

Design, Adoption, and Assessment of a Socio-Technical Environment Supporting Independence for Persons with Cognitive Disabilities

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ABSTRACT

A significant fraction of persons with cognitive disabilities are potentially able to live more independently with the use of powerful tools embedded in their social environment. The Memory Aiding Prompting System (MAPS) provides an environment in which caregivers can create scripts that can be used by people with cognitive disabilities (“clients”) to support them in carrying out tasks that they would not be able to achieve by themselves. To account for the great diversity among clients, MAPS was developed as a meta-design environment, empowering the caregivers to develop personalized prompting systems for the specific needs of individual clients.

This paper is focused on the lessons learned addressing adoption, learning, use, and abandonment of socio-technical environments fitting the unique needs of people with cognitive disabilities.

Author Keywords

Cognitive disabilities, independence, socio-technical environments, meta-design, end-user development, distributed intelligence, assistive technology, ethnographic methods

ACM Classification Keywords

H.5.2 [Information Interfaces and Presentation]: User Interfaces – User-centered design; K.4.2 [Computers and Society]: Social Issues – Assistive technologies for persons with disabilities.

INTRODUCTION

Individuals with cognitive disabilities are often unable to live independently due to their inability to perform

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activities of daily living, such as cooking, housework, or shopping. By being provided with *socio-technical environments* [23] to extend their abilities and thereby their independence, these individuals can lead lives less dependent on others. Traditionally, training has provided support for activities of daily living by utilizing prompting and task segmentation techniques. Clients were prompted through specific steps in their tasks in a rehearsal mode and were expected to use the memorized instructions later on in their daily lives.

Our research was driven by three related topics of interest:

- To gain a fundamental understanding of how people with moderate to severe cognitive disabilities perceive and use information in prompting systems for tasks on mobile handheld devices;
- To engage in a theoretically grounded development process of socio-technical environments supporting mobile device customization, personalization, configuration by caregivers (meta-design) and effective use by clients (distributed intelligence); and
- To analyze and assess the process of adoption of MAPS by dyads of clients and caregivers.

MAPS is one of a number of applications and frameworks developed by the Cognitive Lever (CLever) project [7], a research group within the Center for LifeLong Learning and Design (L3D) at the University of Colorado, Boulder.

PROBLEMS AND CHALLENGES ADDRESSED

“A nation’s greatness is measured by how it treats its weakest members.” — Gandhi

A Large Societal Need. There are 4.64 million persons with significant cognitive disabilities in the United States [4], many of whom might be able to live more independently with properly designed help. Without help, they are often unable to live on their own due to deficiencies in memory, attention, and executive functionalities, leading to an inability to consistently perform typical tasks of daily living. By providing socio-technical environments to extend their independence, these clients can lead richer lives.

Identifying the Client Community. An individual with cognitive disabilities is defined by the Diagnostic and Statistical Manual of Mental Disorders IV (DSM-IV) [2] as a person who is “*significantly limited in at least two of the following areas: self-care, communication, home living social/interpersonal skills, self-direction, use of community resources, functional academic skills, work, leisure, health and safety.*” Four different degrees of cognitive disability are defined: mild, moderate, severe, and profound. The target populations for MAPS are individuals with cognitive disability in the mild (IQ 50-55 to 70) and upper range of moderate (IQ 35 to 55) levels.

Independence. Independence emerged as one of the critical concepts in our research. Clients have the desire to live independently without the need for help and supervision by caregivers (similar to the desire expressed by elderly people [25]). This independence from human “coaches” is achieved with the availability of innovative tools supporting a *distributed intelligence* approach [10]: the clients’ limited internal scripts are complemented by powerful external scripts [9]. Our research has explored independence specifically in the following contexts: (1) to extend the ability to choose and do as many activities of daily living as possible; (2) to be employed, but without the constant or frequent support and supervision of a professional job coach; and (3) to prepare meals and to shop for weekly groceries. Independence is not at odds with socialization; it is the foundation of inclusion and engagement in society.

Abandonment Based on the “Universe of One”

People with cognitive disabilities represent a “*universe of one*” problem [14]: a solution for one person will rarely work for another. The “*universe of one*” conceptualization includes the empirical finding that (1) *unexpected islands of abilities* exist: clients can have unexpected skills and abilities that can be leveraged to ensure a better possibility of task accomplishment; and (2) *unexpected deficits of abilities* exist. Accessing and addressing these unexpected variations in skills and needs, particularly with respect to creating task support, requires an intimate knowledge of the client that *only caregivers* can provide [11]. Currently, a substantial portion of all assistive technology is abandoned after initial purchase and use—as high as 70 percent in some cases [28]—causing the consequence that the very population that could most benefit from technology is paying for expensive devices that end up in the back of closets after a short time.

Socio-Technical Environments

Our research addresses these problems with socio-technical environments [23]. These environments consist of more than the coincidental concurrence of people and technical components: they are designed to recognize the strong and co-evolutionary interactions between people and technology. They require a co-design of social and technical systems, and use models and concepts that focus not only on the artifact but exploit the social context in which the systems will be used.

Design Time versus Use Time

In all design processes, two basic stages can be differentiated: design time and use time. At design time, system developers (with different levels of user involvement), create environments and tools creating complete systems for a “world-as-imagined.” At use time, users use the system, but because their needs, objectives, and situational contexts could only be anticipated at design time, systems require modification to fit the real needs of users. To accommodate unexpected issues at use time, systems need to be underdesigned [5] by providing a context and a background against which situated cases can be interpreted thereby allowing the “owners of problems” to create the solutions themselves at use time.

Meta-Design

Meta-design, or “design for designers” [15], is grounded in the basic assumption that future uses and problems cannot be completely anticipated at design time, when a system is developed [29]. It is an emerging conceptual framework aimed at defining and creating social and technical infrastructures in which new forms of collaborative design can take place. Socio-technical environments have as a critical component meta-design because it provides the caregivers the design power to modify and evolve the technical systems according to the needs of individual clients. Meta-design extends the traditional notion of system design beyond the original development of a system to include co-adaptive processes in which the users become co-developers or co-designers.

Meta-design is a design method that deals with situatedness to fit new needs at use time, to account for changing tasks and to embed computer artefacts in daily life and practices. A unique challenge of meta-design in the domain of cognitive disabilities is that the clients themselves cannot act as designers, but the caregivers must accept this role (see Figure 1).

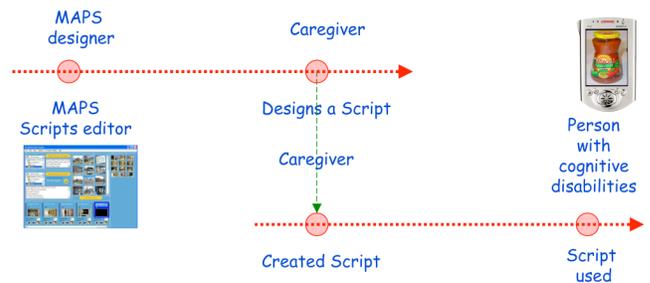


Figure 1 Meta-Design: Empowering Caregivers to Act as Designers

The lack of support for co-evolution causes much of the *abandonment* [28] of assistive technology tools. Caregivers, who have the most intimate knowledge of the client, need to become the “programmer/end-user developer” of the application for that person by creating the needed scripts.

RELATED WORK

Computationally enhanced prompting systems have been studied in academia [20] and have been developed in the commercial world [1]. ISAAC[18] was a Scandinavian research initiative in the early nineties that investigated various aspects of mobile computer-assisted task support; unfortunately, the state of the art was not able to support the development of robust prototypes.

VISIONS [3] is a system for supporting task completion by using a PC and touch screens located in the residence of a client. Our research was substantially influenced at an early stage by an evaluation of the VISIONS system, which identified two fundamental shortcomings in that system: (1) clients were left without support outside of their homes; and (2) no support was provided for caregivers to develop scripts. A significant cause for abandonment of the VISIONS system was the fact that meta-design was not supported; the caregiver had no control to personalize the environment.

THE MAPS ENVIRONMENT

MAPS [6] consists of two major subsystems that share the same fundamental structure but present different affordances for the two sets of users: (1) MAPS-DE, for caregivers, employs web-based script and template repositories that allow content to be created and shared by caregivers of different abilities and experiences; and (2) MAPS-PR, for clients, provides external scripts that reduce the cognitive demands for the clients by changing the task.

The MAPS-Design-Environment (MAPS-DE)

The scripts needed to effectively support users are specific for particular tasks, creating the requirement that the people who know about the clients and the tasks (i.e., the local caregivers rather than a technologist far removed from the action) must be able to develop scripts. Caregivers generally have no specific professional technology training nor are they interested in becoming computer programmers. This creates the need for design environments with extensive end-user support to allow caregivers to create, store, and share scripts [15]. Figure 2 shows MAPS-DE for creating complex multimodal prompting sequences. The prototype allows sound, pictures, and video to be assembled by using a film-strip-based scripting metaphor.

MAPS-DE supports a multi-script version that allows caregivers to present the looping and forking behavior that is critical for numerous task support situations. MAPS-DE (see Figure 2) is implemented on a Microsoft OS (Windows 2000 or XP) platform connecting to and supporting PDAs that run the WIN-Compact Edition (WIN-CE) operating system.

The MAPS-Prompter (MAPS-PR)

MAPS-PR presents to clients the multimedia scripts that support the task to be accomplished. Its function is to display the prompt and its accompanying verbal instruction. MAPS-PR has a few simple controls (see

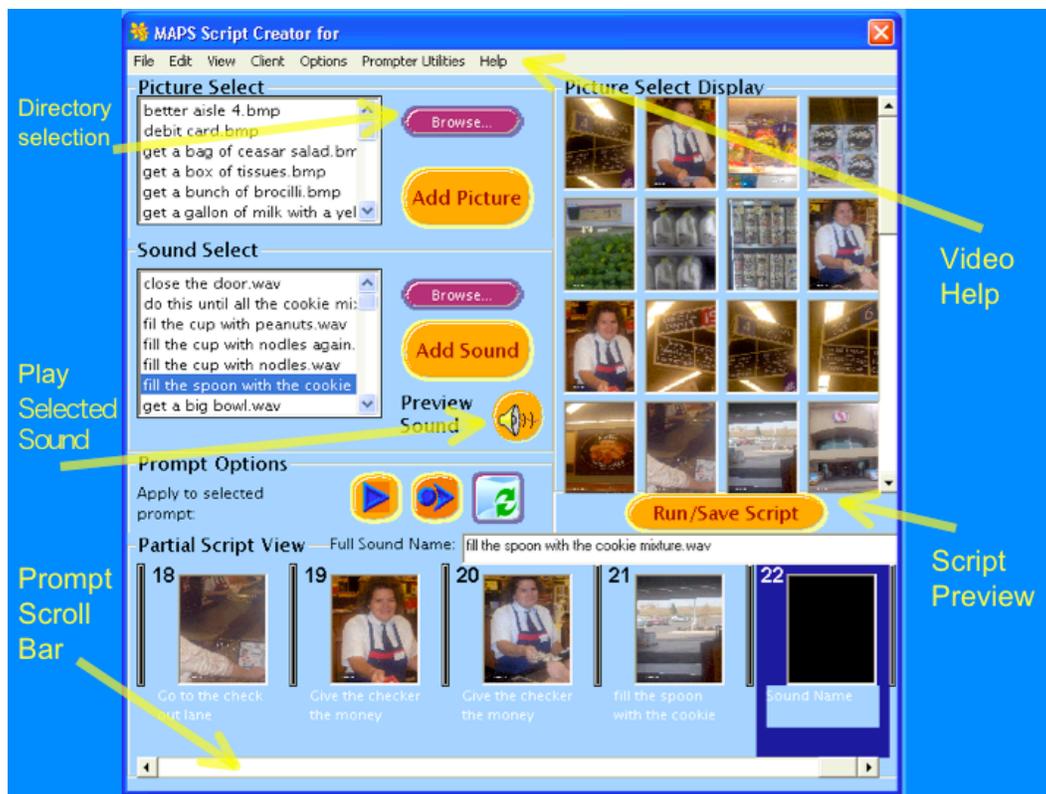


Figure 2 The MAPS-Design-Environment for Creating Scripts

Figure 3): (1) the touch screen advances the script forward one prompt; and (2) the four hardware buttons on the bottom, which are mapped to: (i) back up one prompt, (ii) replay the verbal prompt, (iii) advance one prompt, and (iv) activate panic/help status. The mapping of the buttons to functions is configurable to account for the needs of individual users and tasks.

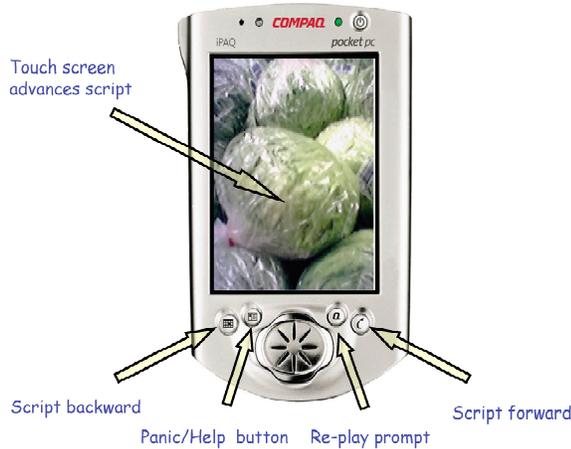


Figure 3 - The MAPS Prompter (MAPS-PR)

The current platform for the MAPS-PR is an IPAQ 3850. The system was implemented for any machine that runs the WIN-CE operating system. MAPS-PR has cell phone and GPRS functionality. The prompter software was originally written in embedded Visual Basic, and then ported to the faster and more flexible C# .net environment. The prompter software supports single-task or multi-task support.

ASSESSMENT

To assess the usability and usefulness of MAPS, we paid equal attention to the social environment and the

performance environment. There were two goals in doing this: (1) to understand the world of the client, and (2) to understand the process of adoption (or rejection) of the MAPS task support system (a similar approach was pursued by Dawe [13]). Understanding the process meant that the system had to be tested not in laboratories but with field trials in the real world [26] by closely observing the participants in action and applying *ethnographic participant observation* [24] as an analytical technique.

Table 1 provides a summary of the assessment phases in designing and evaluating MAPS. The initial PDA testing demonstrated the applicability of handheld multimedia prompting as task support for clients.

Participants were recruited with the aid of local experts such as the Boulder Valley School District (BVSD) special education staff, and Imagine!, an organization that runs group homes for 1600 persons with cognitive disabilities in Boulder County [16]. Parents, guardians, and the clients participated in deciding that this study was appropriate for them. Specific clients were identified and chosen as appropriate for specific areas of task accomplishment such as cooking, housework, shopping, and employment.

Usability Testing. The design of the MAPS-DE was based on “*task-oriented design*” [22]. The initial design was derived from scenarios of a caregiver creating and modifying a task-support script. Once the basic functionality was determined, users were asked to participate in formative assessment sessions to analyze interactions in order to improve the initial design. Three kinds of users were selected: (1) assistive technology professionals and special education teachers from the BVSD special educational team, (2) parents of clients, and (3) professional caregivers working for Imagine!. We particularly looked for realistic users with low PC competency.

| Trial | Participants | Method / Procedure | Data Analysis | Result | Interpretation of the Results |
|--|--|---|---|---|---|
| Initial PDA field trial | 8 BVSD Special Education students | Use of a prompter for simple task, semi-structured interview | Audio recording, script log, fieldnotes | Seven succeeded, one succeeded with help | Data led to the hypothesis that clients could successfully use MAPS-PR |
| Participatory design of MAPS-DE | 9 people, 3 iterations and review by assistive technology expert | Think-aloud protocols, semi-structured interviews, videotapes | Compiled list of bugs and interface difficulties | Three design iterations driven by usability issues | Design was simple enough to use with minimal (10-minute) introduction |
| Initial trial of MAPS-PR with complex script | 19-year-old female with cognitive disabilities | Create and install 42-step script on MAPS-PR; participant used script to bake | Field notes from observation, videotape, and script log | Successful accomplishment of real world task with MAPS-PR | Step skipping showed internal scripts that script designer had missed; log file indicated collapsibility |
| Realistic MAPS field trial | BVSD Families (2) Imagine! Group Homes (1) BVSD Transition Team (1) | Give dyads MAPS-DE and MAPS-PR; Observe process of use of system | Audio recordings, field notes, secondary artifacts | For all dyads the process of adoption of MAPS was documented and analyzed | Heuristics for script designing and use; effects of internal/external script inventories on task success identified |

Table 1 Summary of the Assessment of MAPS

The next step was the participative design process of creating and doing usability testing for MAPS-DE, with particular emphasis on the importance of successful initial script designing by relatively unskilled computer users. Tests were conducted with representative clients using a typical-sized script, and the complete MAPS system was evaluated with representative pairs of caregivers and clients.

Field Trials. MAPS was tested with representatives of three groups: (1) young adults living with their parents while still in school, (2) young adults enrolled in a transition program in their local school system (typically 18 or 19 years old), and (3) adults living in group homes with varying levels of caregiver support. The study used several *ethnographic methods*, particularly *participant observation* and *semi-structured interviewing* [21]. The goals of the participant observations were to:

- Discover and learn about the client’s and caregiver’s world and their interactions;
- Observe and analyze how tasks and learning of tasks were currently conducted;
- Understand and explicate the process of creating and updating scripts;
- Comprehend and analyze the process of using the scripts with a real task; and
- Gain an understanding of the role of meta-design in the dynamics of MAPS adoption and use.

Careful tagging of the fieldnotes and transcriptions of the audio recordings of the process revealed patterns enabling and authenticating generalized statements about the assistive technology adoption process in general, with specifics about the MAPS socio-technical environment.

The set of real tasks included: clients (1) doing laundry by themselves, (2) shopping solo, (3) folding clothing out of the dryer by themselves, and (4) training for employment without job coach support.

The initial visits with the client were both with and without the caregiver present, designed to gain insight into the general life of each participant and more specifically about the client’s world with respect to abilities, relationships, learning style, and employment.

BRIEF DESCRIPTION OF SPECIFIC ASSESSMENTS

For each dyad, the intent was to make and test an increasingly challenging set of scripts. The content and environment of the scripts was typically from simplest to most complex:

- Controlled environment (e.g., a housekeeping chore), in which neither the task nor the environment is dynamic and the environment is familiar;
- Less controlled script (e.g., cooking), in which the task doesn’t change and the environment is dynamic but familiar;

- Least controlled script (e.g., shopping), in which the task and the environment are unfamiliar and the environment changes

The names used in the descriptions of the three dyads discussed here have been changed to protect individual identity.

High school student and stay-at-home mom dyad (Dyad 1). The first dyad consisted of a 16-year-old and her mom. Marsha was in 10th grade in a local high school but not completely mainstreamed. She could read at a 3rd-grade level and played violin in a middle school orchestra. Her stay-at-home mom, Leslie, used her time at home to provide Marsha with additional tutoring and assistance.

The process of the caregiver learning about scripts and the MAPS system consisted of starting with a session about script building and task segmentation. This was aided by the use of a video that illustrated the skills needed to properly segment a task and translate it into a series of prompts for people with cognitive disabilities [30] and a checklist of topics to be covered. From the video and the checklist, the caregiver and the researcher brainstormed to create an idea for the first script and what the steps should be. That done, the study moved onto designing and assembling three scripts.

The first script chosen and designed by Leslie was a simple script to help Marsha properly sweep the kitchen floor. Leslie also added a section of prompts to the beginning of each of her task scripts that explained the use of the hand prompter controls. This “generic” sub-script of six steps was reused by two of the other dyads—an example of script reuse. Task segmentation added to this generic preface sub-script resulted in a 28-step script.

Leslie decomposed the task into steps, and then took pictures of each step and wrote a script for the verbal prompts. With the use of the sweeping script, the *first scripting heuristic* was discovered by observing results in its absence: “*always have someone other than the script author physically do the task with only the script in the actual task environment.*” In this case, the script at one step left the daughter holding the broom while being asked to pick up something else.

For the last script, Leslie decided that her daughter was capable of going shopping for groceries by herself, if supported by the script on the prompter. Leslie put together a shopping list of eight items, and walked through the local supermarket, taking the path that she wanted her daughter to take and taking pictures of way points (e.g., “Next go to aisle 12” combined with a picture of the aisle 12 sign); target items (e.g., “Get a box of tissues” combined with a picture of the tissues); and checkout procedure (e.g., “Give the checker the money” combined with a picture of a hand coming out to the checker they usually went to). The resultant script was 25 steps long.

On the afternoon of the test, Marsha was driven to the store, given the handheld prompter, \$60.00, and a customer

card for that store. Previous to our arrival, a colleague who was not familiar to Marsha was stationed in the store with a cart and a copy of the shopping list that was in the script. The researcher and the colleague kept in touch by cell phone. Marsha went into the store at 3:29 and came out at 3:45 (from the script log), with every item on the list, all correct except for getting whole milk instead of low-fat milk. Leslie said that Marsha would not have been able to do the same task with a paper shopping list without training and repetition. The colleague reported hearing the checker say to Marsha, “*Oh, you’re shopping by yourself now?*” with a delighted answer, “*Yes!*”

Group home resident and professional caregiver dyad (Dyad 2). Another group of young adults with cognitive disabilities that could benefit from the use of MAPS was living in group homes with professional caregivers. The Imagine! [17] organization provides, among other services for persons with cognitive disabilities, several group homes in the Boulder Valley. After interviews of several likely participants, a dyad of a professional caregiver (Carrie) and a 37-year-old man (Fred) was selected to participate in realistic field tests of MAPS. Fred had lived in the group home for 14 years. The group home had three apartments and a caregiver’s office. Each apartment was home to two persons with cognitive disabilities. The caregiver was on site in the morning and in the afternoon, helping the residents with scheduling, getting to appointments, taking medications, and participating in recreation activities.

Fred worked at a gymnasium five days a week. His job included caring for the men’s changing room and doing other janitorial tasks. He was able to take the bus to work by himself, yet he was consistently unable to do certain household tasks, such as folding and storing his clothes properly after doing the laundry. Each member of the group home cooked for the group as a whole every other week or so. To get acquainted with his world, the researcher spent several afternoons with Fred in his daily life, as had been done with the other field-trial participants. The setting was an exercise club where Fred was an authentic member of the workplace community, having worked there for many years and had many friends among both the staff and the members. Later that week, Fred was observed while cooking a meal for the other members of the group home.

Carrie had been turning simple recipes into scripts for Fred to follow for some time, so the introduction of MAPS and the need to properly segment tasks was an easy transition for her in that respect. She proposed that the first, easiest script would be to guide Fred through folding and putting away his laundry. The resultant 61-step script walked him through removing the laundry from the hamper to hanging his dress shirts on hangers. One problem that Carrie had with creating the script—and one that other caregivers also had—was confusion over how to start up the MAPS application and the locations of the directories for the recorded prompts and pictures. Eventually, shortcuts were created for these directories, and shortcut creation was

subsequently added to the installation script of the MAPS-DE. Carrie took the pictures, recorded the prompts, and created the script, relying on the video help to guide her through the difficult parts.

The 61-step script was downloaded to the handheld PDA, and Fred followed the script instructions in doing the task. In several instances he did not stop when the instructions for a given prompt were completed, so the next several times that the folding script was run (he did it once a week), Carrie sat with him and helped him focus on using the MAPS-PR during that part of the script. Each time the script was run, Fred improved his performance, so by the fourth week the clothes were being folded and stored in a way that was acceptable to the caregiver. The original vision of the clients’ initial use of the MAPS-PR was for them to be shown how to use the MAPS-PR, and perhaps guided through the first use of it with a script, but subsequent uses would be done solo. Carrie, however, had a different idea of use. She approached the task of learning the use of the handheld PDA *and* the script running on it as being scaffolded by her, as the caregiver. As a result, for the first three runs of the script, Carrie stayed in the room with Fred and intervened when she thought it was needed. By the fourth and subsequent runs, she left him in the room alone, and his performance continued to improve. This finding demonstrates *a use of the MAPS system as a training tool*, which was not expected at original design time.

After the first two runs of the folding script, Carrie decided that some of the sections of the script were too long and that several of the steps were not sufficiently illustrated to ensure success. Fortunately, in the initial design of the script she had made modifications easy by inserting “collapse points” so that the steps directly below each collapse point could be removed and the verbal and visual prompts of the collapse points would be a sufficient external script trigger for Fred to do that part of the whole task. IT is envisioned that in later context-aware versions of MAPS collapse points could dynamically expand or contract depending on the user being frustrated (expand for more support) or bored (collapse for less support) providing an interesting perspective on Csikszentmihaly’s ideas on *flow* [12]. Carrie removed these superfluous subscripts in the case where the instructions for folding T-shirts was repeated because Fred had learned the process to some degree. She also redid several of the steps for clarity and flow.

The new script had 51 steps (compared to the previous 61). Fred was pleased with the script and the MAPS-prompter. He said to the other staff members that he had “learned how to fold.” His success and the need it was built on are good examples of the “islands of deficits in seas of abilities” and “causes of unexpected activity failures” [11]. Before our assessment studies, we assumed that the client might not need task support for something as simple as folding his clothes, but this was a task that he had not accomplished in many years of trying.

Transition program dyad (Dyad 3). The third category of dyads that was a good candidate to benefit from using the MAPS system comprised young adults in the transition program of the local school system. The transition program was designed to build a bridge from the support of special education school systems to more independent adult living. Allyson, chosen as the young adult with cognitive disabilities in the dyad, was 19 years old. She was diagnosed as having multiple cognitive disabilities. As an illustration of the skill variability that many of the young adults with cognitive disabilities have, Allyson has an amazing, professional-quality singing voice. She worked in “supported employment” at a local used clothing store. Her job coach, June, typically would be standing next to or near her during her shifts.

The clothes in the store are segregated by gender and style. Within the type, the clothes are further sorted by size, and within each size sorted by color, or “colorized.” The colorization task is a multi-pass procedure: the first pass is to remove empty hangers; the next is to pull the clothes that are not of the same gender, type, and size as the section being colorized, and the final task is going through the homogeneous rack to reorder the items until they are in the correct color order. Allyson’s job was, at first, to colorize a rack of clothes.

The first set of scripts that June wrote was for the primary task of colorizing the racks, plus two supplementary tasks from which Allyson could choose at the end of colorizing: (1) removing empty hangers from other racks, or (2) cleaning up and organizing shelves. After Allyson used this script for a week, the management of the store offered her a position with pay. June agreed that Allyson was ready to leave supported employment.

June found this job offer to be unusual in that it came after a much shorter time than she thought it would have taken without MAPS-PR. Also, they offered Allyson more hours at the start. She was offered 25 hours per week employment, when typically “*our kids get offered 5 hours on their own or 20 hours subsidized with support.*” June felt the voice on the prompts would be sufficient support for Allyson so that she could rely on that rather than needing a job coach with her all the time. Allyson was excited as well as apprehensive to move into non-supported employment. On the last scheduled day of supported work, Allyson asked June many “what if” questions; the answers to many of these questions was “*listen to your prompter.*” Afterwards, June emphasized that she was comfortable with Allyson moving on because she would have June’s voice to comfort her and give her direction. From this observation emerged the notion that, for many clients, a prompt consisted of not two but three components: the image, the wording, and the voice of the prompter.

EXPERIENCES AND INSIGHT

Clients. Analysis of the fieldnotes and audio recordings of the MAPS-PR adoption exposed several motifs. These can

be seen from two perspectives: the client’s and the caregiver’s. In several instances, the client’s ability to perform the task with MAPS-PR support was extended to unsupported task completion, in some cases achieving the result while no longer performing the exact steps of the task’s script. Leslie’s comment about Marsha’s internalizing the floor-sweeping task is illustrative of this: “*She [Marsha] may not do it my way, but she does it.*”

Several instances of the client expressing feelings of further independence were observed: Marsha’s interaction with the checker (“*Oh, you’re shopping by yourself now?*”) and Fred, the resident of the group home (Dyad 2), saying several times to fellow residents and staff, “*I can fold my clothes now.*”

As the field trials proceeded, there were instances in which the system was not used as originally intended. In one case, MAPS was extended to fill the needs of a particular class of tasks. Fred required training to use the MAPS-PR and script together, being guided through the task several times by Carrie, rather than learning the use of the MAPS-PR first and then using it to play the script without further guidance. This could have only been discerned by a caregiver who had long experience working with him. This strategy worked well, as a later suit-folding script created by his parents (after the formal trials ended) demonstrated that he was able to use a new script without requiring help in using the MAPS-PR.

For Dyad 3, the use of MAPS in an employment training environment required MAPS to support the use (and training in) “soft skills.” Soft skills are the ability to properly interact with the job environment and other actors in the job environment; examples might be appropriate interactions with the job supervisor or filling the time in between assigned tasks with productive work (instead of just stopping and waiting for the supervisor to assign the next task). June, the caregiver in Dyad 3, related that this lack of social skills is a frequent cause of dismissal from employment. In order to support the presentation and guidance through alternative tasks on the MAPS-PR, the MAPS system was augmented with an ability to present a choice of three tasks at any one time. The complex details of the graphical user interface (GUI) presenting the choices and the specifics of programming the system by the caregiver in presenting these choices in a comprehensible manner is beyond the scope of this paper (for more details see Carmien [6]).

Caregivers. During the course of our assessment studies, caregivers made important contributions to the MAPS system. Leslie (Dyad 1) wisely asked for a neutral voice to record her verbal prompts, due to expectation of authority issues between her and her daughter, typical of most teenagers. Her experience with problems in the first script caused by not actually doing the task with her prompts before taking the pictures and recording the prompts for it, led to careful crafting of the shopping script and its successful use. June (Dyad 3) saw the potential of the MAPS system, in concert with Allyson and her

employment environment, to support soft skill performance and (possibly) learning, provided that MAPS could be extended to support multiple tasks in one script. To properly use the modified MAPS system, June had to become much more of an application programmer than the other caregivers. June was able to see and exploit the possibilities inherent in the task domain; this was possible because of her deep domain knowledge and (more important) knowledge of Allyson and her abilities and needs.

The interplay of caregiver, client, environment, and task as well as the perspective of the dyad as a persona with two “faces” is illustrated in the case of Dyad 2. In this case Carrie saw that the client would not be able to “get” MAPS immediately, without a properly contextualized example. She introduced both guided learning of the MAPS-PR and the notion of collapsing scripts to reflect Fred’s increasing gain of task skills.

Two script *failures* illustrate the critical role that caregivers have in MAPS; in particular, the need for the caregiver to have both (1) an intimate knowledge of the client’s abilities and needs, and (2) skill in constructing scripts (including both the choice and the segmentation of tasks). One failure type consisted of “*shooting too high*” by overestimating the client’s abilities. The other kind of failure was illustrated by the second script of Dyad 2. Carrie decided that, having success with clothes folding, the next step might be a script that took Fred from the home, by foot, to the local library, through the process of checking out DVDs, and walking back home. In this case, Fred used the MAPS-PR to start out on his errand, but proceeded through all the other steps of the task with no assistance from the script. This was a case of “*shooting too low*,” or underestimating the client’s skills.

Impact of MAPS. The central goal of MAPS is to support independence. We briefly provide here several accounts (derived from our field trials) that illustrate the impact of MAPS to help clients act more independently:

- The family dyad, Dyad 1, provided the most convincing example of supporting independence: Marsha’s use of MAPS-PR to successfully shop for family groceries was a proof by existence of how computationally supported prompting can provide a lever to extend the existing skills of a client.
- The group home dyad, Dyad 2, provided an example of MAPS being used by a client who was on the edge of “not needing to use MAPS for task support.” It also represented an example of the “*island of deficits in a sea of abilities*” principle. Although Fred did not need MAPS-PR to support a trip to the library, the large script for folding clothes was a big success, both for his self-esteem and for his day-to-day living skills.
- The transition team dyad, Dyad 3, used MAPS to support real employment being offered to the client in a much shorter time than her job coach expected. When Allyson expressed anxiety about being able to

successfully do her job without her job coach, June told her that she did not need her support, that “*all you need is either up here [gesturing to her head] or in here [gesturing to the MAPS-PR].*”

One of the biggest indications of the success of MAPS was that all four of the dyads requested to keep the system after the studies were completed.

CONTRIBUTIONS

The value of our research lies not solely in the existence of MAPS-PR and MAPS-DE, but in the principled study of its adoption and use in the field. The ethnographic approach contributed to the close attention paid to the process of initial use of MAPS, allowing us to identify breakdowns and articulate successful heuristics. Examples of this process include the folding script of Dyad 2 becoming difficult to use due to the difference between the partial learning of the tasks and the current granularity of the script, leading to the notion of *collapsible scripts*. *Script patterns* can become heuristics that can be propagated to situations involving other caregivers and clients.

The specific problems that had contributed to abandonment of the VISIONS system (being tethered to the stationary PC and the difficulty in script creation and modification) were successfully addressed by MAPS. In the absence of these issues, others emerged: the importance of estimating the client’s ability, the need for skills in task segmentation, and matching task and skills.

The design of MAPS was grounded in and extended the theoretical frameworks of distributed intelligence and meta-design. The theme of design over time was illustrated in both MAPS-DE with the addition of the multiscript modality and in MAPS-PR with the collapsing of groups of script steps and the reuse of script sequences. By designing the MAPS environment to enable script re-design and reuse, caregivers were able to precisely create a program for the user with cognitive disabilities. MAPS represents an important example for democratizing design by supporting meta-design, embedding new technologies into socio-technical environments, and helping people with cognitive disabilities and their caregivers have more interesting and more rewarding lives.

CHALLENGES FOR FUTURE DEVELOPMENTS

MAPS at the technical level is a fully operational environment that has been used extensively in the real-world settings described in this paper. In addition to our own use, several other research groups (e.g., AT Sciences, Pittsburgh, PA; NC Assistive Technology Program, Raleigh, NC; Imagine!; and the Boulder Valley School District) have acquired and used MAPS, and we have made the system available as an open source environment¹. Our

¹ http://fit.fraunhofer.de/~carmien/Open Source Code /MAPS_script_editor.zip and /OpenSource Code/MAPS_Prompter.zip

research over the last six years has exposed several rich areas for further research. The content of the prompts, images, and verbal recordings is critical for success, yet there are few research results about this issue. Despite the success of our preliminary work on this problem [6], much remains to be explored. For prompting to provide a robust error recovery and safety net functionality, MAPS-PR needs to become *context aware* of the possible errors in performing the task at hand, and the script content requires specific remedies to get the client back on track [27]. We have developed initial prototypes for those problems [8], but further development of the prototypes and field testing is needed.

In our discussion of independence earlier in the paper and embedded in our objective of creating socio-technical environments, we have indicated the need for *human involvement* in case the technology breaks down. MAPS provides the opportunity for clients to act, work, and learn as they engage in independent activities, able to return to the task when sidetracked by errors instead of avoiding breakdowns at all costs. Kaptelinin and Nardi [19] argue in their analysis of MAPS (Pg. 264-267), that our design is consistent with the principles of activity theory “to encourage development.” MAPS will be integrated with LifeLine [16], a system under development at our center to allow caregivers to monitor and intervene in case clients experience problems. The panic button of MAPS-PR (see Figure 3) can be used by the client at any time to invoke the LifeLine system to summon appropriate assistance.

CONCLUSIONS

MAPS was designed based on two objectives: (1) that clients could develop more independence in exploiting distributed intelligence by using MAPS-PR, and (2) that the “universe of one” world of cognitive disabilities requires personalized systems. The second objective was addressed by a meta-design approach supported by MAPS-DE that empowered caregivers to develop scripts for specific tasks and specific clients. It is critical for the adoption of assistive technology to have an ecologically valid approach to study the use of these systems, and ethnographic approaches are well suited for this. We pursued an integrated approach among theory, systems developments, practice, and assessment. The assessments of a number of dyads that were studied in detail demonstrated that, by using MAPS, clients were able to live more independently and caregivers were able to develop the scripts needed.

Even though people with cognitive disabilities might seem to be a special case for human-computer interaction (HCI) research and practice, we are convinced that this is not the case at all. All human beings have limited cognitive abilities (if we had perfect memories, there would be no need to write things down), and advances in human cognition and intelligence have been made possible by powerful socio-technical environments.

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REFERENCES

1. Ablelink, Ablelink Technologies website, 2007, www.ablelinktech.com,
2. American Psychiatric Association Task Force on DSM-IV, *Diagnostic and statistical manual of mental disorders: DSM-IV-TR*. 4th, text revision. ed., Washington, DC: American Psychiatric Association. xxxvii, 943. 2000
3. Baesman, B. and Baesman, N., Visions System website, 2007, www.thevisionssystem.com,
4. Braddock, D., *2006 Cognitive Disability in US*. 2006, University of Colorado, Coleman Institute: Boulder Colorado.
5. Brand, S., *How Buildings Learn: What Happens After They're Built*. New York: Penguin Books. 1995
6. Carmien, S., *Leveraging Skills into Independent Living- Distributed Cognition and Cognitive Disability*. Saarbrücken: VDM Verlag Dr. Mueller e.K. 256. 2007
7. Carmien, S., Dawe, M., Fischer, G., Gorman, A., Kintsch, A., and Sullivan, J.F., *Socio-Technical Environments Supporting People with Cognitive Disabilities Using Public Transportation*. Transactions on Human-Computer Interaction (ToCHI), **12**(2): 2005. p. 233-262.
8. Carmien, S., DePaula, R., Gorman, A., and Kintsch, A., *Increasing Workplace Independence for People with Cognitive Disabilities by Leveraging Distributed Cognition among Caregivers and Clients*. Computer Supported Cooperative Work (CSCW), **13**(5 - 6): 2004. p. 443-470.
9. Carmien, S., Fischer, F., Fischer, G., and Kollar, I., *The Interplay of Internal and External Scripts - A Distributed Cognition Perspective*, in *Scripting Computer-Supported Learning - Cognitive, Computational, and Educational Perspectives*, F.

- Fischer, et al., Editors. 2007, Springer: New York, NY. p. 303-326.
10. Carmien, S. and Fischer, G., *Tools for Living and Tools for Learning*, in *Proceedings of the HCI International Conference (HCII), Las Vegas, July 2005*. 2005. p. (published on a CD).
 11. Cole, E. *Patient-Centered Design as a Research Strategy for Cognitive Prosthetics: Lessons Learned from Working with Patients and Clinicians for 2 Decades*. in *CHI 2006 Workshop on Designing Technology for People with Cognitive Impairments*. 2006. Montreal, Canada.
 12. Csikszentmihalyi, M., *Flow: The Psychology of Optimal Experience*. New York: HarperCollins Publishers. 1990
 13. Dawe, M., *Desperately Seeking Simplicity: How Young Adults with Cognitive Disabilities and Their Families Adopt Assistive Technologies*, in *Proceedings of CHI 2006: ACM Conference on Human Factors in Computing Systems*. 2006, ACM Press: New York, NY, USA. p. 1143-1152.
 14. Fischer, G., *User Modeling in Human-Computer Interaction*. *User Modeling and User-Adapted Interaction (UMUAI)*, **11**(1): 2001. p. 65-86.
 15. Fischer, G. and Giaccardi, E., *Meta-Design: A Framework for the Future of End User Development*, in *End User Development — Empowering people to flexibly employ advanced information and communication technology*, H. Lieberman, F. Paternò, and V. Wulf, Editors. 2006, Kluwer Academic Publishers: Dordrecht, The Netherlands. p. 427-458.
 16. Gorman, A., LifeLine Website, 2005, <http://l3d.cs.colorado.edu/clever/projects/lifeline.html>,
 17. Imagine! Imagine! website, 2004, www.imaginecolorado.org,
 18. Jönsson, B. and Svensk, A., *Isaac - A Personal Digital Assistant for the Differently Able*, in *Proceedings of the 2nd TIDE Congress*. 1995: Paris, France. p. 356-361.
 19. Kaptelinin, V. and Nardi, B., *Acting with Technology: Activity Theory and Interaction Design*. Cambridge, MA: MIT Press. 2006
 20. Lancioni, G., O'Reilly, M., Seedhouse, P., Furniss, F., and B., C., *Promoting Independent Task Performance by Persons with Severe Developmental Disabilities through a New Computer-aided System*. *Behavior Modification*, **24**(5): 2000. p. 700-718.
 21. LeCompte, M. and Schensul, J., *Analyzing & Interpreting Ethnographic Data*. Walnut Creek, CA: Altamira Press. 1999
 22. Lewis, C. and Rieman, J., *Task-Centered User Interface Design: A Practical Introduction*. 1993, University of Colorado, Boulder: Boulder, Colorado.
 23. Mumford, E., *Sociotechnical Systems Design: Evolving Theory and Practice*, in *Computers and Democracy*, G. Bjerknes, P. Ehn, and M. Kyng, Editors. 1987, Avebury: Aldershot, UK. p. 59-76.
 24. Nardi, B.A., *The Use of Ethnographic Methods in Design and Evaluation*, in *Handbook of Human-Computer Interaction*, M.G. Helander, T.K. Landauer, and P.V. Prabhu, Editors. 1997, Elsevier Science B.V.: Amsterdam. p. 361-366.
 25. National-Research-Council, *Technology for Adaptive Aging*. Washington, DC: National Academy Press. 2004
 26. Newell, A. *A User Centred Approach to Supporting People with Cognitive Dysfunction*. in *ACM CHI 2006 Workshop on Designing Technology for People with Cognitive Impairments*. 2006. Montreal, PQ.
 27. Paganelli, F.S., E. Mamelli, A. Bernazzani, R. Barone, P. *ERMHAN: A multi-channel context-aware platform to support mobile caregivers in continuous care networks*. in *IEEE International Conference on Pervasive Services*. 2007. Istanbul, Turkey.
 28. Phillips, B. and Zhao, H., *Predictors of Assistive Technology Abandonment*. *Assistive Technology*, **5**(1): 1993.
 29. Suchman, L.A., *Plans and Situated Actions*. Cambridge, UK: Cambridge University Press. 1987
 30. The Oregon Research Institute, *Teaching People with Developmental Disabilities*. 1988.