

Task Support for People with Cognitive Impairments and Their Caregivers

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Introduction

In the U.S, there are approximately 20 million persons with cognitive impairments, or 7% of the U.S. general population (The American Association on Mental Retardation 1992). Individuals with cognitive disabilities are often unable to live independently due to their inability to performing daily tasks. These deficits can lead to failure in consistently performing normal activities of daily living such as cooking, shopping for groceries, and taking public transportation. By providing socio-technical tools to extend their independence, persons with cognitive disabilities can have richer, fuller lives.

Researchers at the University of Colorado, from the disciplines of computer Science and Cognitive science formed a group to develop socio-technical environments for people with disabilities and their support communities, called the Clever project. A socio-technical environment is composed of technical and social subsystems. An example for this is a hospital where people are organized, e.g. in social systems like teams or departments, to do work for which they use technical systems like computers or x-rays. One part of the project, MAPS (Memory Aiding Prompting System) (Carmien 2003), is produced as a research platform to provide a simple effective prompting system with an interface for caregivers and is designed to affect high rates of integration into daily life.

Scope and Definition of Cognitive Disabilities

The target populations for MAPS are cognitively disabled individuals (The American Association on Mental Retardation 1992) in the ‘trainable Mentally Handicapped’ (IQ 55-72) range and in the upper range of ‘Severely Mentally Handicapped’ (IQ >55); as well as the caregivers who would compose MAPS scripts. We are at a happy juncture in history, one that is particularly supportive for the introduction of this technology; the current population of young adults with cognitive disabilities has been raised with a plethora of electronic devices – cell phones, MP3 players and computers. These devices are seen as just another utility, like hot water taps or the telephone. Having personal devices of this kind demonstrates their ability of constantly correctly use and safely carry a PDA (Personal Digital Assistant, e.g. Palm devices and handheld computers like IPAQ).

Caregivers

In studying this population, it became obvious very soon that the role of caregivers in day-to-day life is key to a successful and satisfying life for persons with cognitive disabilities. In this context, caregiver refers to both the immediate family member that helps the person with cognitive disabilities on a day-to-day basis as well as occupational therapy (OT) practitioners and assistive technologists who provide intervention to initially assist in the setup and use of cognitive orthotics. An orthotic device or orthosis is defined here as a device that is applied externally to the limb or body. The purpose can be to provide support or extension of a function. In this case a cognitive orthotic supplements (not replaces) cognitive function.

Besides social support, caregivers are key to successful adoption of support devices in that they carry the burden of adapting them to the changing abilities and needs of the user with cognitive disabilities. Successful design of the configuration and modification aspects of

computationally based independence augmentation devices requires that they be very easy to use. Our goal is to approximate ATM ease-of-use.

OT practitioners often work with persons post head injury and with developmental disabilities in the community or with people transitioning from rehabilitation to community living. The concerns of these practitioners are to help persons with disabilities to be as independent as possible in completing activities of daily living such as shopping, preparing meals, and working at a job. The MAPS/LifeLine system is designed to make configuration and adaptation of this device easy enough to pass on this skill to the family caregiver, to allow the OT practitioners to focus on his or her expertise, and to remove the need for being a PC 'expert', that many of the existing systems force on the occupational therapists and caregivers. In our design, process caregivers were assumed to have computer skills on the level of being able to compose a letter on a word processor.

Assistive Technology Device Abandonment

Device rejection is the fate of a large percentage of purchased Assistive technology (King 1999). Caregivers report difficulties in configuring and modifying configurations in assistive technology which often lead to abandonment (Kintsch and dePaula 2002). Some experts estimate that as much as 75% of all such devices and systems are purchased and not used over the long run (Reimer-Reiss 2000). By viewing the configuration and other caregiver tasks as a separate and equally important interface, this abandonment problem could be mitigated.

Prompting

Prompting by OT practitioners and independent living transition professionals, with and without picture cards or other materials, are an established technique used for both learning and performing a task by cognitively impaired adults and older children. Prompting has been

historically part of instructional technology: being prompted through tasks in a rehearsal mode, and then using the memorized instructions in daily life. The world of special education and rehabilitation services has focused on studies comparing techniques and creating a principled understanding of prompting techniques with a perspective of maximizing internal recall and unaided performance of the steps to complete a task by persons with developmental disabilities (Aist 1973; Reed 1989). Tasks are typically in duration from a few minutes to several hours, and about a single topic. Appropriate tasks for prompting do not span the various items that might make up a larger more complex task (i.e. mopping this floor rather than the set of tasks that constitute a janitorial job description).

Key to the production of good task scripts is the appropriate segmentation of the chosen task into subtasks. (Snell 1987; Saskatchewan Learning - Special Education Unit 2003). A common method to do this is activity analysis where each step of an activity is broken down and defined. The client's performance in the activity on each step is observed, and teaching techniques and cues are determined and implemented, often using various chaining strategies. The sequence is taught by prompting the client using physical, verbal and gestural cues. The user must be able to hold that whole subtask (step) in his or her mind and accomplish it in one single act. For some users that may be as complex as 'go to the post office and get stamps' where for others 'get out two slices from the open bag of bread' may be an optimal segment size.

Prior to the possibility of providing support of task performance via handheld computationally enhanced prompters, prompting was used as a tool to aid the cognitively disabled user memorize sequences of behavior that constituted a complete task. With the arrival of the aforementioned tools, the memorization and decision making elements of the task could be offloaded to the device and the system that supports it. Using these tools, it is possible to create

scripts that are composed of a series of visual and verbal prompts, sequentially displayed on a handheld computer. By seeing and hearing the instruction for each step (or prompt) the cognitively disabled person can perform the task without relying on her own memory and executive function (i.e. the ability to manage organization, priority setting, time management, and decision-making.) The hand held device now transforms the skills needed for task accomplishment from memory and executive functionality to those involved with using the prompter and following its instructions

The MAPS System

MAPS consists of two components: the handheld prompter (figure 1 – right) for the persons with cognitive disabilities, and the script editor (figure 1 – left) that enables the caregiver to create, store, and share these scripts. A script is composed of a series of visual and verbal prompts that guide the user through the performance of a task. Providing the active distributed support for the MAPS system is the LifeLine system (Gorman 2003). LifeLine monitors the use of the prompter and provides safety net functionality for the user by providing corrective instructions to the handheld user if needed. Lifeline is a web-based application that runs on a server that is connected wirelessly with the MAPS handheld prompter. Using LifeLine, the caregiver can monitor the script as well as be actively called into help (via cell phone text messaging) if needed.

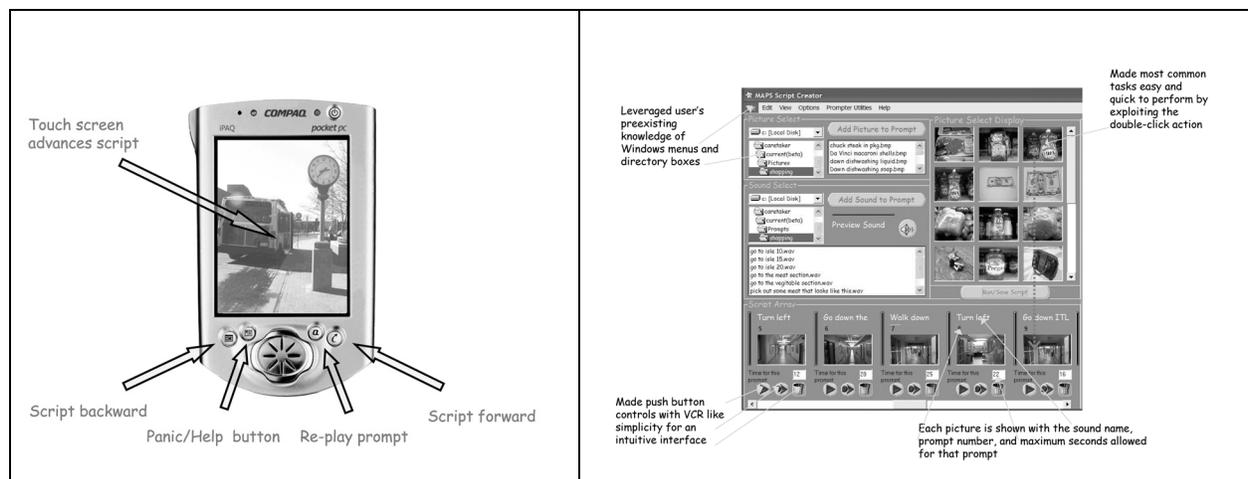


Figure 1 - MAPS prompter and MAPS script editor

During our interviews with caregivers in group-homes, concern for safety, and accountability were among the most common issues that were raised. In considering these issues as well as the analyses of potential situations they might encounter, we identified the following vulnerabilities associated with the physical separateness created by a client's increased mobility. There was a concern with script errors, due to either user actions or changing environmental conditions. If the system allowed the person with cognitive disabilities to attempt tasks that were previously too difficult for them, what would happen when they became confused, or the device broke-down (an event anyone who has used personal computers is uncomfortably familiar with)?

LifeLine, a project of another group within our research group, attempts to answer these concerns of the caregivers. The LifeLine server communicates with the MAPS handheld prompter via a built-in cellular phone and monitors the progress of the script that is being displayed on the prompter. LifeLine is told the script that is running and its expected behavior by the handheld. Embedded in the database on the handheld that contains the images and sound files for the current script are instructions for determining if the script is running correctly (i.e. this step should take about 70 seconds to do; when the script has gotten to this step the GPS coordinates should be XXX). The LifeLine server also knows how to solve simple problems (i.e.

it instructs the MAPS handheld prompter to tell the user to repeat a step), and when to pass on requests for assistance (i.e. the user has missed her bus stop and it's 2 AM, so the caregiver/911 should be called). The MAPS handheld prompter has, besides a mini-computer, speaker and touch-screen, a cell phone and GPS location sensor (all available off-the-shelf)

MAPS – Design Rationale

I will describe some of the underlying principles behind the design of the MAPS and LifeLine systems. The first and biggest challenge is to surmount, by design, the earlier mentioned abandonment problem. As a result we view this system as having two user interfaces, one (more obvious one) for the user with cognitive disabilities, the other, and equally important, for the caregiver who would be creating and modifying the scripts of prompts that would be 'played' on the handheld device. The two interface approach, will, we believe provide a solution to many of the abandonment causes in AT design of these kind of devices. The second, more difficult, challenge is to properly respond to the caregivers, OT practitioners , and assistive technologist concerns about two things: one, the reliability of the handheld computer system and it's support understructure, and two, the reality that plans rarely are exactly fitting the behavior path of successful task completion. It is this need to modify the presented scripts in response to a changing environment that the LifeLine application is designed to support. To provide this support we incorporate into the database that holds the script elements on the handheld (which is created and modified by the caregivers script editor) groups of tests that the LifeLine system will use to determine that the script is on or off track, as well as the appropriate corrective action for this problem. What is needed is a way to insert these questions for the LifeLine server to evaluate as the prompted task is displayed, in an automatic way for this person performing this task.

During the initial setup of the script editor information about the person with cognitive disabilities that will use the scripts that are being created is collected and afterwards inserted into every script created for this person the appropriate tests and corrections for errors. The specific concerns for error trapping/ correction differ from task to task; our solution is to consider that, for this population, there are few types of tasks appropriate (travel, recreation, shopping, and employment) and these types of typical tasks can be further broken down into segments. For instance a bus trip consists of preparation, travel to the bus stop, travel on the bus (with possible transfer), and travel from the far bus stop to the goal. By capturing the appropriate error tests and corrections for each task/segment/user combination at the initial configuration, the caregiver can focus on creating the script and allow the computational understructure to automatically take care of inserting tests, running tests and serving up corrective actions.

MAPS Design

We have created a prototype system to demonstrate and test our design and hypothesize. The caregivers' script editor (figure reference) uses a PC platform and stores the scripts on either a database running on the local PC or may draw on a repository of scripts and templates for scripts that reside on an internet database server. The hand held prompter runs on any device that is able of running the Microsoft windowsCE The LifeLine server runs on a PC located anywhere on the internet.

In implementing the caregivers script editor we were careful to frame all the systems functionality in graphic terms as similar to the Microsoft family of application and operating systems to leverage existing computer literacy skills of caregivers. We went through several iterations of design guided by input and experiences with actual users.

Assessment and Status of Project

This is a research platform and is not ready for commercial release. However, it shows promise of being a useful tool that can be easily produced. We have done some preliminary testing of the elements of the system and will soon move to a complete system evaluation phase.

Our initial test was to determine that this population would be able to successfully use a handheld prompter to complete a simple task. This study included six high-school students with moderate cognitive disabilities. Several of the students had communication disabilities and several students had slight physical disabilities, on the order of poor coordination and a slight visual acuity problem. The participants were chosen with the assistance of the teacher, on the basis of having cognitive impairments (DSM-IV classified as 40-80 IQ), and being between the ages of 16 and 22, when life skills and independence goals become an important educational focus. The participants were given the task of assembling a plastic glider model. Each student was given a MAPS device that was loaded with an eight-step script of images and voice prompts for assembling the glider.

We demonstrated the basic interface of the MAPS handheld prompter to the students, taught them which buttons to use to advance and rewind the script, and how to use the panic button. We instructed the students to press the panic button whenever they had a question, the panic button elicited help from one of the experimenters, they responded as if she were the computer. Our focus for this study was to validate that the basic input and output devices of the interface (touch screen, display, four small buttons near the bottom of the device) could be learned and used with proficiency.

Each student successfully completed the assembly task in a single trial. Each student used the buttons in addition to the touchscreen. Students used the panic button about 50% of the time

that they had a question. This gave us confidence that these users were able to learn and use the basic functionality of the handheld interface.

Next, we studied the caregivers' script editor in a real use environment. Three special education teachers participated in this study. We especially were interested in teachers that were not 'early adopters' and who have minimal computer skills, so as to replicate the barriers that contributed to AT adoption failure. The teachers were asked to write a script using the MAPS script creator. For this task we choose a complex set of instructions to make Chinese noodle cookies that would be representative of the outside bound of the domain of representative tasks. The number of steps (42) and the large number of images and prompts comprising the steps were a good approximation of typical use of the scripiter. The teachers selected from pictures and audio prompts that were already loaded into the system.

All subjects were successful in completing the task in a single trial, although they needed some help along the way. The task took approximately one hour to complete. We used the feedback from this set of trials to add needed support and functionality to the caregivers' editor.

Assessment Approach and Opportunities

Our assessment approach will continue to be a series of design interventions and controlled studies. We will carry out a series of experimental studies to evaluate the interfaces and eventually to move to real-world settings to evaluate the effectiveness of the design approaches. Equipped with the basic understandings we will gain from these studies, we intend to carry out a series of comparative studies in real-world settings with real users doing real activities to evaluate the effectiveness of the proposed socio-technical environment.

Conclusion

The MAPS and LifeLine system are a research platform for learning about how to successfully design socio-technical systems for those with cognitive disabilities and caregivers. The results so far have confirmed several of our hypotheses:

- The dual user interface approach is critical to high functionality AT device acceptance.
- The active distributed support framework (Carmien and Gorman 2003) is both possible in the current technical infrastructure, and holds tremendous promise to contribute to independent living for persons with cognitive impairments.

Acknowledgments

I thank my advisor Gerhard Fischer and the members of the CLever research project, at the University of Colorado, who have contributed to the ideas, conceptual frameworks, and systems described in this paper. The Coleman foundation provided financial support for this research.

For more information about this project, go to MAPS website at: <http://www.cs.colorado.edu/~l3d/clever/publications.html>.

References

Aist, E. H. (1973). The Effect if Two Patterns of Visual Prompting on Learner Achievement in Industrial Arts, Arizona State University.

Carmien, S., MAPS Website,2003, www.cs.colorado.edu/~l3d/clever/projects/maps.html

Carmien, S. and A. Gorman (2003). Creating Distributed Support Systems to Enhance the Quality of Life for People with Cognitive Disabilities. 2nd International Workshop on Ubiquitous Computing for Pervasive Healthcare Applications (UbiHealth 2003), Seattle, WA, USA.

Gorman, A.,LifeLine Project,2003, <http://www.cs.colorado.edu/~l3d/clever/projects/lifeline.html>

King, T. (1999). *Assistive Technology – Essential Human Factors*. Boston, Allyn & Bacon.

Kintsch, A. and R. dePaula (2002). *A Framework for the Adoption of Assistive Technology*.
SWAAAC 2002: Supporting Learning Through Assistive Technology, Winter Park, CO,
Assistive Technology Partners.

Reed, R. W. (1989). *An Investigation of Two Prompting/Fading Procedures to Teach
Independent Direct Evacuation Behaviors to Individuals with Severe/Profound Mental
Retardation*, University of New Orleans.

Reimer-Reiss, M. (2000). *Assistive Technology Discontinuance*. Technology and Persons with
Disabilities Conference.

Saskatchewan Learning - Special Education Unit, Task Analysis, 2003, <http://www.sasked.gov.sk.ca/k/pecs/se/docs/meeting/s6analysis.html>

Snell, M. E. (1987). *Systematic Instruction of Persons with Severe Handicaps*. Columbus, Ohio,
Merrill Publishing Company.

The American Association on Mental Retardation, AAMR definition of Mental Retardation, 1992,

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