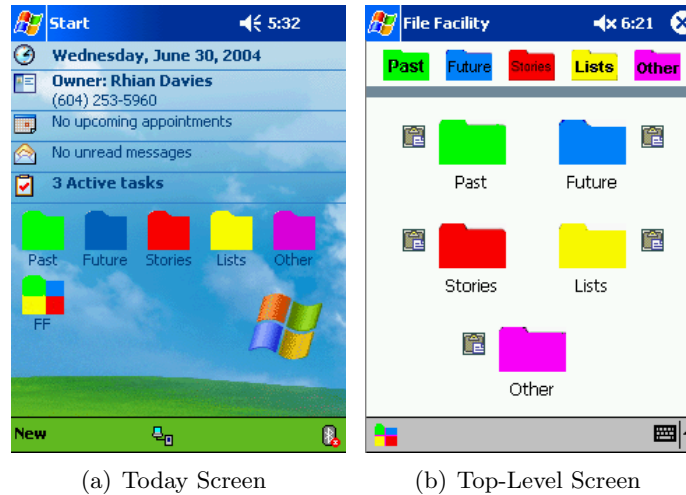


Figure 4.3: Opening the File Facility from the Today Screen. Tapping on the File Facility icon in the Today Screen (a) opens the Top-Level Screen (b). Tapping on one of the top-level folder icons in (b) opens its sub-folder screen (Figure 4.4(a))

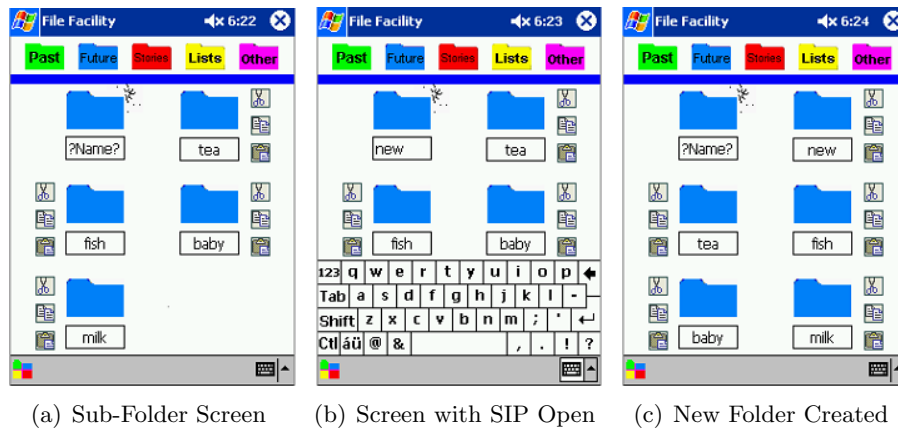


Figure 4.4: Creating a new sub-folder named *new*. Tapping on the textbox under the *Create Folder* icon in (a) results in the SIP opening, as seen in (b). Typing in *new* and then tapping on the *Create Folder* icon results in a new folder. The *new* folder icon appears on the screen (c).

*Screen*, or one of the small icons in the top command bar, opens a screen that shows the sub-folders within the selected top-level folder (Figure 4.4(a)). Each of the sub-folders has an accompanying cut, copy, and paste icon. We discussed the images on the icons at some length, and tried alternatives. One example for the *cut* icon was an image of a small garbage can. We were hoping to find images that were less abstract, but such images do not scale down well, and the size of the icons constrained our options.

Tapping on the *cut* icon opens a dialog window that asks for confirmation before a folder is deleted. Tapping on the *copy* icon opens a dialog window that confirms the folder has been copied. Tapping on the *paste* icon opens the associated *File Screen* (Figure 4.6(a)), which includes the icon representing the new file that has been copied to the sub-folder. We initially did not use dialog boxes, except for the *delete* icon, to minimize the requirement to read messages. However, Marcella preferred to have feedback confirming each action. We therefore attempted to make our dialog messages as short as possible.

Figure 4.4 shows the sequence of screen shots that would occur when creating a folder named *new*. The icon in the top left of Figure 4.4(a) is a *Create Folder* icon. Tapping on the textbox underneath this icon causes the SIP to open, allowing a user to enter a folder name (Figure 4.4(b)). Once a folder name is entered, tapping the *Create Folder* icon completes the interaction and results in a new folder, an iconic representation of which appears to the right of the *Create Folder* icon (Figure 4.4(c)). If the *Create Folder* icon is tapped but no new name was typed, no folder is created. We attempted alternative images for the *Create Folder* icon, but went with the common technique of adding a *burst* behind a folder to indicate creation. Together with the textbox, this seemed sufficient to distinguish this icon from the sub-folder icons.

Tapping on the background in the lower panel, below the coloured line, is equivalent to tapping on the *Create Folder* icon, and completes the interaction sequence of creating a new folder. This functionality was added because during walk-throughs of the prototype, some users kept tapping on the background expecting this behaviour. It seemed more intuitive than tapping on the *Create Folder* icon.

When the sixth sub-folder in a top-level folder is created, an overflow, or *Next Screen* is created. An arrow icon replaces the fifth folder icon in the main *Sub-Folder Screen* (Figure 4.5(a)), and the fifth and sixth folders are moved to the *Next Screen* (Figure 4.5(b)). Tapping on the *Next* arrow results in the *Next Screen* appearing. When the top-level folder has more than ten sub-folders, a scroll bar is made visible on the *Next Screen* (Figure

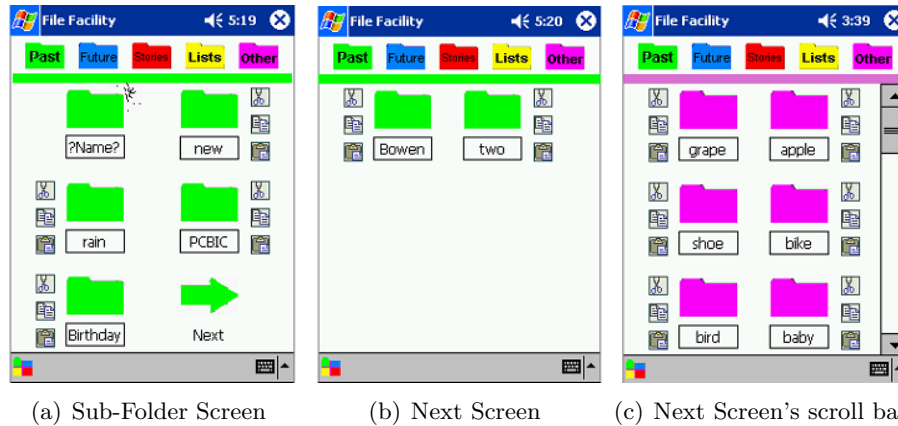


Figure 4.5: Screen shots of the Sub-Folder Screen and the Next Screen. A Next arrow icon is placed on the Sub-Folder Screen (a), and a Next Screen is created (b), when there are more than five sub-folders in a top-level folder. A scroll bar is added to the Next Screen when there are more than ten sub-folders (c).

4.5(c)). Folder icons are moved from the *Next Screen* to the main *Sub-Folder Screen* when they are opened, therefore the least-recently-used folders are seen on the *Next Screen*. Using an adaptive interface was not ideal; Marcella did not like files or folders moving automatically. However, he also wanted to access files quickly, and scrolling through a long list of files was not desirable for files that were opened frequently.

Tapping on any of the folder icons in Figure 4.5 opens a *File Screen* which displays file icons representing all files in the current sub-folder (Figure 4.6(a)). Each file icon has an accompanying delete and copy icon, allowing the user to delete the file, or copy it to the clipboard and then paste it into another selected sub-folder. Two new icons are added to the bottom toolbar in the File Screen. In the second position is the Nexicam icon; tapping on this icon opens Nexicam. All photos taken after Nexicam is opened with the icon, until Nexicam is closed, are moved to the current folder; thumbnails are created and placed on the File Screen.

In the third position is the *Notes* icon. Tapping on this icon opens the *Notes* application; a note icon will be placed on the screen and the note created will be moved to the current folder. This functionality corresponds to the requirement of easily selecting a folder in which to place a new file.

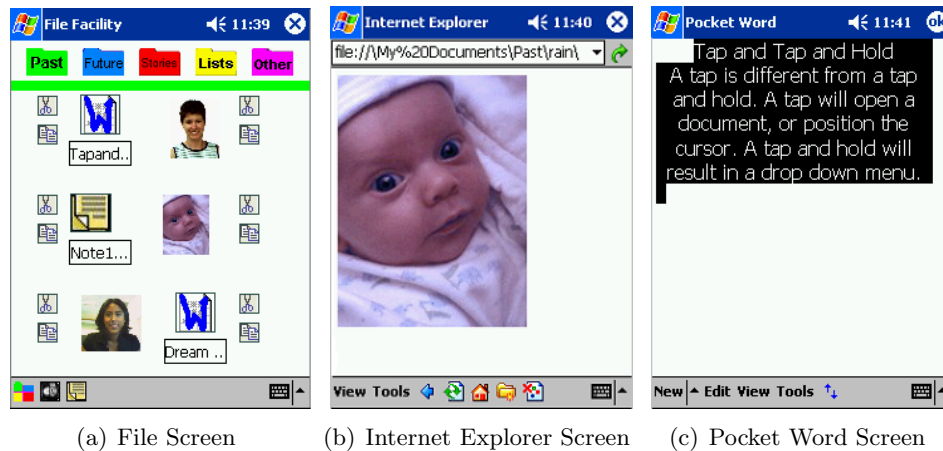


Figure 4.6: Screen shots during file interactions, starting with a File Screen  
 (a). When an image icon is tapped, it opens in Internet Explorer  
 (b). When a *Pocket Word* icon is tapped, it opens in *Pocket Word*, and is automatically copied to the OS Clipboard (c).  
*iSpeak* then reads the document.

There are only two application icons in the prototype as Marcella generally only created new *Notes* and images using the PDA, with the one sound clip he created being the exception.

Tapping on the icons or thumbnails in Figure 4.6(a) results in the file opening in its associated application. Tapping on a thumbnail opens the image in *Pocket Internet Explorer* (Figure 4.6(b)), and tapping on a *Pocket Word* icon opens the document in *Pocket Word*, initiates simulated user taps to select and copy the contents of the document to the operating system clipboard, and opens *iSpeak Clipboard*, which reads the document, i.e., the contents of the operating system clipboard (Figure 4.6(c)). The prototype also supports *PDF* and *Notes* files; other files appear with an *unknown* icon, and do not open in an application.

### The Archiving Facility

The *Archiving Facility* starts when *ActiveSync* detects a device is connected to the desktop. A window opens informing the user that archiving is occurring (Figure 4.7). The utility first checks if the following folders exist in the folder *My Documents* on the desktop: *PocketPC\Past*, *PocketPC\Future*,

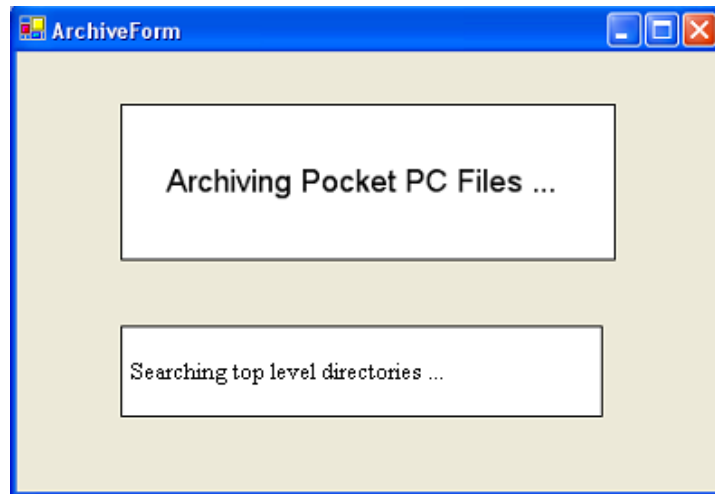


Figure 4.7: Archiving window seen on desktop PC during archiving.

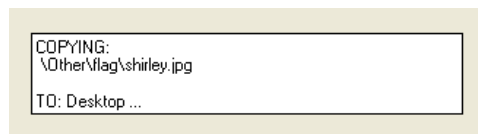


Figure 4.8: The text in the lower panel of the Archive window indicating a PDA file is being saved to the desktop.

PocketPC\Stories, PocketPC\Lists, and PocketPC\Other. If those folders do not exist, they are created. The top-level folders in the PDA are then checked and each file within those hierarchies, if it does not already exist on the desktop, is copied to the desktop within a folder hierarchy that mirrors the one on the PDA. As each file is copied, the user is informed in the lower textbox of the window (Figure 4.8). When all files in the top-level folder hierarchies have been checked, the text in the lower textbox indicates the application is closing, and the archiving application then closes. Although the flashing text-based messages are of limited use, particularly to a user with aphasia, they do give a visual cue that some action is occurring.

Marcella requested that the archive folder be placed directly under My Documents folder on his desktop PC, and the folder be named PocketPC as this name was short and easy to recognize.

## 4.2 Implementation Details and Challenges

The *File Facility* application was implemented in C# in the .NET Compact Framework using the Visual Studio IDE. A Microsoft development environment was chosen because of the desire to integrate the final application as seamlessly as possible into the existing native interface with which Marcella had become accustomed.

The .NET Compact Framework offers both C# and Visual Basic programming languages as options; although Visual Basic is a quick prototyping language, previous experience in the Aphasia Project had shown that its limitations would impact development of a high fidelity prototype. We believed C#, as the more powerful language, would enable us to more easily implement the design requirements of our prototype, namely the smooth interoperability of our application with others residing on the PDA, including the operating system itself.

During the development phase, the requirements defined by Marcella were the dominant influence in our implementation decisions. We also turned to the guidelines in *Designed for Windows Mobile Software Application Handbook for Pocket PCs* [55] in making some of our implementation decisions. For example, the top right hand button minimizes, rather than closes, the *File Facility*. This behaviour is the preferred implementation for Pocket PC applications, according to the guidelines, as the operating system controls for memory demands by closing the least recently used application.

Our application required a text-to-speech feature; the software package we used was *iSpeak*, a commercial product available from Fonix [30]. *iSpeak* reads email messages, wav files, and text files, and its *Clipboard* application reads the contents of the operating system clipboard. This last feature allowed us to integrate *iSpeak* into our own application, enabling any file or folder label to be read when tapped.

Accessing the content of *Pocket Word* documents proved difficult; the most straightforward approach on a desktop PC would be to use a macro, but *Pocket Word* does not support macros. Our solution was to simulate user input. Once a *Pocket Word* document was opened, our application would simulate user input to select and copy the entire document. When the *iSpeak Clipboard* starts, it reads the current contents of the operating system clipboard. Unfortunately, simulating user input relies on low-level calls to the operating system with the parameters passed being the co-ordinates of the screen; these co-ordinates change from device to device and must therefore be calibrated. This implementation issue could be overcome by establishing the coordinate system the first time the application runs on a

device. This is the approach taken by the Pocket PC operating system; the first time the device is used, or after a hard reset, users are asked to touch the four corners of the screen.

## Chapter 5

# Phase III: The Evaluation of the File Facility

The design of the *File Facility* was motivated by the usability problems that arose when Marcella integrated a PDA into his communication strategies. Whether the *File Facility* meets the needs of other users with aphasia hinges on two orthogonal factors. First, whether the communication strategies employed by other people with aphasia are similar to those of Marcella, and second, whether others would encounter similar usability problems, and find the solution designed to address them helpful. Also of interest is whether the usability problems identified by Marcella are unique to users with aphasia or if these same problems would be encountered by the general user population.

The literature on aphasia, as discussed in Chapter 2, would suggest that other people with aphasia do use similar communication strategies to Marcella. Strategies, however, vary depending on the type of deficit. Garrett has described different potential communication strategies available to different *communicator types*, a categorization system based on severity of deficit as it affects a person's ability to meet current communication needs [32].

In this chapter we describe an evaluative study designed to address the second factor, the generalizability of the usability problems Marcella encountered with *File Explorer* and the usability of the *File Facility*. The two main goals of the study were: (1) to compare the usability of the *File Facility* to the *File Explorer* for users with aphasia, and (2) to compare the patterns of performance and preference of people with aphasia to those of the general user population.

In addition to the evaluative study, an informal field evaluation of the *File Facility* will be briefly discussed. This evaluation is based on Marcella's use of the *File Facility* in his daily life, which continues today.



## 5.1 Background

The evaluative study was conducted jointly by Gaw and Davies. Gaw took the lead on task creation and automated the installation of folder and file structures used in the task sets. Davies took the lead on the interview questions and reports and on study logistics<sup>1</sup>. After a common coding scheme for video analysis had been agreed upon, both Gaw and Davies proceeded with video coding and data analysis separately. The results reported here are based on the coding and analysis done by Davies.

## 5.2 The Two File Management Systems

The design of the *File Facility* differs from *File Explorer* in a number of ways.

- It is more icon and image-based than the more menu and text-based design of *File Explorer*.
- It has a reduced set of functions, and there is only one way to complete a function, with two exceptions.
- Applications are integrated into the *File Facility*, whereas *File Explorer* is integrated into applications.

The two functions in the *File Facility* that can be completed in two different ways are (1) navigating to a Sub-Folder Screen and (2) creating a new sub-folder. A user can navigate to a Sub-Folder Screen by (1) tapping on an icon in the top toolbar or (2) returning to the Top-Level Screen, and selecting an icon from there. The last step in new folder creation is to (1) tap on the *Create Folder* icon, or (2) tap anywhere in the background of the lower panel. A complete description of the *File Facility* is given in Chapter 4. Here, we summarize the differences between the *File Facility* and *File Explorer* applications.

### 5.2.1 Icon and Menus

The steps to complete an action in the *File Explorer* include displaying and selecting from a menu; in the *File Facility* an action is accomplished by

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<sup>1</sup>Study logistics included finding appropriate participants, communicating arrangements appropriately given the communication deficits of the participants, arranging for travel and accommodations where needed, etc.

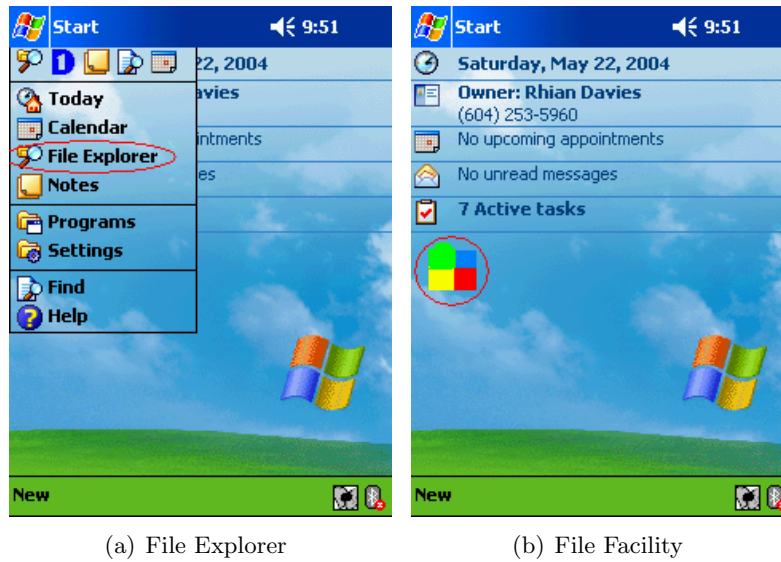


Figure 5.1: Today Screen. The red circle indicates where to tap to open (a) *File Explorer* or (b) *File Facility*.

tapping on an icon. For example, the *File Explorer* program is opened by tapping on the appropriate menu item (circled in red in Figure 5.1(a)) from the drop down menu displayed when *Start* is selected. *Start* is on the top left side of the *Today Screen*. The *File Facility* is opened by tapping on its icon (circled in red in Figure 5.1(b)) in the *Today Screen*. Figure 5.1 shows the two states of the *Today Screen* prior to opening the *File Explorer* and the *File Facility*.

### 5.2.2 Number of Functions Offered

*File Explorer* offers many options through context sensitive *tap and hold* drop down menus. This action requires a user tap on the screen and hold the stylus down until a menu appears under the stylus. When a folder icon is selected, the drop down menu allows a user to select *Cut*, *Copy*, *Rename*, or *Delete* the folder (Figure 5.2(a)). If a file icon is selected, two more menu options are offered, *Send via E-mail...* and *Beam File...*. The target area of the file and folder icons includes the background space spanning the height of the icon and the width of the screen. Menu options change when the background area below the file and folder icons is selected (Figure

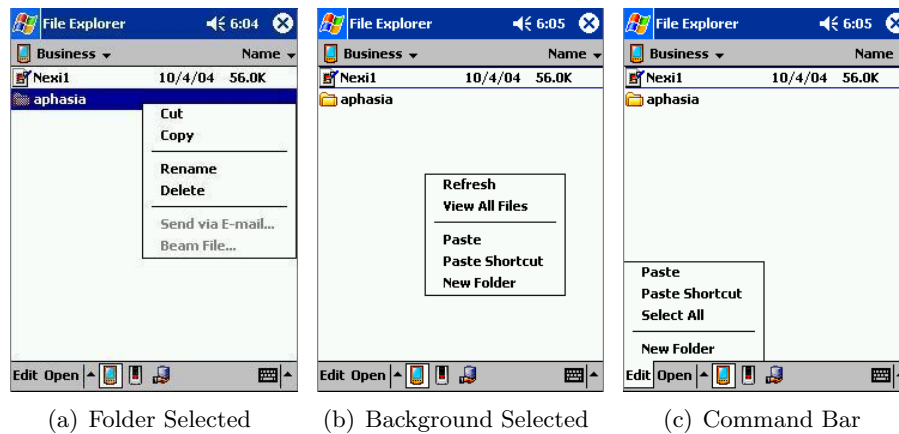


Figure 5.2: File Explorer menu options. The drop down menu options in File Explorer change depending on what part of the screen is selected. A folder is selected in (a) and the background is selected in (b). A command bar Edit menu item (c) offers additional options.

5.2(b)). In addition, two bottom toolbar menus are available, each with their own commands (Figure 5.2(c)). This is not a complete list of all that can be done through *File Explorer*, but it already surpasses the number of options available through the *File Facility*, as described in Chapter 4.

### 5.2.3 File Management and Application Integration

Similar to *File Explorer* on a desktop running an *MS Windows* operating system, the Pocket PC version of *File Explorer* is both (1) a stand alone program and (2) a program integrated into applications such as *Pocket Word* and *Notes*, allowing users access to the file system through applications. Unlike the desktop *MS Windows* environment, in Pocket PC in the second context, the file view offered is limited to only those files with extensions associated with the current application, with no option to show all files. The file view does not open in a separate window, but rather fills the screen, making the two contexts closer in appearance in the Pocket PC than on the desktop; however, the behaviour in the two contexts is different. In addition to limiting the view to associated files, access is limited to certain folders when viewing the file system through an application. A drop down menu available from the top toolbar lists the subset of folders accessible through

the application, and includes the menu item *All Folders*; selecting this will result in a view of files residing in the supported folders. These folders, one level deep, reside in **My Documents** or **iPAQ File Store**. A file not residing in this subset of folders would not be accessible through this menu. For example, a *Notes* file residing in the path `\My Documents\Past\ASubFolder` would not be accessible through the *Notes* application, and therefore would have to be opened through the *File Explorer* application itself. Therefore, although Pocket PC does not constrain the creation of a deep folder hierarchy, it does not support access within applications to files that reside deep within the folder hierarchies.

The *File Facility* appears in only one context; access to other applications is available through icons in the *File Facility*. The *File Facility* constrains the creation, and view, of folders to within the top level folder hierarchy, and the creation and view of files to within the sub-folders of the top-level folders. The *File Facility*, therefore, constrains both the structure and depth of the hierarchy.

### 5.3 Participants

There were a total of 12 participants in this study. Six people with aphasia were recruited from stroke and aphasia clubs, and through snowball sampling<sup>2</sup>. These six participants were then matched on age, education, and computer usage, with six people without aphasia.

The participants ranged in age from 28 to 80. Of the 12 participants, three were female, one with aphasia and two without. The education levels ranged from completion of high school to six years of post-secondary education. Computer use varied from participants with no prior computer experience to participants who used computers several times a week. We matched on computer use based on the following criteria:

- a:** No prior computer experience, or rarely use a computer and then only with help.
- b:** Rarely use a computer, no more than three times a month.
- c:** Occasionally use a computer, more than three times a month, but at most once or twice a week.
- d:** Regularly use a computer, at least three times a week.

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<sup>2</sup>In snowball sampling, the participant pool is increased through referrals from initial participants.

Table 5.1: Overview of participants matched on criteria of age, education, and computer use

Participants	Age	Education	Computer Use
A1, N1	29, 28	14, 16	d, d
A2, N2	52, 52	12, 13	d, d
A3, N3	80, 78	12, 14	a, a
A4, N4	64, 69	15, 18	b, d
A5, N5	47, 47	16, 17	b, d
A6, N6	55, 53	12, 14	b, d

None of the participants had used a Pocket PC device prior to the study, with the exception that some of the participants had taken part in a laboratory study of a daily planner [57]. Only one had prior experience with a PDA, a Palm device, outside of a study setting. Table 5.1 shows a complete description of all participants. Each row shows the matched pairs of participants, the first number corresponding to the participant with aphasia, and the second to the participant without aphasia. Most matched pairs were within two years in age. The criterion of education is measured in the number of years of education, starting with grade one; grade 12 graduation being equivalent to 12. All pairs had a comparable number of years of education; there was at most three years difference within pairs. The matching on computer use was based on the criteria described previously. A4, A5, and A6 all used a computer regularly prior to their aphasia but not after due to difficulties they experienced as a result of aphasia.

### 5.3.1 Western Aphasia Battery Scores

Scores for the Western Aphasia Battery (WAB) test, a test used to evaluate language function [42], were available for all participants. Purves either administered the test for the current study, or had access to the scores of a previously administered WAB. Because aphasia is an umbrella term that encompasses both a range of deficits and a range of severity within those deficits, it was necessary to evaluate the communication abilities of the participants with aphasia to allow us to interpret our results in light of the severity, and type, of each participant's deficits.

The WAB gives an indication of the overall severity of aphasia in the area of speech and auditory comprehension through the Aphasia Quotient (AQ),

Table 5.2: Raw WAB scores for participants with aphasia

	A1	A2	A3	A4	A5	A6
Speech:						
Information Content <sup>a</sup>	7.0	8.0	4.0	5.0	9.0	5.0
Fluency <sup>a</sup>	4.0	6.0	4.0	2.0	5.0	4.0
Naming <sup>a</sup>	6.1	8.8	6.2	3.0	6.4	6.5
Repetition	3.4	8.8	5.9	3.3	5.9	7.3
Mean	5.1	7.9	5.3	3.3	6.9	5.7
Auditory Comprehension	5.5	9.6	9.2	7.4	8.0	9.8
Reading	5.6	9.4	6.9	5.1	9.4	8.1
Writing	3.4	8.0	4.8	3.5	6.0	3.6
<b>Aphasia Quotient</b>	<b>52.0</b>	<b>86.4</b>	<b>60.5</b>	<b>40.8</b>	<b>70.8</b>	<b>65.1</b>

<sup>a</sup>In spontaneous speech

a measure of the discrepancy of an individual's language performance from normal language performance. A higher percentage indicates a performance closer to normal proficiency, and therefore a less severe deficit. Table 5.2 shows the AQ scores of all participants with aphasia in our study; scores ranged from 40.8% to 86.4%. Also seen in this table are the individual raw scores assigned to each participant for each of the language modalities; the highest raw score attainable is 10.

The participant's four modalities of language tested by the WAB, speech, auditory comprehension, reading, and writing, were also given overall ratings, based on the raw score, of mild (8.0-10.0), moderate (4.0-7.9), or severe (0.0-3.9). Table 5.3 gives an overview of the overall ratings of the four modalities for all participants. For speech and writing, scores ranged from moderate to severe, and for auditory comprehension and reading, they ranged from mild to moderate.

## 5.4 Methodology

A two (application, within subjects) by two (aphasia group, between subjects) design was used. The within subjects factor was counterbalanced to control for learning effects. Therefore, there were three participants in each of the four application by aphasia group conditions:

1. FF(aphasia)—FE(aphasia)

Table 5.3: Ratings based on raw WAB scores for participants with aphasia

	A1	A2	A3	A4	A5	A6
Speech	Mod	Mod	Mod	Severe	Mod	Mod
Auditory Comprehension	Mod	Mild	Mild	Mod	Mild	Mild
Reading	Mod	Mild	Mild	Mod	Mild	Mild
Writing	Severe	Mild	Mod	Severe	Mod	Severe

2. FF(non-aphasia)—FE(non-aphasia)
3. FE(aphasia)—FF(aphasia)
4. FE(non-aphasia)—FF(non-aphasia)

When recruiting participants we offered them a choice of either coming to the university or conducting the study in a setting of their choosing. As some of the participants lived in another city, and many of the participants with aphasia had disabilities that affected their mobility, this offer made it possible for a wider range of people to participate. One participant came to the university, all other participants chose to conduct the study in their home or local stroke club.

During a pilot session, a participant with aphasia did not complete the study due to fatigue; because of this we reduced the length of time for the session, setting the length of each condition to 25 minutes. In other walk-throughs, some participants failed to complete trials because they became lost in non-task related applications or functions. To ensure that this did not dominate an entire session, we set a time limit of three minutes for each trial. If a participant was able to recover from an error, this was ample time to complete the trial. Extending beyond this time was a good indication that the participant was in an irrecoverable state.

#### 5.4.1 Procedure

All participants took part in one 90 minute evaluation session. Participants with aphasia for whom we did not have WAB scores attended a subsequent session of between 60 and 90 minutes in which a WAB test was administered.

The participant and two researchers were present at all sessions. A number of sessions were conducted with someone else in the room but not

interacting with either the participant or the researchers. In one session a family member assisted in communicating the study guidelines, but not task instructions, to the participant.

A tutorial was given in *Pocket Word* on the interaction technique of *tap* and *tap and hold*, both to teach this technique and ensure that participants had the minimum motor ability to take part in the study.

The two conditions, each lasting 25 minutes, were separated by a break during which participants were offered a snack. During the conditions, a video camera was focused on the Pocket PC screen, and an audio recording was made. One Pocket PC was used for the demonstrations, and another was used for the trials. The trial Pocket PC was attached with Velcro to a mouse pad with a weighted arm rest that was heavy enough to remain stationary during the sessions.

A demonstration walk-through was given with a researcher leading the participant through the task, pointing with her stylus at the place where the participant should tap next. During the demonstration participants were encouraged to ask questions<sup>3</sup>. The demonstration occurred prior to the task trials, although there were exceptions, as discussed in the next section (5.4.1) and seen in the task overview table (Table 5.4). After the demonstration, trials for the task were completed without a demonstration; however, a participant could request another demonstration between trials.

After the demonstration, participants were shown a trial instruction (see Figure 5.3), and the trial Pocket PC was placed in front of them with a *Post-It Note* covering the screen. Participants were asked to remove the *Post-It Note* and commence the task when they felt ready. When they were finished, they were instructed to cover the Pocket PC screen with the *Post-It Note*. If either the three minutes allotted for each trial, or the 25 minutes allotted for each condition, elapsed, the participant was asked to stop the task.

After the two conditions were completed, an open-ended interview was conducted, which lasted between 15 and 30 minutes. An audio recording was made of the interview. Both Pocket PC devices were placed in front of the participant, one with the *File Facility* open and the other with the *File*

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<sup>3</sup>There was a large range in the number of questions asked and in the length of time taken to answer, in part because of the range of communication abilities of participants. Participants who asked fewer questions and received quick answers had more time to complete trials during the sessions. Increasing the length of sessions was not an option as fatigue would then become a factor. Overcoming this design limitation, which existed in our study, remains an important challenge to others attempting to compare participants with aphasia to those without.



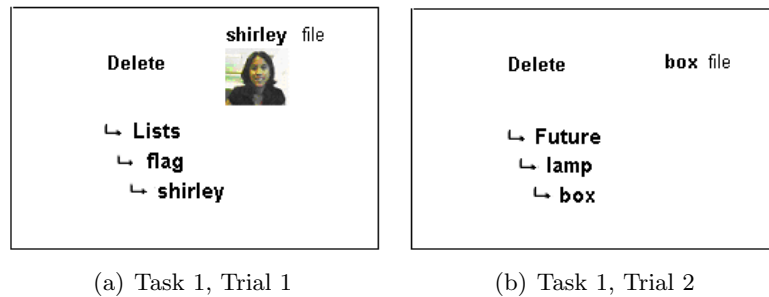


Figure 5.3: Example of trial instruction (Delete File).

*Explorer* open. This was done both to remind the participants of the applications being discussed, and to aid in communicating with participants with aphasia. Notes were made during the interviews and after each interview a report was made based on the notes and recordings.

As all tasks were focused on files and folders, a file and folder structure was needed for the demonstrations and each of the two conditions. File and folder names were chosen with the assistance of Purves to ensure the lexicon used was one which was likely to be readable by someone with aphasia. Three separate folder hierarchies that drew from the same set of names were created and installed for each of the two conditions and for the demonstration tasks.

## Tasks

A number of tasks were chosen based on the frequency these tasks are done within a file management system. These basic operations are task 1, deleting a file, task 6, copying a file, and task 7, copying a sub-folder.

In addition to covering basic operations, we wanted to test if the adaptive interface caused usability problems. Tasks 2, 3, 4, and 5 were designed to evaluate the adaptive behaviour of the *File Facility*. The demonstration walk-through for these tasks was done as a set, prior to task 2. In task 2, the participant was asked to find a sub-folder. In tasks 3 and 4 the participant was asked to create the fifth and sixth sub-folder, resulting in the *Next Screen* being created. In task 5, the participant was asked to find the same sub-folder they found in task 2; however, the sub-folder would now be in a different position. The trials for tasks 2, 3, 4, and 5 were done as a set; the second trial for task 2 following the first trial of task 5.

Table 5.4: Overview of tasks given during sessions

Task #	Task Name	Trials <sup>a</sup>	Task Description
1 <sup>1b</sup>	Delete File	2	Delete a specified file.
2 <sup>2,3,4,5</sup>	Find Sub-Folder	2	Open a specified sub-folder.
3	Create Sub-Folder	2	Create a new sub-folder.
4	Create Sub-Folder	2	Same as above.
5	Find Sub-Folder	2	Same as task 2.
6 <sup>6</sup>	Copy File	2	Copy a file to a new location.
7 <sup>7</sup>	Copy Sub-Folder	2	Copy a sub-folder to another top-level folder.
8 <sup>8,9</sup>	Find Sub-Folder	2	Open a sub-folder, selected from 20 sub-folders.
9	Find Sub-Folder	2	Same as above.
10	Copy a Sub-Folder	1	Same as task 7.
11	Create a Sub-Folder	1	Same as task 3.
12	Delete a Sub-Folder	1	Delete a sub-folder.
13 <sup>13</sup>	Create File	2	Create a new note.

<sup>a</sup>The number of trials for the current task.

<sup>b</sup>Subscripts indicate that a demonstration occurred prior to the task with the subscript. Subscript numbers indicate the tasks that were demonstrated during that demonstration.

The adaptive behaviour of *File Facility* also occurs when a sub-folder in the *Next Screen* is opened. After being opened, the sub-folder icon moves to the main *Sub-Folder Screen*. Tasks 8 and 9 were included to evaluate whether this behaviour was confusing. The demonstration walk-through for both tasks was done together, and preceded task 8. In task 8, the participant was asked to find and open a sub-folder in a folder containing 20 sub-folders, which, in *File Facility*, required that the participant scroll down through the *Next Screen*. In task 9, the participant was once again asked to find and open the same sub-folder opened in task 8; however, the sub-folder would now be in a different position. The trials for tasks 8 and 9 were done as a set; the second trial for task 8 followed the first trial of task 9.

We wanted to compare whether the two interfaces differed in the memory demands placed on the user. Tasks 10, 11, and 12 were a repeat of three basic operations shown in previous tasks, and no demonstration was given prior to these tasks. In task 10, the participant was asked to copy a sub-folder, in task 11, create a sub-folder, and in task 12, delete a folder. These three tasks required that participants recall how to do a previously completed task.

Finally, we wanted to evaluate file creation. In task 13, the participant was asked to create a *Note*. Given the different way the two file management systems integrate with applications, the note was created directly in the *Note* application in the *File Explorer* condition, and through the *File Facility* in that condition. It was saved in two different locations in the two conditions, based on their support for files.

There were two trials for each task, with the exception of the memory tasks, which did not have a demonstration and had only one trial per task. Table 5.4 shows an overview of all tasks.

### 5.4.2 Measures

#### Quantitative Measures

The data for the quantitative dependent measures were based on video analysis and session notes. The following quantitative measures of performance were used:

**Total Successful Trials:** The number of trials successfully completed in the condition. A trial was considered successful if a successful state had been achieved during the trial. Some participants would forget to indicate the trial was successfully completed, others would ask, and others would time out before indicating to us the trial was complete. Some participants were unsure if they had reached a successful state,

and would continue tapping the PDA. In all the above cases, we would count the trial successful if the successful state had been achieved prior to the trial timing out.

**Total Errors:** The number of errors made during the session. An error was counted when a tap was made that deviated from the path towards successful task completion. No other error was recorded until the participant was again on the path to successful task completion.

### Qualitative Measures

The data for the qualitative dependent measures were based on the initial interview notes, the interview recordings, and the interview report. Although the interview was open ended, all participants answered the following questions.

- Do you prefer the *File Facility* or the *File Explorer*?
- If you have a computer in your home, are you the person who maintains it?
- Do you use folder structures to keep your files organized?

In addition to the interview, qualitative data was obtained from the video recordings made during the two conditions.

### 5.4.3 Hypotheses

Our first study goal, (1) to compare the usability of the *File Facility* to the *File Explorer* for users with aphasia, motivated the following hypotheses:

- *Hypothesis 1:* Participants with aphasia will successfully complete a greater number of tasks in the *File Facility* condition.
- *Hypothesis 2:* Participants with aphasia will have fewer errors in the *File Facility* condition.
- *Hypothesis 3:* Participants with aphasia will prefer the *File Facility*.

Our second study goal, (2) to compare the usability problems encountered by users with aphasia with those of the general user population, was more exploratory. Two obvious hypotheses that relate to this second goal follow:

- *Hypothesis 4:* Participants without aphasia will successfully complete more trials than those with aphasia.

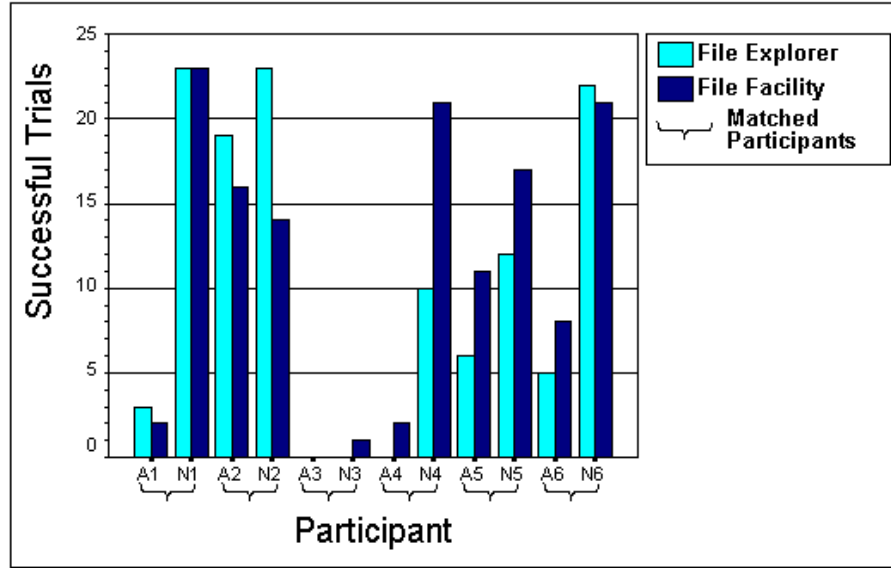


Figure 5.4: Successful trials of participants. Participants with aphasia are to the left of their matched participant without aphasia.

- *Hypothesis 5:* Participants with aphasia will have more errors than those without aphasia.

By asking participants if they maintained a computer and used folder structures we hoped to tease out whether performance and preference differences we might attribute to differences in aphasia group could be explained by grouping participants by the type of computer activity in which they engage.

- *Hypothesis 6:* Participants who maintain a computer and use folder structures will have a greater number of successful trials and will be more likely to prefer *File Explorer* than those who do not, regardless of aphasia group.

## 5.5 Findings

We first report our results with respect to our six hypotheses. The quantitative data obtained had a high degree of variability and therefore did not always satisfy the assumptions of the statistical tests used. We report

Table 5.5: Mixed ANOVA results for successful trials by aphasia group, application order, and application.

Source	SS	df	MS	F	Sig of F
<i>Between Subjects</i>					
Aphasia	570.375	1	570.375	4.218	<b>0.074</b>
App Order	15.042	1	15.042	0.111	0.747
Aphasia * App Order	22.042	1	22.042	0.163	0.697
Error (Between)	1081.667	8	135.208		
<i>Within Subjects</i>					
Application	9.375	1	9.375	0.911	0.368
Application * Aphasia	0.375	1	0.375	0.036	0.853
Application * Order	45.375	1	45.375	4.409	<b>0.069</b>
Application * Aphasia * Order	12.042	1	12.042	1.170	0.311
Error (Within)	82.333	8	10.292		

the results here with the caveat that we are looking for trends only; for all inferential statistical tests,  $\alpha = 0.1$ .

Note that the mean number of trials completed successfully for all participants in the *File Facility* and the *File Explorer* conditions were 11.33 and 10.25 respectively, out of a possible 23 trials. Figure 5.4 shows the number of trials successfully completed in each condition by each of the participants. In the graph, each participant with aphasia is to the left of his or her paired participant without aphasia.

*Hypothesis 1: Participants with aphasia will successfully complete a greater number of trials in the File Facility condition.*

A univariate repeated-measures analysis did not reveal a main effect of application successes within the aphasia group, indicating that the number of successes was not influenced by the application used (Table 5.5). There was, however, a significant within subjects two-way interaction of successful trials by application and order of condition ( $F(1,8) = 4.409$ ,  $p < 0.069$ ), indicating that performance differences in the two conditions by all participants was influenced by which condition was seen first. The mean number of successful trials for the four application by aphasia group orderings can be seen in Figure 5.5. This two-way interaction is pictured in Figure 5.6. Regardless of which condition was seen first, there was little impact on the *File Explorer* performance (9.84 vs. 10.67). In contrast, those who saw the *File Facility* first did significantly worse (9) compared to those who saw it second (13.67).

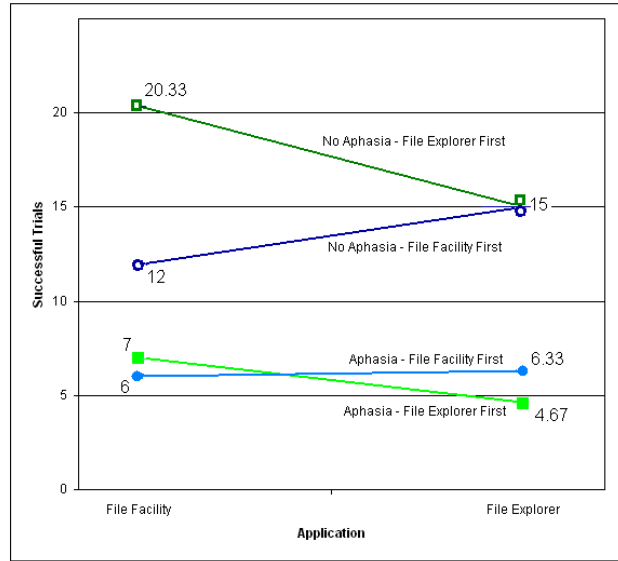


Figure 5.5: Mean number of successful trials for the four application by aphasia group orderings.

This may suggest that the *File Explorer* scaffolded the learning of the *File Facility*. However, additional studies are required to investigate this pattern further.

*Hypothesis 2: Participants with aphasia will have fewer errors in the File Facility condition.*

A univariate repeated-measures analysis did not reveal a main effect of application errors within the aphasia group, indicating that the number of errors made was not influenced by the application used (Table 5.6). There was, however, a significant within subjects three-way interaction of errors by aphasia group, application order, and application ( $F(1,8) = 5.293$ ,  $p < .05$ ). This indicates that the number of errors made in each condition was influenced by which condition was seen first, and this influence is different for each group. This will be discussed under *Hypothesis 5*.

*Hypothesis 3: Participants with aphasia will prefer the File Facility.*

This hypothesis was not supported. The participants with aphasia were equally divided in their stated preferences for the two applications, with 50% preferring the *File Facility*. Interestingly, a higher percentage of participants without aphasia preferred the *File Facility* (67%). Speculations on why this

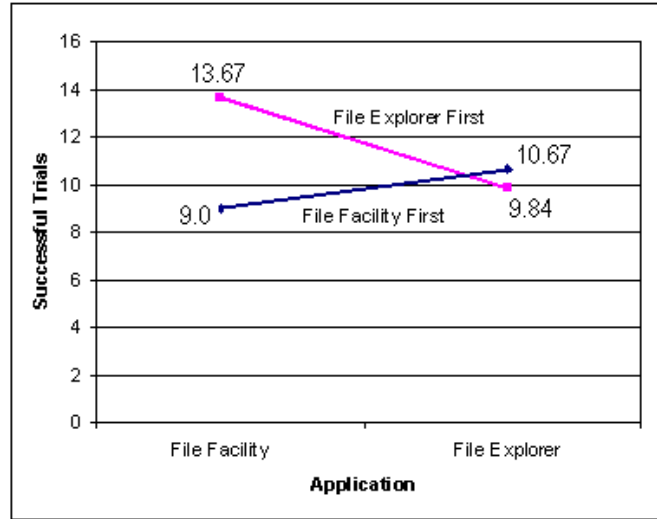


Figure 5.6: Two-way interaction of successful trials by application and order. The mean number of successful trials for each condition is shown.

Table 5.6: Mixed ANOVA results for errors by aphasia group, application order, and application

Source	SS	df	MS	F	Sig of F
<i>Between Subjects</i>					
Aphasia	888.167	1	888.167	2.132	0.182
App Order	2.667	1	2.667	0.006	0.938
Aphasia * App Order	0.667	1	0.667	0.002	0.969
Error (Between)	3332.000	8	416.500		
<i>Within Subjects</i>					
Application	130.667	1	130.667	1.372	0.275
Application * Aphasia	2.667	1	2.667	0.028	0.871
Application * App Order	121.500	1	121.500	1.276	0.291
Application * Aphasia * Order	504.167	1	504.167	5.293	<b>0.050</b>
Error (Within)	762.000	8	95.250		



difference was seen are discussed in Section 5.6.

*Hypothesis 4: Participants without aphasia will successfully complete more trials than those with aphasia.*

A univariate repeated-measures analysis revealed a main effect of aphasia ( $F(1,8) = 4.218$ ,  $p < 0.074$ ), indicating that people without aphasia were indeed able to successfully complete more trials (Table 5.5). The two-way interaction of successful trials by application and order of condition also seen in this analysis was discussed under *Hypothesis 1*, and is shown in Figure 5.6.

*Hypothesis 5: Participants with aphasia will have more errors than those without aphasia.*

A univariate repeated-measures analysis did not reveal a significant main effect of aphasia (Table 5.6), indicating that there was no significant difference in the number of application errors made by people with and without aphasia. However, as reported under *Hypothesis 2*, a 3-way interaction of errors by application, aphasia group, and application order was seen. The number of errors made within each application was disproportionately influenced by which application was seen first (order), and by aphasia group. People with aphasia made more errors in their second condition, regardless

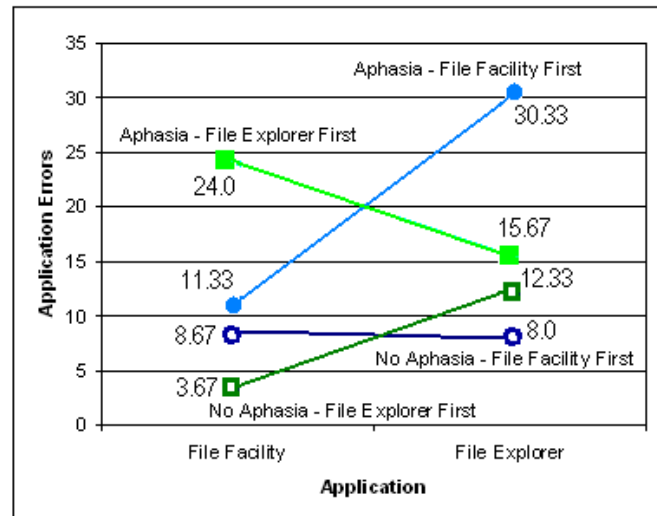


Figure 5.7: Three-way interaction of errors by aphasia group, application order, and application.

of application (Figure 5.7). People without aphasia either made roughly the same number of errors in both applications (when *File Facility* was seen first), or made fewer errors in the second condition (when *File Facility* was seen second). This may indicate that the *File Explorer* condition acted as a scaffold for the *File Facility* condition for both groups, but the *File Facility* condition acted as a scaffold for the *File Explorer* condition only for participants with aphasia. Perhaps the similarity of the Pocket PC *File Explorer* application to the desktop PC version helped those participants who were familiar with the desktop PC version and who first conducted the tasks in a familiar environment before moving to a new application. However, the *File Facility* may not have acted as a scaffold for those without aphasia as all information obtained from the *File Facility* condition could be obtained during the *File Explorer* condition. For those participants with aphasia, however, seeing the *File Facility* condition first may have acted as a scaffold as the tasks were first done in an environment that was not text-dependent. Another possible explanation for this result is that participants with aphasia may have made more errors in the second condition because of fatigue. The interaction is shown in Figure 5.7.

*Hypothesis 6: Participants who maintain a computer and use folder structures will have a greater number of successful trials and will be more likely to prefer the File Explorer than those who do not, regardless of aphasia group.*

We found that all participants who said they maintained a home computer also said they created and used folder structures; no participant did one but not the other. This type of computer activity corresponded with a higher number of total successful trials, and a preference for *File Explorer*. The four participants who maintained and used folders had the four highest numbers of total successful trials, and three of the four preferred the *File Explorer* (75%). Of the eight who did not maintain a household computer or use folders, six preferred the *File Facility* (75%). Figure 5.8 gives an overview of participant preference, with participants ordered by total trial successes; indicated is the trial successes in each application, and whether or not the participant maintains a household computer and creates folder structures to keep their files organized. The AQ of the participants with aphasia is shown under their participant identification code.

Although computer maintenance and folder use is a better indicator of the total number of successful trials and a better predictor of preference for *File Explorer*, than is aphasia, the two, computer usage and aphasia, are confounded in our study. The only participant with aphasia who currently maintained a computer and used folder structures had the highest AQ of

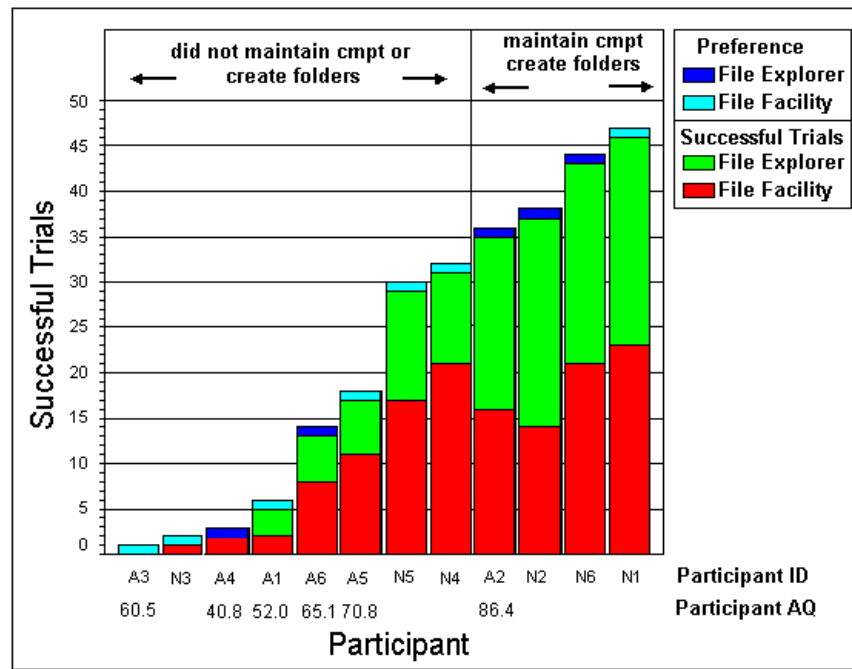


Figure 5.8: Participant preference shown, with participants ordered by total number of successful trials. Below participant ID is their AQ.

all participants with aphasia. All the other participants who, prior to their aphasia, would have been in this group, no longer carry out these activities. However, this pattern does indicate that people without aphasia, who are computer novices, have similar performance to people with aphasia.

## 5.6 Other Findings and their Implications for the File Facility Design

Several implications for the design of the *File Facility* emerged from this study. They are categorized into those that are dependent on a more judicious use of screen space, and therefore may conflict with the original motivation for the design, those that have implications for the cognitive demands of the *File Facility*, and those that have implications for the physical demands or appearance of the system. Findings on the patterns of performance between people with and without aphasia will also be discussed.

### 5.6.1 More Information on each Screen

Many participants expressed a preference for the ‘overview’ offered by *File Explorer*; there is more information about files (e.g., file size), and more files and folders can be listed on the screen. A few participants did not like the lack of a label indicating the current sub-folder in the *File Facility*; knowing which hierarchy you were in, through colour, was not enough to replace knowing which sub-folder you were seeing. One participant mentioned the name of the sub-folder as part of the benefit of an overview. Adding the sub-folder name could be done using a minimal amount of screen space.

Across all file and folder trials that required pasting in the *File Facility* condition, seven errors were made in which the participant first opened the destination folder before looking for the *paste* icon. This may indicate that having the *paste* icon located on the screen beside the destination folder icon is not intuitive. However, the Top-Level Screen has room for a paste icon beside each top-level folder but the Sub-Folder Screens that show all folders within a top-level folder do not have room for a top-level folder paste icon. Therefore, accommodating what may be a more intuitive placement is difficult.

### 5.6.2 Cognitive Demands of the File Facility

We were not sure if an adaptive interface would confuse users. This did not appear to be the case. During trials of tasks 8 and 9, designed to target this

behaviour, only one error was made, and the participant immediately said “oops” and recovered. Participants may have relied less on their memory than we had assumed would be the case, or they easily grasped the concept during the demonstration walk-through. However, of the six participants who reached these tasks, only two were in the aphasia group. Further investigation is required to properly evaluate whether the use of an adaptive interface is appropriate for users with aphasia. Tasks 2, 3, 4, and 5 were also designed to evaluate the adaptive interface. A number of users, however, had difficulty with other aspects of the interface in these tasks, for example using the soft keyboard to name the new folder, and therefore the total errors in these tasks did not give a clear picture on the usability of the adaptive technique.

One participant commented that she would not have adopted the *File Facility* on her own given the similarity between the Pocket PC’s *File Explorer* and her desktop PC’s *File Explorer*. The requirement of learning a system that looked so different from the system with which she was familiar would have been too great a deterrent. Findings from the field study suggest this familiarity may be deceiving, however. The appearance of familiarity, together with subtle differences in behaviour, caused confusion for Marcella.

Many participants had difficulty remembering the meaning of the *cut*, *copy*, and *paste* icons in *File Facility*, particularly differentiating between the *copy* and *paste* icons. Adding an additional cue would be helpful to remind users of the meaning of these icons.

### 5.6.3 Physical Demands and Appearance of the File Facility

Many participants had difficulty hitting the *cut*, *copy*, and *paste* icon targets, particularly those participants with motor deficits. Although the height of these targets is similar to the height of the targets in the *File Explorer*, the width of the *File Explorer* targets span either the menu window or entire screen window. The narrower width in the *File Facility* icon was noticeably more difficult to hit. The remaining screen space between the icon and the edge of the screen could be utilized to make the targets wider, although the targets would still be narrower than those in *File Explorer*.

Several participants commented that the *File Facility* looked ‘childish’ or that it appeared to be designed for novices. One participant mentioned that this appearance contrasted with the more business-like look of *File Explorer*, which he preferred. Several participants felt the appearance of the *File Facility* did not reflect their self perception. Others said it did not reflect their way of thinking.

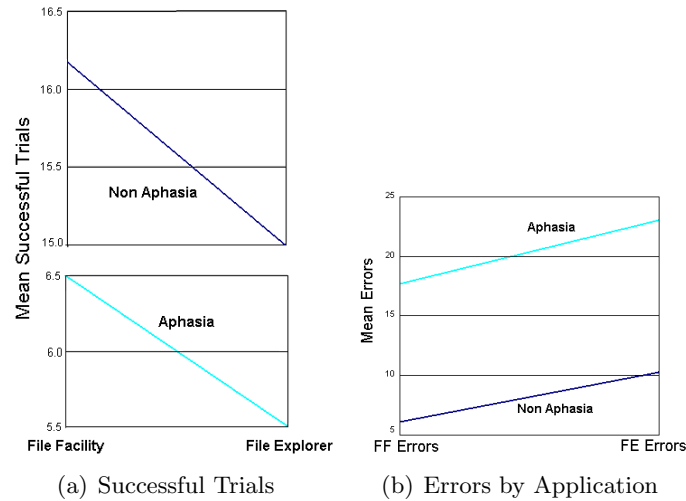


Figure 5.9: Pattern of performance between aphasia groups. Figure (a), showing the mean of the total successful trials, is split into two graphs to conserve space.

When stating their preferences, a number of participants linked their preference to their identity of being either ‘visually-oriented’ or ‘text-oriented’. This may be difficult to address as the *File Facility* is more visually-oriented, and we assumed that people with aphasia who have difficulty reading would prefer a more visually-oriented application. However, this may not be the case, as their self-perception may still be that they are text-oriented. In addition, of the six participants with aphasia, four had only a mild reading impairment, and two only a moderate reading impairment (see Table 5.3).

We speculate that the above comments indicate a perception of the *File Facility* that leaves a greater negative impression on participants with aphasia than on those without, and that this is reflected in the lower percentage of participants with aphasia who preferred the *File Facility*.

#### 5.6.4 Patterns of Performance Between People with and without Aphasia

Although the absolute performance values differed between participants with aphasia and those without, there was a surprising similarity to the pattern of performance seen in the two groups. This pattern, although not statistically significant, is suggested by the graphs of the mean number of total successful

trials across both applications (Figure 5.9(a)), and of the mean number of total errors across both applications (Figure 5.9(b)), in each group. A similar pattern, again not statistically significant, can also be seen in the interaction effect of condition order on the successful tasks completed, seen in Figure 5.5. Additional studies will be required to validate these patterns.

## 5.7 Informal Field Study

The *File Facility* was installed on Marcella's PDA after the evaluative study was completed, and he began using it in his daily life. Through informal interviews, a number of issues emerged.

Marcella experienced the same difficulty with differentiating between the *copy* and *paste* icons as participants in the evaluative study. Textual cues, *Del*, *Cpy*, and *Pst*, were added to each of the *cut*, *copy*, and *paste* icons respectively. This proved to be sufficient to alleviate this problem for Marcella.

The top-level folder structure provided by the *File Facility* did not prove to be as useful as we hoped. The difficulty in supporting continuous categorization of a variety of material for easy recall is a challenging problem that needs further work.

Marcella had become comfortable with the *File Explorer* by the time the *File Facility* was installed, and he tended to use both in combination. What he clearly found most useful about the *File Facility* was the creation of thumbnails when he used the Nexicam.

## 5.8 Summary

The findings from the above exploratory study suggest trends that need further investigation. Similar patterns of performance between the two aphasia groups, although not statistically significant, suggest areas where further investigation may be useful. The study also illuminated challenges in designing a study to compare participants with and without aphasia. A design must ensure that participants with aphasia have adequate time to ask questions and receive answers they understand, without being penalized by a reduction in time to complete the trials. However, study designs must also ensure the length of experimental sessions do not last too long, fatiguing participants.

## Chapter 6

# Discussion

In this chapter we discuss the collaboration between the Aphasia Project and Marcella. We then discuss the process of evaluating technology that is designed with an ethnographic approach.

### 6.1 A Word About Collaboration

#### 6.1.1 Ideal Collaborators and Typical Users

Marcella was an ideal collaborator in this research for three reasons. He is a gifted communicator, he is an enthusiastic user of technology, and he has a very easy going personality.

Marcella enjoyed and was good at public speaking prior to his accident. He is outgoing and embraces opportunities to socialize and connect with people. He has a natural gift as a communicator, and is motivated to communicate given his outgoing personality. This combination of traits made it highly likely that he would develop communication strategies, and that those strategies would be effective. Through reading literature on aphasiology and alternative and augmentative communication, and meeting a range of people with aphasia, it is clear that there are many ways to respond to acquiring aphasia, and Marcella's response is uniquely his own.

Marcella used technology prior to his accident. He enjoys technology and is not frustrated by technological breakdowns or irritated by the time spend *tinkering* with technology. He was an enthusiastic adopter of the PDA; he was even more enthusiastic in his adoption of this technology than any member of the Aphasia Project.

Marcella has a very relaxed, easy going nature. He is funny, yet he is also very clear about his boundaries and his needs. In addition, the author and Marcella had a very similar sense of humour, political outlook, and simply got along very well together.

Although an ethnographically informed methodology has worked very well in this instance, it is difficult to assess how much of that was dependent on the participant selected or the synergy between Marcella and the



author, or a combination of these two factors. It is easy to imagine other combinations that would have made this research very difficult to pursue.

Marcella was an ideal collaborator, but not a typical user. Given the range of deficits seen in people with aphasia, however, and the diversity of capabilities of older users generally [84], the concept that such a representative user exists is questionable. Newell and Gregor [63] have suggested that when including people with disabilities, the term *centred* should be replaced by *sensitive* in *user centred design*, in part to emphasize that producing a small, representative sample of the user group is not meaningful for certain populations of users.

We believe that although Marcella may not be a typical user, he has a set of characteristics and skills that make him an ideal *advocate user*. As Luke et al. pointed out, PD requires that participants have an understanding of both their work and technology [48]. In our research, the *work* being investigated was the communication strategies used. Alternative communication strategies are not always embraced by people with aphasia, and therefore, this understanding cannot be assumed.

When asked what he gained from collaborating on this research, Marcella responded by listing two aspects of the research. The first was participating in the process of designing technology. The second was gaining a meta-understanding of the communication strategies he used. Through discussions of his communication strategies, his appreciation for and understanding of those strategies deepened to the point where he now wants to actively share his strategies with others with aphasia, in particular the way he incorporates technology into his communication strategies. His response reaffirms our perception of him as an ideal advocate user.

### 6.1.2 Challenges of Collaboration

Newell and Gregor [63], in discussing a new methodological approach they refer to as *user sensitive inclusive design*, identified a number of issues in “designing for all” that present challenges to researchers. In this section we discuss these as they relate to our research.

#### Ongoing Technical Support

One concern we share with Newell and Gregor [63] is the issue of long term support. Newell and Gregor suggest it is essential to make clear prior to including participants that such support is not the responsibility of the research team. This is a particularly thorny issue after conducting an ethno-

graphically informed study for over a year. Technological support has been available throughout that time, and the research effort depended on Marcella's commitment to the handheld technology supplied. Although we suggested a long-term loan to encourage this commitment, we had not anticipated the extent of ongoing technical support required to make such a device usable in supporting daily communication. Marcella will continue to have access to members of the Aphasia Project, but the level of support will be drastically reduced outside the context of this study. Ideally, the resources of the Aphasia Project would be such that more ongoing technical support would be available to participants actively engaged in the project. However, given the limited resources available, taking the approach of Newell and Gregor may be more realistic.

### **Contributions of Clinicians**

Newell and Gregor have pointed out that merely consulting with clinicians does not engage them in the research ethos. Their research project, homed in Dundee's Applied Computing Department, employs professionals such as speech-language pathologists. Reflecting on the experience of the Aphasia Project, Moffatt has also noted the difficulty in imparting to busy professionals the exact nature of the research, specifically, that technology being designed was not rehabilitative [56]. The Aphasia Project has addressed this issue through an interdisciplinary approach, and has as members on the research team both a psychologist and speech-language pathologist.

Having Purves on the research team, a speech-language pathologist who is also pursuing research in aphasia, has been particularly invaluable in this research, given the ethnographic approach taken. Purves was the initial liaison between the Aphasia Project and Marcella. Her history as a clinician has brought with it an understanding not only of aphasia, but of the community of people with aphasia. As Newell and Gregor [63] have stated, including people with communication impairments in a research effort is not straightforward, and selecting participants to be included as full members of the design team must be done with care. Purves has played a crucial role in selecting participants for the research studies, and this has been a significant contributing factor in the success of the Aphasia Project thus far.

### **6.1.3 Technological Resources**

People with aphasia often do not return to work, or are underemployed relative to their employment prior to the aphasia[61]. This has obvious

economic implications if the person acquired aphasia prior to retirement. It is necessary that researchers are sensitive to potential issues that may arise because of this. One implication is that, unlike PD conducted in a work setting, researchers cannot assume that the technological resources available to people with aphasia will be up-to-date and compatible with the technological resources with which the research team is working.

One example from the current research is that the *Archiving Facility*, implemented on a desktop PC running *Windows XP*, failed to run on Marcella's home computer running *Windows 98*. The development environment used, *MS Visual Studio .NET*, does not run on *Windows 98*, and there was no machine at the university readily available that was running *Windows 98*. Consequently, this application was not installed on Marcella's home computer.

A related concern is that a number of people with aphasia, when they saw the PDA, were very interested in acquiring one for their own use. The PDA we are using is not cheap, and given Marcella's difficulties in successfully adapting the PDA to his needs, it is debatable how useful an off-the-shelf PDA would be to someone with aphasia. The prototypes we are developing are not robust enough for people to use without support, and further, have been developed in a technologically current environment. Researchers need to be wary of promoting expensive technology that will fail to meet the expectations of participants.

## 6.2 Limitations of Ethnographic Approach

The ethnographically informed approach motivated a solution that was closely tied to how Marcella used the off-the-shelf PDA, and the communication strategies he used in his daily life. This is the strength of this approach, but it can also be seen as a weakness. It has been argued that tying a solution too closely with the solutions envisioned by participants early in the design process can unnecessarily constrain the design [12, 63]. We believe, however, that this approach is particularly appropriate in the early stages of our project and will help ground further research in current practise.

Newell and Gregor caution against following participants too much [63]. They suggest that other factors, such as a participant's belief that certain designs are impractical, or solutions too costly, will limit the solutions considered. Limiting potential solutions would be a disservice to disabled users of the future. Bødker and Iversen suggest that this may occur because the designers, rather than contributing equally with their understanding of the-

ories and technologies, take a back seat to users and their understanding of current practice [12]. Rather than following participants, PD requires engaging them in a reflective process, using artifacts to ground the discussion.

In our work, it became apparent that Marcella had many more ideas to contribute to the design of the prototype after using it in his daily life. For example, he expressed a need for some way to support a telephone conversation. He was taking a solo trip, and the telephone was going to be the main way to stay in contact with his partner. To quickly accommodate this need, the method of creating notes was changed. Instead of notes being given default names when created in the *File Facility*, a textbox appeared in which a user typed the filename. Marcella could then create a number of notes with different filenames. If, prior to a telephone conversation, he knew he wanted to communicate a number of things, for example the current weather, his current location, etc., he could create notes with filenames reflecting this information, tap the filename during the conversation, and *iSpeak* would read it. The idea to use the *File Facility* in this way came out of using the prototype in his daily life, rather than from his current practice. The prototype acted as a catalyst between current practice and future potential solutions, making it easier for alternative strategies to be envisioned. Continuing this process would be the natural next step for this research, and it would involve stepping away further from, while still being grounded in, current practice.

### 6.3 Evaluation

The *File Facility* was designed using an ethnographic approach, and tested using an experimental evaluation done in a pseudo laboratory setting. This choice of evaluation methodology is problematic for two reasons. First, it is unclear that applications designed to be used in a mobile environment on a handheld can be adequately evaluated in a laboratory setting. Second, the communication strategies supported by the *File Facility* are not measured as successful solely based on their efficiency, yet the evaluation we conducted used measures based, to some degree, on efficiency.

Usability testing of applications designed for PDAs are likely designed to be used in a mobile context, however usability testing done within this mobile context is challenging. Newcomb, Pahley, and Stasko [62] conducted an evaluation of their application in a store, as the context was intrinsic to the design, intended as it was to be used in a retail environment. Although testing in a store proved challenging, they believe it was crucial in evaluating

their application realistically. Although actions on the PDA were not easily monitored, other factors surfaced that would not have come to light outside the situated context, for example environmental noise made the auditory messages of their application inaudible. We believe that testing done in a situated context with tasks geared towards communication exchanges would be a appropriate in evaluating the *File Facility*.

Muller, Wharton, McIver, and Laux suggest that HCI has not developed a methodology to adequately evaluate applications that do not have efficiency and productivity as their core requirement [60]. The methodology we used in evaluating the *File Facility* did focus on measures more appropriate to a productivity tool than on an application to support human needs.

An example of the need to evaluate more than the efficiency and productivity aspects of a design exists in Moffatt's study [56, 57]. Moffatt compared how easily people with aphasia used a day planner with image and sound support over a text only planner. Marcella was familiar with the image and sound enhanced planner as he had been involved in the PD process. One day, during an exchange between Marcella and the author, Marcella pointed to an appointment that was identified only by a name. The author did not recognize the name, but Marcella was sure she knew the person. After a few minutes of trying to communicate who the person was, Marcella gestured to Moffatt's office. In the ensuing discussion, Marcella asked if he could use Moffatt's day planner. Although he did not need the image and sound support to make his own appointments, having them there better supported his use of the day planner as part of his communication strategy. The experimental evaluation of the image and sound enhanced day planner did not evaluate what is potentially its biggest strength when compared to the text-based day planner: its improved ability to be used as a communication tool in ongoing daily interactions with others.

## Chapter 7

# Conclusions and Future Work

The high-level goal of this research was to discover how a PDA could be used by people with aphasia to support their communication strategies. This goal was met through three sub-goals, enumerating Marcella's communication strategies, describing how he incorporated a PDA into those strategies, and designing and testing a PDA application to better support those strategies. An orthogonal goal was to adapt the PD process to better accommodate participants with communication deficits. In this chapter we will summarize how these goals were accomplished, and discuss areas where further research is needed.

### 7.1 Satisfaction of Thesis Goals

#### 7.1.1 Communication Strategies

The first goal of this research was to identify the communication strategies of someone with aphasia. This was accomplished through conducting a field study in collaboration with Marcella who, when the study commenced, had lived with aphasia for two years.

Marcella's communication strategies are dynamic and change continuously in response to his communication partners and to the context within which he is communicating. He incorporates written and spoken words, photographs, serendipitous props, gestures, pre-written stories, and a variety of reference materials in his daily interactions. Marcella uses technology to support his communication, in particular he uses email and a word processor extensively.

Coming to a shared understanding with Marcella of the communication strategies he uses grounded this research in current practice. Further, the description of these communication strategies, found in Chapter 3 Section 3.4.2, can be used as a resource by the Aphasia Project, both as a reference

for communication strategies used by people with aphasia, and as a source of ideas for future projects.

### 7.1.2 Use of PDA in Communication Strategies

The second goal of this research was to develop an understanding of how a PDA would be incorporated into the communication strategies of someone with aphasia; this was accomplished through the field study. This goal required that the potential of the PDA to support current communication strategies be described, and the usability problems that arose from its use be identified.

Immediately prior to the field study, Marcella began using a PDA supplied to him by the Aphasia Project. During the field study, he began incorporating the PDA into his communication strategies. Marcella identified the capabilities of the PDA to play sound files, display images, and display documents copied from his desktop as very useful.

In addition to an off-the-shelf PDA, Marcella was supplied with a digital camera attachment to the PDA, and a text-to-speech application, *iSpeak*, was installed in his PDA. The digital camera enabled him to make greater use of photographs in his communication strategy than did the non-digital camera he was using prior to the study. He used *iSpeak* when he shared personal stories with others, which eased the communication between himself and others with aphasia, and gave him more control in the process of sharing his stories.

The PDA enabled Marcella's use of technology to expand from exclusively supporting non-situated communication to supporting here-and-now interactions. However, integrating the PDA into his communication strategies was not without its challenges, the most frustrating of which was accessing files quickly and easily during interactions.

The field study succeeded in both identifying the potential of the PDA, and the usability problems frustrating the smooth integration of the PDA, as a communication device.

### 7.1.3 Design of a PDA Application to Better Support Communication

The third goal of this research was to design and evaluate an application to better support Marcella's communication strategies than was provided by the native interface of the PDA.

An ethnographically informed participatory design methodology was used to design the prototype application. This process was defined as ethnographically informed as it was not only informed by the results of the field study, but communication during the design process depended on the shared context that the field study provided. This process resulted in the implementation of the *File Facility*.

The *File Facility* was evaluated in an evaluative study conducted with twelve participants, six of whom had aphasia, and six who did not. Not surprisingly, people with aphasia did not perform as many tasks in the time allotted, and had more errors than people without aphasia. However, the patterns of performance, reflected in the total number of successful trials and errors made, and the influence of condition order on successful trials, were very similar between the two groups of users. This suggests that the usability problems experienced by people with aphasia are not unique to them. Rather, our results suggest that the same usability problems found in the general user population will be experienced, albeit more acutely, by people with aphasia.

In addition to the experimental evaluation, Marcella began using the *File Facility* in his daily life, and he continues to use it today. His pattern of use suggests more flexibility is needed in establishing the top-level directories. The problems he experienced with accessing and saving files during the field study, using *File Explorer*, however, were considerably diminished when using the *File Facility*.

## 7.2 Evaluation of an Ethnographically Informed Approach

Each phase of the research, with the exception of the experimental evaluation of the *File Facility*, was conducted using an ethnographically informed methodology. This was motivated by one of the goals of the Aphasia Project, that is, to explore ways PD can be adapted to meet the challenge of working with participants with communication deficits.

This methodology takes time; Marcella and the author spent over 70 hours together during the field study. The communication challenge identified at the outset of this research was successfully overcome as a result of the time requirement this methodology demanded. Time spent together ensures a shared context develops, and allows for the development of communication skills. Those skills, and the shared context, supported communication between Marcella and the author during the design process. Design ideas



were easier to formulate for the author after having witnessed *in situ* the ways the PDA was used to support communication. The ability of Marcella and the author to communicate easily allowed a truly participatory design process to emerge, with Marcella actively involved in the creation of the prototype.

## 7.3 Future Work

There are three areas where further work could extend this research, (1) the *File Facility* could be further developed to explore the usability issues the experimental study illuminated; (2) the field study report on Marcella's use of his desktop PC could motivate further work; and (3) an ethnographically informed approach could be used to evaluate the *File Facility* in the field with people with aphasia who were not involved with its design.

### 7.3.1 Further Development of the File Facility

Both the evaluative study, and informal field study, brought to light a number of design decisions that could be further examined using the *File Facility* prototype.

Many participants commented that the *File Facility* appeared to be designed for children or novices, and some identified the colour scheme as contributing to this impression. This could be tested by using a grey scale, among other colour schemes, to determine if colour contributes to a negative impression for some people. If people could customize the colour scheme according to their own preferences, would that alter their impression of the application?

Some participants found the targets too small. Following one of the guidelines suggested by Moffatt [56, 57], we ensured that there was inactive space around targets. This led to the *cut*, *copy*, and *paste* icons being smaller in length than targets in the *File Explorer*, although equal in height. The difference in length made the targets in *File Facility* harder to accurately tap.

Some participants found the target icons not understandable enough. They depended on memory when deciding which icon referred to what action.

After the study, both issues, the size of the icons and the requirement of a better cue to their meaning, were addressed in the application that Marcella uses. Adding these cues also lengthened the target, but resulted in no inactive space between the target and the edge of the screen. This

solution worked for Marcella, who was also finding it difficult to remember the meaning of the icons. However, further studies should be conducted to see if having no inactive space between the target and the edge of the display screen will cause further problems for some users. Further studies should also be done to determine the optimal size of targets.

Modifications to the *File Facility* could be done to explore options not used in the current design. For example, spatial cues or folder icons of different shapes could be used to test whether alternative layouts and icons are superior in supporting memory, and would thus result in a more efficient design of an application to support communication.

### 7.3.2 Other Potential Projects Identified During the Field Study

The field study identified a number of ways Marcella uses technology to support his communication. He uses a variety of software on his desktop PC, *MS Word*, *MS Power Point*, *MS Outlook*, *Adobe PageMaker*, and *ReadPlease*. There are several ways that this software could be adapted to better support Marcella's communication strategies. *ReadPlease*, like *iSpeak*, can only read text that has been copied into the operating system clipboard. This means it cannot be used to read names of files and folders, graphical representations of text, *adobe* files, and some web pages. Expanding the ability of *ReadPlease* to handle these formats would be very useful.

An application to support the collection of phrases from emails would make this strategy easier to use. Such an application would automate the addition of phrases into a database, and the organization of saved phrases into categories. Ideally, this application, integrated into *MS Outlook*, would have a feature to find and insert phrases into email and allow easy navigation through the database. Integrating *ReadPlease* would further increase the usability of the application.

Integrating the same, or similar, application into *MS Word* with the addition of a feature to assist in the process of writing and editing documents, would be very useful to Marcella. Further research would be required to establish the generalizability of the usefulness of such an application for other people with aphasia and other communication deficits.

### 7.3.3 Exploring an Ethnographic Approach

The methodology used in this research took an ethnographic approach. Exploring this approach further with a different researcher and participant

would allow us to identify how well this approach generalizes, and determine the extent of the generalizability of Marcella's communication strategies.

An ethnographically informed approach to the evaluation of the *File Facility* would help identify how useful and usable the design is to other people with aphasia in their daily lives. As Muller et al. have pointed out, adequate methodologies do not exist within HCI to evaluate applications not designed for productivity and efficiency [60]. Developing an ethnographically informed methodology to evaluate applications designed to support communication for people with aphasia would not only be beneficial to the field of assistive technology, but to HCI as a whole.

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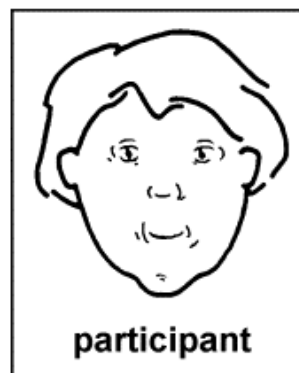
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## Appendix A

# Consent Forms for People with Aphasia

Participants were asked to sign a consent form prior to participating in the evaluative study. The following pages show the aphasia-friendly consent forms used for this study.

# INFORMED CONSENT For **RESEARCH**



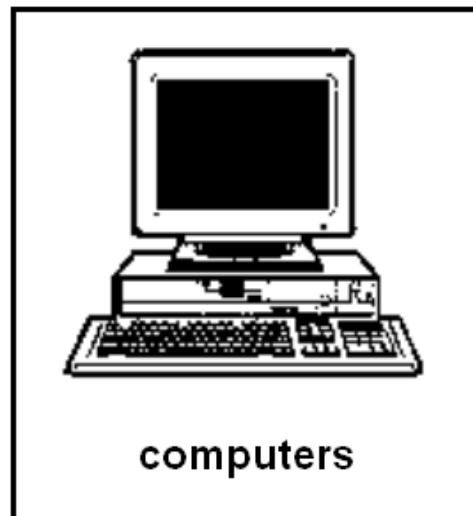
**Participant:** \_\_\_\_\_

**Investigators:** Peter Graf, Ph.D. (604-822-6635)  
Joanna McGrenere, Ph.D. (604-827-5201)  
Barbara Purves, M.Sc. (604-822-2288)

**Project Title:** Designing Technology for People with  
Aphasia

Adapted from Kagan, A. Winckel, J. & Shumway, E. Pictographic  
Communication Resources. Aphasia Centre – North York, 1996.

## Computer Technology



Designing computer technology for people with aphasia.

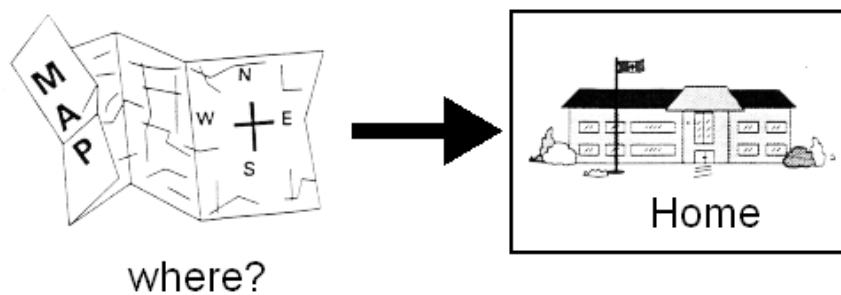
We want to know if you can use it.

Can you use it? ☐ YES  ☐ NO 

## How often?

1 Session

## Where?



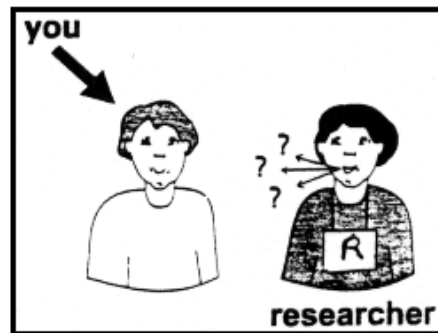
## When?





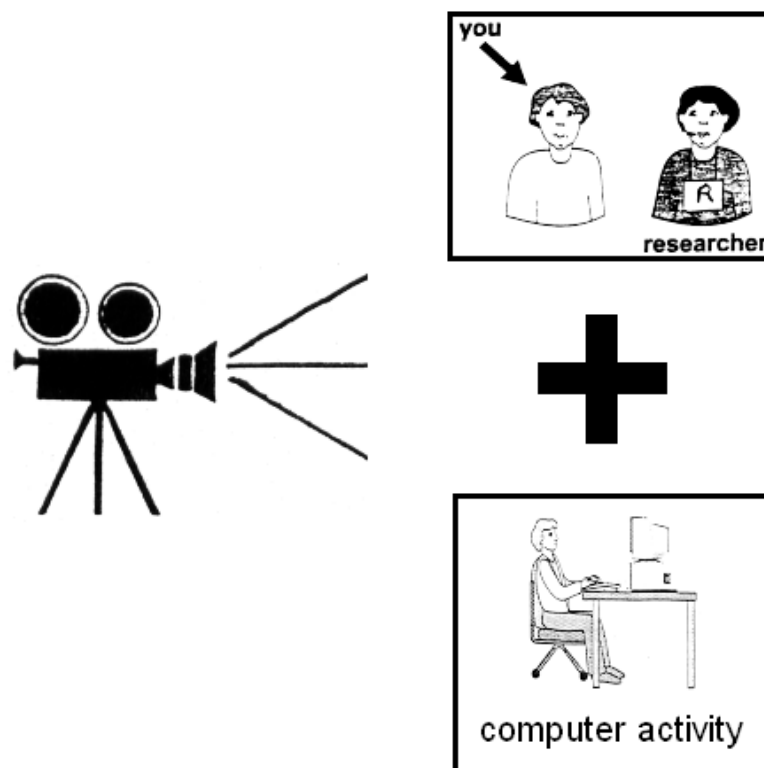
What  can you expect?

Meeting with a  
researcher  
= 1.5 hour

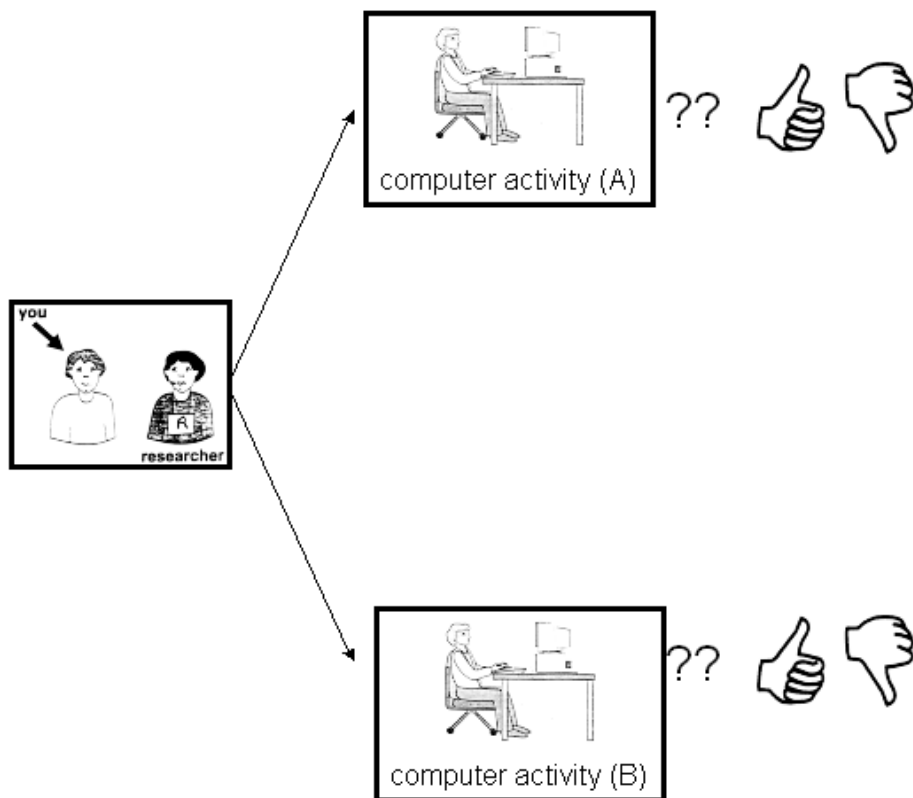


The researcher  
will show you  
some computer  
activities.

We will make a **videotape**.



You and the researcher will find out which computer activity is best for you.



## Potential Risks:



There is **NO** danger in participating in this study



no danger

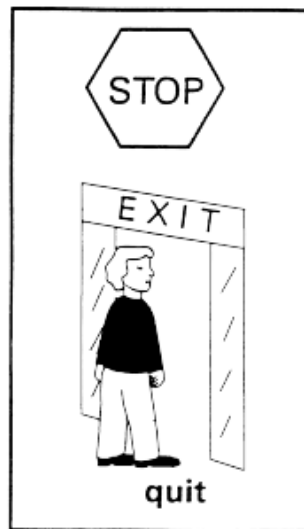


Everything is **confidential**



Will this **harm** you? **NO**

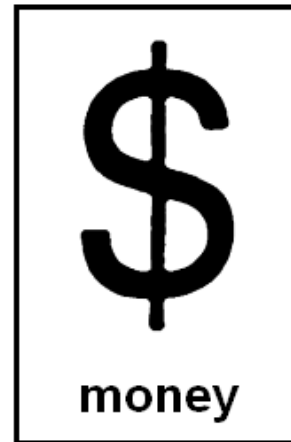
## Right to Withdraw



- ✓ You **can stop** at any time
- ✓ It is **your choice**
- ✓ It is **ok** to quit

## Thank you

We will pay you  
\$10 as a thank  
you.



? ? ?  
**? QUESTIONS ?**  
? ? ?

You can call the researchers to ask questions.



Barbara Purves, M.Sc., S-LP(C)

604-822-2288

Rhian Davies

604-812-4231

Shirley Gaw

609-812-4231

Joanna McGrenere, Ph.D.

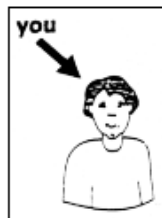
604-827-5201

## Concerns



**not** satisfied

If you have concerns about your treatment or rights, you can call the UBC Office of Research Services.



**Research Subject Information Line: 604-822-8598**



## Project Title: Cognitive Demands of an Assistive Communication Device

### Project Consent:

YES



The information on the previous 11 pages has been **explained** to me.

I **agree** to participate in this research project.



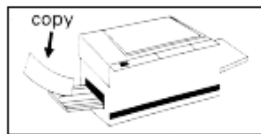
YES



NO



I have been given a **copy** of this form.



YES



NO



Signature of Participant

Date

Signature of Witness

Date

## Appendix B

# Consent Forms for People without Aphasia

Participants were asked to sign a consent form prior to participating in the evaluative study. The following pages show the standard consent forms used for this study.



## THE UNIVERSITY OF BRITISH COLUMBIA

Department of Computer Science  
2366 Main Mall  
Vancouver, B.C., V6T 1Z4

April 14, 2004

### **Consent Form (videotaping included)**

#### **Cognitive Demands of a Assistive Communication Device**

#### **Principal Investigators**

Peter Graf, Ph.D. (604-822-6635)  
Joanna McGrenere, Ph.D. (604-827-5201)  
Barbara Purves, M.Sc. (604-822-2288)

#### **Student Investigators**

Rhian Davies	604-812-4231
Shirley Gaw	609-812-4231

#### **Project Purpose and Procedures**

This project is designed to investigate how people interact with certain types of interactive technology on handheld devices. Interactive technology includes applications that run on handheld technology, such as the datebook on the Pocket PC.

The purpose of this project is to gather information that can help improve the design of interactive technology. You will be asked to use one or more forms of interactive technology to perform a number of tasks. We will observe you performing those tasks and analyze how the technology is used. We will ask to interview you to find out your impressions of the technology. You will be asked to participate in 1 session, each lasting no more than 1 ½ hours. The session will also be videotaped. Videotapes will be used for analysis and may also be used for research presentations in the Department of Computer Science at the University of British Columbia and Princeton University.

This project will be used by the student investigators to form the basis of their thesis research.

#### **Confidentiality**

The identities of all people who participate will remain anonymous and will be kept confidential. The one exception is that excerpts from the videotape may be presented as described above, and your identity may be revealed through those video excerpts. Identifiable data and videotapes will be stored securely in a locked metal filing cabinet or in a password protected computer account. All data from individual participants will be coded so that their anonymity will be protected in any reports, research papers, thesis documents, and presentations that result from this work.

**Remuneration/Compensation**

We are very grateful for your participation. However, you will not receive compensation of any kind for participating in this project.

**Contact Information About the Project**

If you have any questions or require further information about the project you may contact Joanna McGrenere, Assistant Professor, Department of Computer Science, University of British Columbia (604) 827-5201.

**Contact for information about the rights of research subjects**

If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598.

**Consent**

We intend for your participation in this project to be pleasant and stress-free. Your participation is entirely voluntary and you may refuse to participate or withdraw from the study at any time.

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature indicates that you consent to participate in this project. You do not waive any legal rights by signing this consent form.

I, \_\_\_\_\_, agree to participate in the project as outlined above. My participation in this project is voluntary and I understand that I may withdraw at any time.

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Student Investigator's Signature

\_\_\_\_\_  
Date

## Appendix C

# Task Instructions for Demonstration Walk-Through

During the evaluative study participants completed trials of various file management tasks. The following pages show the task instructions used during the demonstration walk-throughs prior to the trials. Each page was cut in half horizontally, so that the word *DEMO* appeared to the left of each page. The pages were then collated and stapled together to form a booklet. Note that the *Memory* tasks do not have a demonstration, as these trials were not preceded by a demonstration walk-through.

DEMO



DEMO

**Delete**



↳ **Past**

↳ **gas**

↳ **shield**

DEMO



DEMO

**Find**

**piano** FOLDER

**Where:** ↳ **Future**  
↳ **piano**

DEMO DEMO

**Create** **pick** FOLDER

**Where:** ↪ **Future**

**Create** **book** FOLDER

**Where:** ↪ **Future**



DEMO DEMO

**Find** **piano** FOLDER

**Where:** ↳ **Future**  
↳ **piano**

**Copy file**

DEMO DEMO

**Copy**



**From:** ↳ **Future**  
↳ **music**  
↳ **lions**

**To:** ↳ **Past**  
↳ **disc**



DEMO DEMO

**Copy** **grain** FOLDER

**From:** ↳ **Stories**  
↳ **grain**

**To:** ↳ **Future**

**Finding**

DEMO DEMO

**Find** **sugar** FOLDER

**Where:** ↳ **Other**  
↳ **sugar**

**Find** **sugar** FOLDER

**Where:** ↳ **Other**  
↳ **sugar**

DEMO DEMO

**Memory**

**Creating a File**

DEMO

**Create**

file

**Where:** ↳ **Stories**  
↳ **bench**

## Appendix D

### Task Instructions: Set One

During the evaluative study participants completed trials of various file management tasks. The following pages show the task instructions, set one, used during the sessions. Each page was cut in half horizontally. The pages were then collated and stapled together to form a booklet. For each of the tasks, there are two trial instructions, with the exception of the memory tasks, which only have one trial instruction for each memory task. Trial instructions for conceptually linked tasks are repeated as a set, with the first trial of all linked tasks preceding the second trial of all tasks in the set.

**Delete file**

**Delete**

**shirley** file



↳ **Lists**

↳ **flag**

↳ **shirley**



**Delete**      **box** file

↳ **Future**  
↳ **lamp**  
↳ **box**

**Creating & Finding**

**Find**

**baby** FOLDER

**Where:** ↳ **Past**  
↳ **baby**

**Create**

**bc** FOLDER

**Where:** ↳ **Past**

**Create**

**cow** FOLDER

**Where:** ↳ **Past**

**Find**

**baby** FOLDER

**Where:** ↳ **Past**  
↳ **baby**

**Find**

**box** FOLDER

**Where:** ↳ **Stories**  
↳ **box**

**Create**

**tv** FOLDER

**Where:** ↳ **Stories**

**Create**      **cup** FOLDER

**Where:** ↳ **Stories**

**Find**      **box** FOLDER

**Where:** ↳ **Stories**  
↳ **box**

**Copy file**

**rhian** file

**Copy**



**From:** ↳ **Stories**  
↳ **rock**  
↳ **rhian**

**To:** ↳ **Future**  
↳ **milk**

**Copy**                      **flag** file

**From:** ↳ **Past**  
          ↳ **fish**  
          ↳ **flag**

**To:**    ↳ **Lists**  
          ↳ **dog**

**Copy folder**

**Copy**

**ball** FOLDER

**From:** ↳ **Future**  
↳ **ball**

**To:** ↳ **Past**

**Copy**

**box** FOLDER

**From:** ↳ **Stories**  
↳ **box**

**To:** ↳ **Future**





**Finding**

**Find**

**pill** FOLDER

**Where:** ↳ **Other**  
↳ **pill**

**Find**

**pill** FOLDER

**Where:** ↳ **Other**  
↳ **pill**

**Find**

**pen** FOLDER

**Where:** ↳ **Other**  
↳ **pen**

**Find**

**pen** FOLDER

**Where:** ↳ **Other**  
↳ **pen**

**Memory**

**Copy**

**baby** FOLDER

**From:** ↳ **Past**  
↳ **baby**

**To:** ↳ **Lists**

**Create**

**key** FOLDER

**Where:** ↳ **Stories**

**Delete**      **road** file

↳ **Future**  
↳ **hill**  
↳ **road**

**Creating a File**

**Create**

file

**Where:** ↳ **Lists**  
↳ **tea**

**Create**

file

**Where:** ↳ **Past**  
↳ **cup**

## Appendix E

### Task Instructions: Set Two

During the evaluative study participants completed trials of various file management tasks. The following pages show the task instructions, set two, used during the sessions. Each page was cut in half horizontally. The pages were then collated and stapled together to form a booklet. For each of the tasks, there are two trial instructions, with the exception of the memory tasks, which only have one trial instruction. Trial instructions for conceptually linked tasks are repeated as a set, with the first trial of all linked tasks preceding the second trial of all tasks in the set.

**Delete file**

**Delete**

**shirley** file



↳ **Past**

↳ **key**

↳ **shirley**



**Delete**      **cow** file

↳ **Lists**  
↳ **hill**  
↳ **cow**

**Creating & Finding**

**Find**

**tea** FOLDER

**Where:** ↪ **Future**  
↪ **tea**

**Create**

**tv** FOLDER

**Where:** ↪ **Future**

**Create**      **pill** FOLDER

**Where:** ↪ **Future**

**Find**      **tea** FOLDER

**Where:** ↪ **Future**  
          ↪ **tea**

**Find**

**rock** FOLDER

**Where:** ↳ **Lists**  
↳ **rock**

**Create**

**dog** FOLDER

**Where:** ↳ **Lists**

**Create**

**bc** FOLDER

**Where:** ↳ **Lists**

**Find**

**rock** FOLDER

**Where:** ↳ **Lists**  
↳ **rock**

**Copy file**

**rhian** file

**Copy**



**From:** ↳ **Stories**  
↳ **lamp**  
↳ **rhian**

**To:** ↳ **Future**  
↳ **baby**

**Copy**

**flag** file

**From:** ↳ **Past**  
↳ **box**  
↳ **flag**

**To:** ↳ **Stories**  
↳ **road**

**Copy folder**

**Copy**

**milk** FOLDER

**From:** ↳ **Future**  
↳ **milk**

**To:** ↳ **Stories**

**Copy**

**key** FOLDER

**From:** ↳ **Past**  
↳ **key**

**To:** ↳ **Future**



**Finding**

**Find**

**pen** FOLDER

**Where:** ↳ **Other**  
↳ **pen**

**Find**

**pen** FOLDER

**Where:** ↳ **Other**  
↳ **pen**

**Find**

**pill** FOLDER

**Where:** ↳ **Other**  
↳ **pill**

**Find**

**pill** FOLDER

**Where:** ↳ **Other**  
↳ **pill**

**Memory**

**Copy**

**fish** FOLDER

**From:** ↳ **Future**  
↳ **fish**

**To:** ↳ **Past**

**Create**

**cup** FOLDER

**Where:** ↳ **Past**

**Delete**

**flag** file

↳ **Stories**

↳ **ball**

↳ **flag**

**Creating a File**

**Create**

file

**Where:** ↳ **Lists**

**Create**

file

**Where:** ↳ **Stories**