Designing for the "Universe of One": Personalized Interactive Media Systems for People with the Severe Cognitive Impairment Associated with Rett Syndrome

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ABSTRACT

The needs and capabilities of a person with severe disabilities are often so specific that designing for the person is like designing for a "universe of one." This project addresses this problem for women with Rett syndrome, a disorder accompanied by severe cognitive, communication, and motor impairment. The research team adapted participatory design techniques to work with five such women, and their families, to design and evaluate new assistive technology for these women. The process suggests a class of media-playing devices that would be generally useful to women with Rett syndrome: systems that can load multiple audio or video segments; be activated by many different switches; and respond instantly to switch-hits. As well, the systems should permit a caregiver to set the start and end time of each segment, and how the system advances through a sequence of segments. The paper also discusses patterns that were observed when collaborating with the families. For example, parents shared longstanding but untried ideas for new assistive technology; and expressed a strong interest in any device that would help their daughters do things for themselves.

ACM Classification Keywords

H.5.2 User Interfaces – *user-centered design.* K.4.2 Social Issues – *assistive technologies for persons with disabilities.*

Author Keywords

Assistive technology; intellectual disability; participatory design; Rett syndrome; severe cognitive impairment; user training; user-centered design; user observation studies.

INTRODUCTION

There is a tremendous unmet need for assistive technology for people with severe cognitive and motor impairments. The concept of "universal design" is problematic [31] and does not work well for users with profound disabilities. The more disabled a user, the more he or she falls out of the

"universe" of universal design and the more he or she exists in a "universe of one," requiring a personal customized system [7, 20]. This project addresses the need for better practices in the development, delivery, and testing of assistive technology for individuals with severe cognitive disabilities. The project adapts participatory design and user observation study techniques for the design of media systems that can be used by women (and girls) with Rett syndrome, and identifies a class of media-playing assistive technology devices that would likely be useful to this population.

Rett syndrome is a genetic disorder that occurs in roughly one in ten thousand women and is very rare in men [10]. Rett syndrome is accompanied by extreme cognitive, communication, and motor impairment. Women with Rett syndrome have a cognitive ability that is roughly equivalent to that of a 6-month-old infant [37, 41]. Most women with Rett syndrome do not use assistive technology or augmentative communication devices [1, 25].

One of the hallmarks of girls with Rett syndrome is somewhat typical development for roughly the first year of life, followed by regression from roughly one to three years of age, during which time the child loses cognitive, communication, and motor abilities; such as the loss of all language and most hand-use [10]. Roughly half of all girls with Rett syndrome suffer from seizures [10], and roughly half engage in screaming fits [25] which may be most common during the infant years.

The project presented here started with a system that will be referred to as the *Motivating Music* system. It was iteratively designed and developed to provide a 20-month-old girl who was exhibiting substantial developmental delays, and who was not interacting with her environment as would be typical, with a motivation to do so by means of an easy-to-use and engaging music-playing system. The system met this goal. All of the girl's in-home therapists (speech, physical, occupational) observed that the girl was highly motivated to use the system, and they all incorporated it into their in-home therapy sessions. The girl was diagnosed with Rett syndrome at 24 months of age. The girl has now used the system every day for three years, and remains highly engaged when using it.

Prior literature points to the potential for success of the *Motivating Music* system. Many studies document the extent to which women with Rett syndrome greatly enjoy

listening to music [14, 15, 38, 39, 42], and a small number of studies also show that, given the right conditions, women with Rett syndrome can learn to activate a switch to play the music for themselves [24, 36]. And yet most women with Rett syndrome do not use such devices.

There are many possible reasons for why women with Rett syndrome do not generally use media-playing devices that they can control themselves. It seems in part due to a lack of devices that would support this task in the manner specifically needed by these women, and in part due to the difficulty in building a system that would. The *Motivating Music* system, for example, required roughly fifty hours of interface design, computer programming, and user testing. Such resources are not readily available to most parents.

This paper attempts to address this universe-of-one problem for the population of women with Rett syndrome, and perhaps for other people with similar impairments, by addressing the following research questions:

1. How can established participatory-design and user-observation-study techniques be adapted to improve the development of technology for such populations?

2. What functionality and end-user-configurable settings are required in a class of assistive technology devices that would be useful to women with Rett syndrome?

3. What are some of the specific challenges that designers may face when collaborating with this user group, and how might these challenges be addressed?

These questions were pursued by (a) interviewing five sets of families (and caregivers) who have daughters with Rett syndrome to learn about the families and their daughters; (b) engaging the families in participatory design activities aimed at designing assistive technology that would be useful to the families and their daughters; (c) building, deploying, and evaluating the devices for two of the families and daughters; and (d) reflecting on the experience. The questions were also pursued by having a parent of a daughter with Rett syndrome on the research team.

RELATED WORK

User-Centered Design for People with Disabilities
User-centered design techniques, such as participatory design activities and user observation studies, have been successfully adapted for use with people with disabilities [11, 22, 23, 40] including for users with cognitive impairments [6, 8, 9, 26], but there very little prior work (such as [17]) on designing for people with severe cognitive impairment such as occurs in women with Rett syndrome.

This project integrates special-education research practices into the design and evaluation of assistive technology, specifically through the use of operant conditioning [34] techniques, to (a) train users with severe cognitive impairments in the use of technology and (b) evaluate the extent to which the training was successful and to which the technology works for that user. Such techniques are routinely used in special education practice, such as to

reduce challenging behavior in children with autism [27]. The techniques were also used in the studies that successfully created opportunities for girls with Rett syndrome to play music by activating switches [24, 35, 37]. (Note: It is possible to use the techniques, which are quite effective, without embracing the underlying theory, which is seen by some as problematic [5].)

End-User-Customizable Assistive Technology
Previous research, and the marketplace, point to the need and opportunity for assistive technology that can be easily configured by the end-user [18, 19]. This project contributes to the limited body of work that has been done to date that maps directly-measurable aspects of disability to specific interface design recommendations. This approach has been referred to as *ability-based design* [12, 40] and also as *personalized dynamic accessibility* [11]; the goal is to reduce the amount of computer programming that is required to provide useful and usable assistive technology to individuals with disabilities. This project contributes to the design of assistive technology for women with Rett syndrome by identifying a relatively small class of functionality and end-user-customizable settings that might be useful to this general population of users.

Emotional Challenges of Researchers
Prior work demonstrates a number of emotional challenges that researchers may face when conducting research on topics that are potentially sensitive and distressing [29]. For example, researchers engaged in fieldwork investigating mental health and employment [28] found themselves concerned over the "ethics of empathy" [16]; that is, the potential negative effects on both interviewers and participants when interviewers showing empathy towards participants as they conveying emotional content. There was some concern in the project presented here regarding issues such as these, including the potential for interviewer stress, when hearing parents discuss the difficulties associated with having a daughter with Rett syndrome.

THE MOTIVATING MUSIC SYSTEM
This project was conceived based on the success of the *Motivating Music* system discussed in the Introduction. But rather than simply test this system with other women with Rett syndrome, the project explores the specific needs, interests, and abilities of other families and daughters; and tries to develop something specifically useful to each of them. To proceed down that path, it is useful to understand how and why the *Motivating Music* system worked so well.

The 20-month-old target user of the *Motivating Music* system exhibited developmental delays as evidenced by no walking or free-standing, very little use of her hands, and no verbal communication. The girl was not interacting with her world as was needed to learn cause and effect. The girl enjoyed listening to music, as did the parents, who usually had music playing through high-fidelity studio monitors connected to a computer. To fit the family's interests and lifestyle, the system was designed to permit the girl to trigger the music on that computer through those speakers.

The system consisted of a MIDI piano keyboard, a laptop, and the studio monitors. A software program written in Max/MSP caused any MIDI keypress to instantly start playing a short segment of music (such as Bob Marley). Each segment ended after roughly 25 s. If a segment was playing when another key was pressed, the segment was immediately restarted, creating a deejay-sampling effect. The system advanced to a new song segment after roughly a minute. Though designed and implemented as assistive technology, the look and feel of the system was more that of a deejay sampling system. The system was always on, and required no wake-up or startup, such that a keypress always triggered the playing of a high-fidelity audio sample.

The *Motivating Music* system was successful. The girl has now used it daily for three years, and remains enthused with its use. The success can probably be attributed to some or all of the following: (a) The system provides something that the girl can do for herself. (b) It creates a social activity—people cheer her on as she plays it. (c) It provides a desired output—the girl loves the music. (d) Songs segments are edited and ordered so that any sequence of key-hits produces something aesthetic. (e) New song-lists are periodically added to accommodate changing musical tastes, and to keep the system sounding fresh. (f) Every key-hit provides an immediate response, providing "response efficiency" [21]. (g) Song segments are short enough to require the user to actively "play" the system, but long enough to provide substantial reward with each key-hit. (h) It is truly "walk up and use" with the only required user action being the pressing of a piano key.

The project presented here investigates which aspects of the *Motivating Music* system, which was personalized to one user, might be useful to other women with Rett syndrome.

PHASE 1: INTERVIEWS AND PARTICIPATORY DESIGN
The first phase of the project involved meeting with families who have a daughter with Rett syndrome living at home. The goal was to figure out how to develop user-centered design techniques to collaborate with this population, and to figure out what kinds of new assistive technology devices might be useful to it. Each interview set out first to learn about the daughter and her family, and second to identify a specific technology device that that we could build to help this woman and her family.

Methodology
Interviews and participatory design sessions were conducted with five families, each of whom has a daughter with Rett syndrome living at home. The parent-researcher on the team was present at all sessions.

Participants
Five families were recruited through the Northwest Rett Syndrome Foundation in the U.S. The families will be referred to as Family-1 through Family-5; with Family-*n* comprising Mom-*n*, Dad-*n*, and Daughter-*n*; and with Daughter-*n* being the daughter with Rett syndrome. All of the daughters were clinically diagnosed with Rett syndrome. The daughters were 17, 21, 27, 30, and 47 years old (though ages will not be associated with individuals to help maintain confidentiality).

All of the daughters have severe communication and motor impairments. None speak any words except for Daughter-4, who has the unusual ability (among women with Rett syndrome) to do so, but her conversations are atypical and consist of her slowly answering familiar questions with practiced communication partners such as her mother. Daughter-5 is the only woman who cannot walk; she also provides, among these five women, the least evidence of her likes and dislikes. The other four will indicate desired objects by walking, looking, and pointing. Daughter-4 will also sometimes say the name of a desired object. None of the women use any assistive technology, though Daughter-5 has a toy that produces a vibrotactile stimulus when she holds it. All of the women rely on caregivers for all activities of daily living such as eating, toileting, and bathing.

Procedure
Interviews occurred in the families' homes and lasted two to two-and-a-half hours. Each interview started with open-ended questions such as "What is your daughter like?", "How does she express her wants and needs?", and "What does she like?"; and gradually became more focused with questions such as "What assistive technology has your daughter used or does she use now?" and "How has the assistive technology worked for her?" A pivotal question that was generally asked around the midpoint of the interview was some form of "If you could imagine a new device that would be useful to your daughter, what might that be?" at which point the meeting transitioned into a participatory design meeting.

Though we structured each meeting with questions and with the goal of identifying a device that we could build, the discussions were largely open-ended and went in many different directions. Near the end of each interview, each family was asked to complete the standardized Rett Syndrome Behaviour Questionnaire (RSBQ) [30].

Analysis
The interviews were audio-recorded, transcribed, and analyzed. Two separate analyses were conducted: (a) a *time on topic* analysis to measure the minutes spent on different topics during each interview, and (b) a *thematic analysis* in which we looked for patterns in what we observed that seemed relevant to the design and development process.

The *time on topic* analysis was accomplished by applying a straightforward coding scheme to count the number of minutes spent discussing (a) the daughter's abilities, activities of daily living, likes, and dislikes, (b) assistive technology used in the past, (c) ideas for new technology that might be useful to the daughter, and (d) the parent-researcher's personal experiences with Rett syndrome.

The *thematic analysis* was accomplished as follows: (a) Two researchers attended the interviews, listened to the audio recordings, engaged in an extensive discussion, and arrived at a set of themes that they agreed accurately characterized patterns that they both observed. (b) The two

researchers developed a coding scheme based on these themes and applied it to the interview data. (c) A third researcher (who did not attend the interviews or listen to the recordings) reviewed detailed summaries of the interviews and further confirmed the agreed-upon themes.
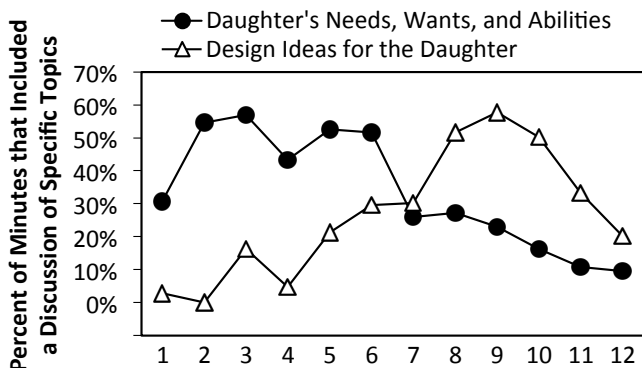
Results

The *time on topic* analysis shows that, on average, 68% of the time (on average 82-102 min of the 2-2.5-hr interviews) included discussion of the daughter's abilities, activities of daily living, likes, and dislikes; 10% (12-15 min) included discussion of past assistive technology; 28% (34-42 min) included discussion of new assistive technology that might be useful to the daughters; and 23% (28-35 min) included discussion of the parent-researcher's personal experiences with Rett syndrome. (The sums of the percentages exceed 100% because multiple topics were sometimes discussed at the same time.) Figure 1 shows how the interviews followed the classic user-centered design approach of first learning about the user, the task, and the context of use; and then exploring ideas for new technology [32].

The *thematic analysis* identified the following patterns.

The Participatory Design Process

Open-ended questions and direct observation contributed to design. Much was learned by visiting each family in the home, by asking open-ended questions, and by observing each daughter and the family's interactions with her. For example, we observed Daughter-1 watching DVDs in the living room, and her parents change the DVD when they heard it ending; this contributed to the design of the *Video Button* system. We observed Daughter-3 walk out of her room and drop a DVD case on her brother to get him to play it, which he did; this contributed to the design of the *Video Bucket* system. We got down on the floor of Daughter-2's bedroom, where she spends a lot of time, and saw that we could fit a MIDI keyboard and powered speaker under her bed for the music-playing system that we are configuring for her. We observed Daughter-5 hold a steering wheel toy, and we are building a system that will use that steering wheel as a switch, which her mother thought was an "awesome" idea.

Progression of the Interviews Across 12 Time Intervals

Figure 1. The percentage of time spent discussing the daughter versus design ideas for the daughter over the progression of the interviews.

Assistive Technology

Families proposed augmentative communication systems that seem out of reach. When asked to imagine new devices that would be useful to their daughters, three families proposed communication systems that would seem to require a higher level of cognitive functioning than these daughters appeared to have based on a variety of factors such as a lack of success in previous attempts to use augmentative communication. For example, two families proposed systems that would permit the daughter to communicate that she is in pain:

> What would be the ultimate thing, because one of the most difficult things I think there is about dealing with Rett syndrome is not knowing... when they don't feel well. So if there's a way you could have... symbols of somebody who looks like upset like they don't feel well or something like that. (Mom-1)

> Another thing technology-wise might be if [Daughter-4] [is] having trouble communicating hurt or pain and so, if she could push a button... [and] a human body shows up and she could push or figure out that she could push it and it'd light up. (Mom-4)

Parents had longstanding specific ideas for new and practical assistive technology. It became clear during the interviews that three sets of parents (Families 1, 3, and 5) have also had, for years, specific ideas for relatively simple assistive technology that they would like to try, but that the execution of each idea was not straightforward. Dad-1 described a system with a few big buttons in which each button would play a different movie. He wanted to see if his daughter would learn to press the button associated with her favorite movie. Dad-3 described how he had even started, many years ago, to write the computer code for a picture-based computer-based communication device but just did not have the time to complete it. Mom-5 explained her idea:

> When we go down the hall she always wants to stop and she just stares at the family pictures on the wall. And so we thought if we could do like a thing on the computer where... we could have her push the button to make it change to the next picture. But nobody could ever help us figure out how to make that happen.

Parents desired any assistive technology that promotes independence. All five sets of parents expressed a strong interest in a device that would support 'anything that the daughter could do for herself.' One mother explained:

> If there was anything that she could have some control over, in my mind that would improve, however little that would be. I mean I can't imagine how frustrating it would be to have zero control over your life. (Mom-5)

Parents expressed a strong interest even in devices that would support seemingly small tasks, such as changing the TV channel on a sibling ("yeah, that would just annoy her sister," Mom-2 laughed) or restarting a DVD after it finished ("that would sort of empower her," Dad-1). Mom-1 stated "anything you can give her that she has to do herself, if she's learning something, that's always a good thing."

Challenges of Having a Daughter with Rett Syndrome
There is hardship and sadness. All of the parents described hardship and sadness associated with having a daughter with severe disabilities. One parent described the pain she experienced during her daughter's regression, during which the daughter lost the ability to say one hundred words:

> I kind of almost wish she didn't [show this early development] because then it's... worse because you knew she could do it, and then... it's like a slow-motion movie, all these things she quits doing. Whereas,... if she didn't do it to begin with,... you wouldn't miss it. (Mom-1)

Parents expressed concern regarding the challenges in caring for their daughters. For example, four sets of parents spoke of the sadness associated with not knowing when their daughter is in pain. And both sets of parents whose daughters have gastrostomy tubes, or g-tubes, which permit liquid food to be delivered directly through the abdominal wall into the stomach, expressed regret that it took them years to accept the need for, and to pursue, the procedure.

Some parents presume high cognitive functioning. Though it contradicts clinical assessments (such as in [37, 41]), some parents presume that their daughters have substantial cognitive ability, and offer alternative explanations for the daughters' inabilities. One mother stated "I think that she understands a hundred percent of what goes on through the day" but that it is difficult to engage her in activities because she is "incredibly mellow," has a "short attention span," and is "terribly bored." Another mother expressed frustration with other people presuming intellectual limitations, saying "they just didn't feel at school that she could understand anything abstract. It was very frustrating for me."

Research shows that parents of daughters with Rett syndrome tend to attribute higher cognitive functioning to their daughters than is attributed by professionals [1]. It is possible that these parents are "presuming competence" as is done to help children with intellectual disabilities reach their highest potential [4]. One of the mothers spoke specifically of the communication breakthroughs that sometimes occur with people with high cognitive functioning but severe motor impairment (such as in [2]).

Each interview was a "family reunion." All of the families knew that one of the interviewers has a daughter with Rett syndrome, showed genuine interest in this, and asked questions about the daughter. The parent-researcher also volunteered personal stories that fit with the flow of the conversation. Mom-1 characterized the social dynamic that occurs when parents of daughters with Rett syndrome get together: "It's like a family reunion.... We're all in the same club, so it's like everybody gets it." Parents offered advice to the parent-researcher, such as to not delay in getting a g-tube if one became necessary. Mom-5 stated, at the end of the interview, "Welcome to the Rett family."

In summary, the interview process followed user-centered design practice and provided the designers with a rich understanding of the user, tasks, and context-of-use. Learn-ing these required hearing of tremendous disability and hardship. Opening the discussion to proposals for new technology led to some seemingly-impossible-to-build ideas from the parents, but also some that were quite feasible. It also became clear that parents welcomed any technology that would help their daughters to do new things for themselves.

Discussion of Phase 1
Each family meeting led to a proposal for some new technology specifically personalized for that family's daughter. Each proposal combined a specific activity that the daughter already enjoys, and aspects of what we were able to learn and observe regarding the daughter's functional and motor abilities. It would seem difficult to have arrived at these designs without direct observation and interaction.

The Rett Syndrome Behaviour Questionnaire [30] provided no useful information for the design of assistive technology. We administered the questionnaire hoping that it might capture user characteristics that could be mapped to design decisions, along the lines of [11], but it did not. A more useful questionnaire for assistive technology for women with Rett syndrome might ask (a) what media the woman enjoys for at least an hour a day, (b) what control if any she has over the playing of the media, including through other people, and (c) what functional use she has of her hands and other parts of her body.

The family interviews and participatory design sessions produced ideas for systems, including video-playing systems for Daughters 1, 3, and 5; a video-chat system for Daughter-4; and a variation of the *Motivating Music* system for Daughter-2. All of the systems, except that for Daughter-2, were effectively designed for a universe of one. Each system is currently in some stage of deployment. Two have been fully developed and evaluated, the *Video Button* and the *Video Bucket*.

PHASE 2: DELIVERY AND EVALUATION OF 2 SYSTEMS
The second phase of the project focused on developing and evaluating the *Video Button* system for Daughter-1, and the *Video Bucket* system for Daughter-3.

Design of the *Video Button* and *Video Bucket*
The *Video Button* was designed based on what was learned in the participatory design process, including that Daughter-1 loves pressing buttons regardless of their function (or lack of function). This last detail motivated us, in our eventual user testing, to try to determine whether she was hitting the button to play the video, or simply because she liked pushing buttons.

The *Video Button* advances through a 3-min-15-s video clip of the song "Under the Sea" from the movie *The Little Mermaid*. The clip pauses every 20 s at which point the video freezes and a button-press is required to resume playback. Ten button-presses are needed to get through the entire clip. A button-press in the middle of a clip has no effect, partly it is not straightforward to decide what would be the most desirable system response to such a switch-hit.

The *Video Bucket* was designed based on learning that Daughter-3 requests videos by dropping them on family members. The parents explained that these were real requests and, in response to our question, yes, she could probably learn to drop the DVD on a specific surface if she knew that it would cause it to play.

We proposed a box or platform with an RFID reader that could sense an RFID card in a DVD case. We returned with the physical prototypes shown in Figure 2. The parents took one look and said that the daughter would not be able to get the DVD into the slot shown in Figure 2, left frame, but that she would be able to get it into the box shown in Figure 2, right frame. She did so shortly after her dad presented it to her and said "put the tape in the bucket." One of the times that she threw it in, it landed sideways and not flat, which would have been a problem for an RFID reader in the base, which motivated us to use a round bowl.

Figure 2. Two prototypes that led to the *Video Bucket* system.

The *Video Bucket* plays a 50-s video clip from a *Franklin* or *Rugrats* DVD after one of the two DVD cases lands in the bowl. In our system evaluation, a parent or caregiver would then remove the DVD and set it next to the bowl. When the clip ends, the screen goes dark. A DVD case landing in the bowl while a clip is playing starts (or restarts) that video.

Both systems were developed using Max/MSP and run on laptops connected to the families' TVs using HDMI. The *Video Button* hardware included an AbleNet Big Beamer and Mini Beamer Receiver, and a Don Johnston Switch Interface Pro 6.0. The *Video Bucket* included an RF-IDeas RDR-80581AKU under thick paper in a plastic salad bowl.

Figure 3 shows Daughter-1 using the *Video Button* and Figure 4 shows Daughter-3 using the *Video Bucket*. Both systems were designed, as in the *Motivating Music* system, to introduce a control mechanism to patterns of activity that each daughter already enjoyed, with equipment that she already used (such as her own TV), and media that she already enjoyed. Also, as in the *Motivating Music* system, the reward was made to be commensurate with the amount of work needed to get it: 20 s of video for pressing a button, and 50 s of video for getting a DVD into a bucket.

Training and Evaluation Protocol
Each system was deployed with a protocol that the parents and caregivers used to train the daughter on how to use the system, and that we used to evaluate whether the training was successful. The training and evaluation followed an operant-conditioning-like regimen as is often used in special education research (as in [24, 35, 36]). The evaluations were rigorous and quantitative to conclusively determine whether the daughters could successfully use the systems, and to avoid the problems sometimes seen in Rett syndrome research (discussed by [33]) such as over-reliance on anecdotal data or the lack of a baseline condition.

Parents and caregivers ran one session per day for six or ten days. Each session included two activities, each corresponding to a unique experimental condition: *user-plays-video* and *system-plays-video*. For *user-plays-video*, the daughter activated the switch to play the video. In *system-plays-video*, the baseline condition, the video played on its own. Each activity lasted approximately five minutes, with an optional break in between the two activities. The order of the two activities was counterbalanced across days.

The *Video-Button–user-plays-video* activity included "hand over hand" prompting in which the parent said "Play the movie!" while holding the daughter's hand and directing it to press the button. The prompting was done immediately after the video paused for the first three sessions, and 30 s after the video paused for the remaining sessions, thus giving the daughter more of an opportunity to press the button on her own in the later sessions.

The *Video-Button–system-plays-video* activity proceeded as follows: The parent or caregiver interacted with the laptop software to deactivate the switch and start the uninterrupted 3-min-15-s video playback; placed the button next to the daughter (so we could evaluate if the daughter would learned to *not* hit it); and sat down next to the her.

The *Video-Bucket–user-plays-video* activity also included prompting but it was only done verbally, with a parent or caregiver saying "Put the tape in the bucket!" The prompt was the same one that the parents used for the physical prototypes (in Figure 2) and, as they explained, used vocabulary that the daughter already knew. The prompting was done at the start of each *user-plays-video* activity, and 30 s after each video segment ended (and the screen went dark). This continued for roughly five minutes.

The *Video-Bucket–system-plays-video* activity proceeded as follows: The parent or caregiver removed and hid the bucket and the DVDs, and interacted with the laptop software to cause the system to play the same sequence of video segments that were played in the previous *user-plays-video* activity. This equalized the content, duration, and pacing of the video playback across the two conditions, helping to isolate the effect of user-control, and thus its effect on the daughter's preference for it. The bucket was removed for the *system-plays-video* activity to prevent the confusion that could have occurred if tossing a DVD into the bowl appeared to sometimes cause a video to play, and to sometimes do nothing, as could happen.

Evaluation Measures
The systems were evaluated to determine the extent to which they were learnable and usable and (following [24, 35, 37]) the extent to which the daughter's control of the media contributed to their happiness. Sessions were video-

Figure 3. Daughter-1 using the *Video Button* to advance 20 s through a video. Her father sits alongside her to offer hand-over-hand prompting following an experimental protocol.

Figure 4. Daughter-3 using the *Video Bucket*. She throws a DVD case into the bowl to start a 50 s video. Her mom (out of frame) removes it and puts it back in front of the bowl.

taped and analyzed for switch-hits, including type and latency of hit, and for indices of happiness and displeasure.

For *Video Button*, a switch-hit was counted each time that Daughter-1 pressed the button. A button-press that was made in the *user-plays-video* condition while the video was paused was classified as *independent* if it was done without prompting, and otherwise as *prompted*; if it was made while the video was playing, it was classified as a *no effect* hit. All button-presses made in the *system-plays-video* condition were classified as *no effect* hits. For *Video Bucket*, a switch-hit was counted each time that a DVD landed in the bowl; each was classified as either *independent* or *prompted*.

A coding scheme for indices of happiness and displeasure was established by showing each family video excerpts from the sessions and asking them to identify signs of happiness or displeasure in their daughter's behavior. Family-1 identified, for example, Daughter-1 rubbing the side of her head above the ears as a sign of happiness, and patting the top of her head as a sign of displeasure.

The recording of each session was divided into intervals, each of which was coded as showing 0 or 1 indices of happiness, and 0 or 1 indices of displeasure. For *Video Button*, the coding was done for the ten intervals corresponding to the ten 20-s segments of the 3-min-15-s video that the daughter watched. In the *user-plays-video* condition, the coding was done for each 20-s segment of video that played as a result of a button-press; coding was not done when the *Video Button*'s video was paused. In the *system-plays-video* condition, the coding was done for each 20-s interval during which the video played. This approach equalized the time analyzed between the *user-plays-video* and *system-plays-video* conditions. For *Video Bucket*, the coding was done for each of the twenty 15-s intervals of the 5-min activity.

A *preference for video control* was then calculated for each session by summing: from the *user-plays-video* condition, +1 for each interval showing happiness, and −1 for each interval showing displeasure; and from the *system-plays-video condition*, −1 for each interval showing happiness, and +1 for each interval showing displeasure.

Results

Video Button

Figure 5 shows the latency of switch-hits across the ten *user-plays-video* sessions for the *Video Button*. The low latencies for Sessions 1 to 3 are from the hand-over-hand prompting that occurred as soon as the video paused. In Sessions 4 to 10, in which the prompting was delayed to around 30 s, most of the hits were independent. If we set target performance to be 8 independent hits under 30 s per session, the data suggest proficiency by Session 8.

Figure 6 shows the number of independent and no-effect hits across the ten sessions, including the no-effect hits from the *user-plays-video* and *system-plays-video* conditions. (Prompted hits are not shown, but mirror the independent hits, as in *prompted = 10 − independent*.) That the user made eight or more independent hits for all of the
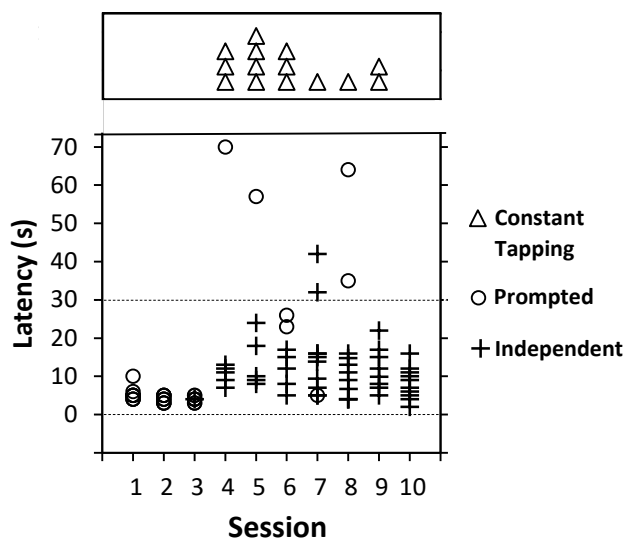

Figure 5. Latency of switch-hits across the ten sessions for *user-plays-video* **with the** *Video Button*, **separated by type of hit. Some independent hits are slightly adjusted to make each visible. The top frame indicates hits from constant tapping.**
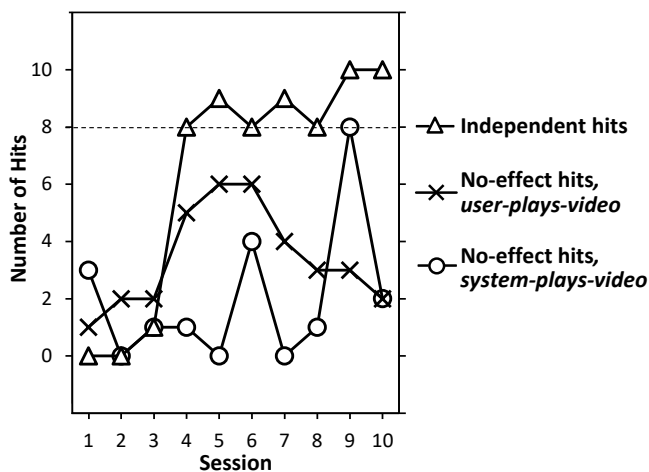

Figure 6. Number of switch-hits per session across the ten sessions with the *Video Button*, **separated by type of switch-hit.**

sessions with delayed prompting again suggests proficiency in using the system. The no-effect hits are particularly revealing given Daughter-1's reported tendency to push buttons no matter what they do. In the *system-plays-video* condition, there are usually 0 or 1 no-effect hits, with a few outliers. In Session 4, in which delayed prompting starts and independent hits jump, the number of *user-plays-video* no-effect hits also jumps from 2 to 5 hits. But the number of *user-plays-video* no-effect hits steadily declines in Sessions 6 to 10 from 6 to 2 hits. The daughter appears to be learning to not hit the switch when it does nothing. In the language of operant conditioning, this would be characterized as "extinction."

Figure 7 shows Daughter-1's preference for video control when using the *Video Button*. A positive score indicates greater happiness in the *user-plays-video* activity, and a negative score indicates greater happiness in the *system-plays-video* activity. The score is close to zero across all sessions, except for drop in the middle. There are no clear trends in this data.

Video Bucket

Figure 8 shows the latency of switch-hits for the *user-plays-video* activity with the *Video Bucket*. Recall that the daughter was verbally prompted at the start of the session, and again 30 s after each video ended. The substantial number of hits that occurred across the sessions, whether prompted and independent, shows that the daughter was able to use the system. If we set target performance to be four independent hits under 30 s per session (recall that each video played for 50 s, and the session was 5 min long), the target was only met in two of the six sessions, Sessions 2 and 5. But it is difficult to interpret this as failure. A target performance criterion such as this is mostly useful when it is met, suggesting that usability, learnability, and motivation all came together. It is difficult to point to a cause or to conclude much of anything when it is not met.

Figure 9 shows Daughter-3's preference for video control when using the *Video Bucket*. Except for one spike in Session 2, as with the *Video Button*, the score is close to zero across all sessions. Again, there are no clear trends.
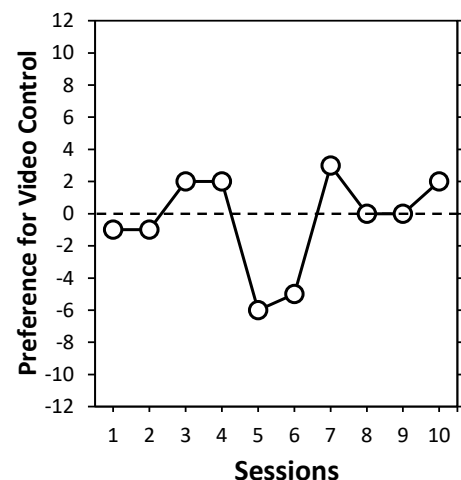

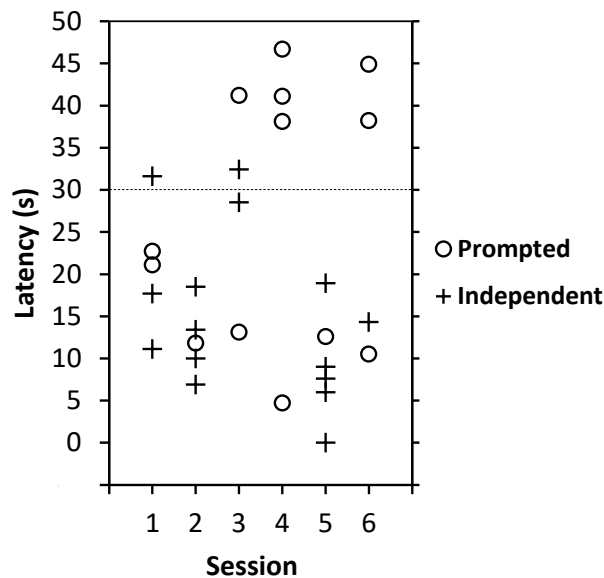**Figure 7.** *Preference for video control* **with the** *Video Button*.

Figure 8. Latency of switch-hits across the six sessions for *user-plays-video* **with the** *Video Bucket***, separated by hit type.**
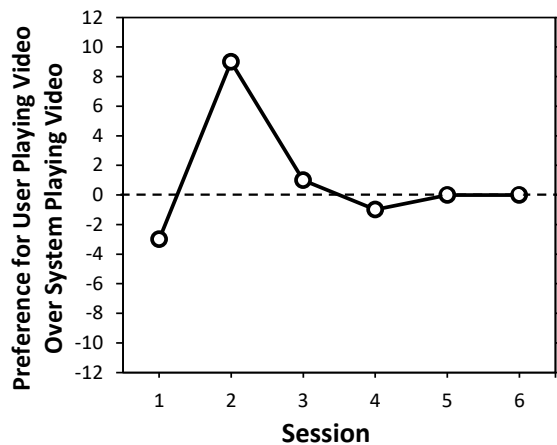

Figure 9. *Preference for video control* **with the** *Video Bucket***.**

Parent Responses

Both sets of parents were quite pleased at seeing their daughters being able to use the systems. This can be seen in Father-1's body language as he sits next to his daughter in the videos using the *Video Button*. When the sessions were completed, Mom-1 asked 'what's next' and was ready for a system that presented choices of different DVDs.

As soon as *Video Bucket* was plugged in, the parents were so excited that they started prompting their daughter to put a tape in the bucket before we were ready to record the first session. This of course interfered with the formal data collection, but the parents are our collaborators and have a say in how things should proceed, and their excitement was data as well. The mom started asking if we could put all of the other DVDs on the system, and the dad went and got his video camera to document his daughter's instant success.

Discussion of Phase 2

The results show that the new assistive technology introduced for these users was learnable and usable. *Video Button* was used independently by Daughter-1 by the 8th session and, while *Video Bucket* did not lend itself to Daughter-3 reaching the criterion that we set for demonstrating fully independent use, she was clearly able to use the system. Even if longer-term use of the *Video Bucket* sometimes required prompting, such as from another room, any time that the daughter put the DVD in the bucket to start a video, the system would still satisfy the parents' goal of 'anything that she can do for herself.'

The carefully designed experimental evaluations permitted us to conclude that the users understood the cause-and-effect relationship between activating the switch, and the video playing. The experimental design permitted us to rule out potentially competing hypotheses, such as that the *Video Button* only appeared to be usable and learnable because Daughter-1 simply liked pushing the button.

We were initially concerned that we were not able to replicate evidence that women with Rett syndrome enjoy listening to music more when they are causing it to be played than when someone else is playing it for them, as previously reported by [24, 35]. We revisited these two studies and realized that, in both studies, the data did not actually support this conclusion. In the two studies, the baseline condition was not a *system-plays-music* condition such as we used but rather, quite surprisingly, it was evidently a *no-music* condition. The increased happiness reported in the *user-plays-music* conditions in these prior studies may have resulted simply from the presence of the music, and not from the users' control of the music.

Controlled experiments are not usually considered to be part of a participatory design process. In this project, however, we incorporated such experiments specifically to include users with severe cognitive impairments in that process. The experiments provided the most direct and clear feedback that these users could provide regarding different system design ideas.

GENERAL DISCUSSION

The project reveals limitations in assistive technology.

The project suggests three reasons as to why there appears to be no assistive technology that is ideally suited for women with Rett syndrome:

First, the disability is profound. As we learned in the interviews, these women have a very limited ability to communicate beyond showing interest in things, and expressing some emotion. Though some parents of daughters with Rett syndrome presume high cognitive function, there is limited data to support this conclusion [37, 41].

Second, currently-available assistive technology does not serve these women well. In general, the technology focuses on communication [3] and, consistent with the research literature [1, 25], the daughters we met have been unable to establish a means of communication with any of the professional attempts that have been made. And currently

available off-the-shelf simple assistive technology, such as that permits pressing a button to make a stuffed animal move, offers "sufficiently limited stimulus appeal that even 6-month-old infants tire of them when they are used more than a few times" [36].

Third, there is the universe-of-one problem: Women with Rett syndrome enjoy listening to music and watching videos, but each woman has different and specific media interests. Different women have different functional motor abilities, which leads to the need for personalized switch configurations. The cognitive impairment may lead to the need for a carefully-designed response to each switch-activation, to help the women learn the cause-and-effect nature of the device, and to be motivated to use it.

The project points to new and useful technology.
The project reveals a lack of appropriate technology for this population. But the interviews, participatory design process, and success of the *Video Button* and *Video Bucket* suggest that appropriate technology is possible. Furthermore, although each of the systems that has been proposed or built in this project to date has been designed for a universe of one, the proposals and systems, when considered *in toto*, suggest a class of assistive technology devices that would be useful to most women with Rett Syndrome.

This project identifies the need for a class of media systems that can (a) load any set of audio or video segments, including full movies; (b) be activated by a wide range of switch devices (such as AbleNet 1/8" mono, MIDI, USB, and various wireless); and (c) respond instantly to switch-hits. Furthermore, the systems should permit a caregiver to set (a) the precise start and end time (and thus duration) of each segment; (b) how switch-hits move through a collection of segments (such as sequentially, or repeating each segment for a period of time); and (c) whether a switch-hit made while media is playing should restart that segment, advance to the next, or do nothing. This class of devices would seem to create a "universe of many" that includes most women with Rett syndrome.

Emotion and expectation must be managed and navigated.
The project presented a number of challenges that might recur when engaging parents of individuals with extreme cognitive impairment in participatory design projects.

The project was sometimes emotionally challenging for the researchers. Every family and daughter presented extensive evidence of hardship and extreme disability, which may have evoked sadness. The general public tends to be more uncomfortable when interacting with people with disabilities, especially intellectual disability, than when interacting with people without disabilities [13]. There is no reason to assume that the research team was immune from such feelings. Though the researchers primarily interacted with the parents, such discomfiture may have come into play, and may have caused stress. Two of the fathers interviewed shared feelings of discomfort that they themselves have regarding their daughters' disability, with one saying, for example, that "she freaks me out" with a particular behavior that she sometimes exhibits.

It has been established quite broadly that some forms of fieldwork can evoke emotional responses in researchers [16] and that this should be considered in the context of the researchers' well-being [28], perhaps even with formal emotional support mechanisms [29]. But there is very little work (with [17] as an exception) specifically advising designers that working with users with extreme cognitive impairment may cause feelings of discomfort.

Some parents proposed communication systems that seemed beyond their daughter's cognitive abilities. These proposals contributed to the researchers feeling somewhat helpless, as if they were being asked to do something beyond their abilities. When this happened, we negotiated the parents down to more basic systems, suggesting that we first establish some initial control capabilities. As mentioned earlier, the families were ultimately open to anything that might work, and happy with anything that did. In retrospect, what we perceived as seemingly unrealistic hope might also be interpreted as optimism and a willingness to keep trying new things, which ultimately probably helped the design and development process. Parental expressions of genuine curiosity regarding what their daughter would be able to do also helped to move the process forward.

The parent-researcher played a role.
Having a parent-researcher on the project likely affected its outcome. At the very least, it influenced the topics that were discussed at the meetings. It may have also affected access to the population, and it perhaps went even deeper. Parents may have had more confidence in that researcher's ability to deliver useful assistive technology knowing that the researcher has a personal connection to the community and perhaps a personal interest in a successful outcome. But it is hard to measure the extent of all of this, and it seems possible that a well-trained service provider experienced in working with such populations could also have gone a long way to connecting with the family.

CONCLUSION

The project expands participatory design techniques to include people with severe cognitive impairments in the design and evaluation of media systems that can be used by women with Rett syndrome. Because our target users could not contribute directly, we elicited their input through extensive in-home operant-conditioning-like training and evaluation sessions—not typical activities in a participatory design process, but widely used in special education and perhaps necessary for including such populations in design. The collaboration identified a class of media-playing devices that would likely be useful to this population and perhaps as well to other people with similar cognitive impairment, motor ability, and interest in music or video. Future work will include building a software and hardware framework that could in turn be used to build the class of media systems defined here, thus helping to address the "universe of one" problem for this population.

ACKNOWLEDGMENTS

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