Journal of Usability Studies
Vol. 13, Issue 2, February 2018 pp. 73–93

Co-Design Process of a Smart Phone App to Help People With Down Syndrome Manage Their Nutritional Habits

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Abstract

People with Down syndrome (DS) often have trouble making healthy food choices. This article describes the user-centered design process of developing a smart phone app that could potentially help people with DS make better nutritional decisions when dining out at a restaurant. This work builds on multiple areas of HCI expertise, including user-centered design, interface accessibility for people with DS, and persuasive computing, as well as areas of medical and psychological expertise including nutrition. Two focus groups and three design workshops were held in 2016, involving 10 adults with DS and their caregivers. Based on the data collected, as well as feedback from a multi-disciplinary team of computer scientists, medical doctors, geneticists, neuropsychologists, and dietitians, a conceptual design was created that detailed key features and areas of concern. Implications for user-centered design, interface designers, and dietitians are presented in this article as well.

Keywords

Down syndrome; accessibility; user-centered design; co-design; persuasive computing; nutrition; participatory design; cognitive impairment, app user interface

Introduction

The model of development and educational growth for people with Down syndrome (DS) has changed in the past 4 decades. In the 1960s and 1970s, adults with DS were often isolated in institutional settings. Due to intensive speech and language therapy, occupational therapy, physical therapy, and inclusive education, people with DS are living more independent lives in the general community. Individuals with DS are employed in a wide variety of jobs, including jobs with a primary focus on using information technology. However, these individuals, as adults, often have trouble making healthy food choices.

A majority of the 200,000 patients with DS in the United States are overweight or obese, more so than neurotypical patients (Cronk et al. 1988; De, Small, & Baur, 2008; Rubin, Rimmer, Chicoine, Braddock, & McGuire, 1998) and patients with other intellectual disabilities (Bell & Bhate, 1992). This is due to a variety of reasons. First, understanding whether a food is healthy requires considering multiple variables—nutrient content, calorie information, portion size, timing of the meal or snack, and so on. This is a lot of information for someone with DS to process before making an estimation of the food's healthfulness. Additionally, understanding each of those variables oftentimes requires math, reading, and reasoning skills that might be above the abilities of someone with an intellectual disability. Yet living in community settings, adults with DS frequently make their own food choices, often without the detailed nutritional knowledge needed to determine which choices are healthy ones and which ones are not. This conundrum formed the basis for this case study. Many smart phone apps that relate to nutrition and exercise already exist. Why couldn't a smart phone app be developed to assist adults with DS in making healthier eating choices? We received an institutional grant from Massachusetts General Hospital (MGH) to explore this question.

To develop a smart phone app to change nutritional decision-making for adults with DS would require a deep understanding of multiple fields of study as well as a full participatory approach involving people with DS throughout the development process. There is no previously published research on user-centered design methods for the development of persuasive computing for people with DS. This case study reports on the methodological aspects of co-design involving people with DS and the conceptual design of a smart phone application to persuade people with DS to make healthier nutritional choices when dining out at restaurants. In this case study, we describe the conceptual design of an app based upon multiple user-centered focus groups and design workshops. Before the app can be fully developed, additional funding will be needed to design and develop the software and for usability testing.

Background Literature

Many of the concepts presented in this case study have been utilized during practice in isolation (e.g., participatory design, persuasive computing), but as far as we know, this is the first time that a participatory design method has been utilized to develop persuasive computing applications for people with DS. This work is informed by research literature on three different topics: user-centered design methods, interface accessibility for people with DS, and persuasive computing for nutrition.

Interface Accessibility for People With Down Syndrome

There is a rich body of literature on interface accessibility for people with disabilities; however, much of that research literature focuses on people who are blind or low vision, deaf or hard of hearing, or people with motor impairments. There is less research specifically on the area of interface design for people with cognitive/intellectual disabilities (the label changes depending on which communities you are working in). Sometimes, researchers group people with DS into the broader category of "people with cognitive impairments," which does not address the specific strengths and weakness of people with DS (Dawe, 2006; Hoque, 2008). For example, people with autism spectrum disorder and those with neurologically based impairments have previously been included in the same research studies as people with DS without differentiation; however, people with DS have strengths in visual learning and deficits in some areas of cognition. As such, it is important to look at their interaction with technology separately from people with other cognitive impairments.

DS is a chromosomal condition that is caused by the presence of extra genetic material from chromosome 21, and people with DS tend to have mild, moderate, or severe intellectual difficulties. Only a small number of people with DS have profound cognitive disabilities; however, the population is often stereotyped as having no ability to interact with technology, which is simply not true. While there is limited research relating to computer usage by people with DS, some findings are informative. For instance, one study found that most children with DS are already using computers at an early age (80% are using computers by age 6), but as they get older, they tend to have trouble with keyboarding skills and passwords (Feng, Lazar, Kumin, & Ozok, 2008). Lazar, Kumin, and Feng (2011) focused on 10 expert adult computer users with DS to learn more about how someone with DS becomes an expert user and found that the expert users had formal computer training classes and that resulted in better keyboarding skills (i.e., multiple finger typing on both hands). Two important findings were that adult expert users were very successful at solving visual CAPTCHAs, and none of the expert users in the study used any type of assistive technology or modification (Lazar, Kumin, & Feng, 2011).

A study of adults with DS focusing on iPad usage found that, despite the findings from the medical literature on often limited fine motor skills, adults with DS were very successful with using multi-touch tablet devices, but passwords were challenging as were unfamiliar icons. Built-in universal design approaches (such as auto-suggest and search boxes) were very helpful, and, on the iPad, some users did have challenges typing using the on-screen keyboard (Kumin, Lazar, Feng, Wentz, & Ekedebe, 2012). Because passwords were noted to be challenging, a further investigation of password study found that people with DS did, on average, take longer to create their passwords and login as compared to neurotypical users, but the strength of the passwords were the same between the two populations (Ma, Feng, Kumin, & Lazar, 2013). Currently, there have been no published studies about smart phone usage by people with DS.

User-Centered Design Methods

There is a long tradition of research on user-centered design methods, including techniques for involving users in some stages of design or in all stages of design as design partners, for instance, with children (Druin, 2002) and older adults (Ellis & Kurniawan, 2000). There is limited research on the involvement of people with cognitive impairments within software development lifecycles. For instance, Dawe (2007) described how she involved people with cognitive impairments in a design utilizing interviews and then placing technology probes (a sample technology) in the homes of two families so they could easily provide feedback.

There is only one previously documented effort that we know of that involved people with DS within the design process (Kirijian, Myers, & Charland, 2007). The Web Fun Central project had the goal of developing online tools to help people with DS learn the basic skills required to use the Internet and had received funding from the National Down Syndrome Society and Ericsson, Inc. The project involved six young adults (aged 16 to 23) with DS as a direct part of the design team. Since the research literature in the previous section had not yet taken place when Web Fun Central was being built (the co-design project took part in 2001 and 2002), a series of test modules were developed to gauge the interface preferences of people with DS, including colors, fonts, and illustrations. Some of the tasks also involved determining the ability to complete tasks, such as pointing, clicking, choosing, dragging and dropping, and using deductive logic (Kirijian et al., 2007). The adults with DS were also observed while web surfing to note the challenges that they faced, which would feedback into developing the training modules that were needed most (such as typing in Web addresses, dealing with plug-ins and pull-down menus, and creating basic web pages using what are now called content management systems).

Persuasive Computing for Nutrition

There is a growing body of research literature at the intersection of the topics of persuasive computing and nutrition. For instance, Chi et al. described the use of a smart kitchen to monitor nutrition and calories of ingredients and portion size (Chi, Chen, Chu, & Chen, 2007). Similarly, Kim, Park, and Lee described a "smart tray" concept that would automatically weigh food portions and determine eating speed to make suggestions to assist people with metabolic syndrome (2016). Bedi et al. described the use of interactive devices built into supermarket store shelves that allows for comparing different items and re-calculating figures for different serving sizes (Bedi, Diaz-Ruvalcaba, Foley-Fisher, Kamal, & Tsao, 2010). Comber et al. focused

on monitoring nutrient intake for older users and others at risk for malnutrition, such as those in hospitals or care homes (2012). Iizuka et al. focused on building a database to allow people with allergies, religious restrictions, or other health-related restrictions (e.g., diabetes or a low-salt diet) to plan out their meals (Iizuka, Okawada, Matsuyama, Kurihashi, & Iizuka, 2012).

The study that most closely relates to the current project is from Johnson et al., who described the development of a mobile app prototype to help users make healthier food choices in fast-food restaurants. The app, developed with nutritionists, makes use of the Traffic Light Diet categories (red, yellow, green) to organize restaurant menus. Users accessing the app would be able to easily see the "green" foods presented preferentially, thus making it easier for them to make better food choices at-a-glance (Johnson et al. 2014). The concept of using a traffic light to describe nutritional choices has been around for a longer time and has been encouraged by legal requirements for more transparency in nutritional information (Fairhurst, 2012).

Co-design Involving People With Down Syndrome

As discussed in the literature review, there is only one previously documented project where people with DS were involved with the design process. In the current project, our goal is to create a mobile application called *MANGO*, which stands for "Meeting A Nutrition Goal when Out." MANGO will incorporate language, design, and behavioral strategies informed by our study participants and consultants that would allow people with DS to set and track personal nutrition goals and provide a learning environment appropriate for their intellectual level.

The development approach used was a participatory design approach, where people with DS, the potential users of the app, take part in all phases of design. Such an approach was needed because the tasks and potential usage are complex and not well understood. Creating a mobile app to influence the nutritional choices of adults with DS is a complex task, far more complex than the project mentioned in the previous literature review about teaching Internet skills. This project would not only need to focus on choosing appropriate interface design but also understanding the many factors that encourage healthy food choices. Influencing food choices is complex because food choices are shaped by our cultural, religious, social, and financial backgrounds. The inherent diversity in people makes it difficult to make population-wide requirements. Generally, the goal is to define a smaller population, look at the available evidence for that population, conduct a needs assessment with key stakeholders, and then plan an intervention. It is essential to do this in the DS community because people with DS access and choose food differently than in the general population. This is because there is a broader range of people providing support on a daily basis who could influence food choices. There is also potential for a lower number of food access points, and there is a higher prevalence of health conditions that impact food choices. There are other factors within the DS community that affect the development of our mobile application such as a range of communication challenges, lower intellectual abilities (although a different set of learning strengths can be leveraged), and a tendency to prefer routine over new food experiences. So, a novel tool is needed to meet the unique needs of the DS community.

The idea for this project didn't arise from the users themselves, as might be considered ideal in strict user-centered design approaches. Instead, the initial ideas came from the various medical professionals who work closely with the population and saw an important need for an app that could improve health outcomes. However, once the project idea was in place, the participatory design process allowed users to drive the development of conceptual design and features. For readers interested in learning more about the theories behind and differences between user-centered design and participatory design, we suggest consulting George's "A Case Study of Balance and Integration in Worth-Focused Research Through Design" (2016).

Participants

Because Massachusetts General Hospital has one of the nation's largest clinical programs designed specifically for people with DS, participants (and their families) were recruited directly from the population of patients in the clinic. One adult with DS, who works at the MGH Down Syndrome clinic, served as the "Captain of Team MANGO" and helped inform the entire process.

All English-speaking patients with DS, ages 13–35, who have some familiarity with computer devices, were eligible to participate. Participants were required to have a first-grade level performance, or better, on the WRAT-IV Math Computation, WIAT-III Numerical Operations, or

any other cognitive battery (e.g., Key Math, Woodcock Johnson, TEMA) that has a math sub-score. This age group was selected to ensure participants share a similar range of intellectual abilities and design preferences as the target user population for the app. However, we expect the application to appeal to an even broader range of ages and math skills. Math skills are important in nutrition because lots of the nutrition information used to determine the healthfulness of a food (e.g., grams of carbohydrates, protein, and fat; percentage daily values; serving size; servings per container) are presented numerically. A first-grade math level was chosen for our project because that is the level where "more" and "less" concepts are mastered. Understanding this concept is necessary for even the most simplified nutrition programs or apps. Institutional Review Board approval (2015P001973) was obtained from Massachusetts General Hospital, and participants were recruited by phone.

A total of 10 adults with DS and their caregivers participated in the focus groups and design workshops for MANGO. Aside from the MANGO Team Captain (who is male), there were 5 female participants and 4 male participants. Scores on the WIAT-III, Numerical Operations, ranged from 1:2 to 2:7; and scores on the WIAT-IV Math Computation ranged from 1:0 to 3:7. In these scores, the first number represents that grade number, and the second number represents the month of that school year. For example, participant 1A had mastered the math skills taught in the first 2 months of first grade. The average age of Team MANGO members was 21.5 years and ranged from 18–30 years old. Adults with DS are also known as "self-advocates"; we use this term in this paper.

Caregivers were also central to the design. There are many advantages to caregiver involvement: (a) research on individuals with DS show improved weight loss outcomes with caregiver involvement, (b) caregivers can help ensure honest reporting by participants, and (c) caregivers can help further personalize the application to make it even more usable for participants. Furthermore, pairing up caregivers and individuals with cognitive impairments is considered to be a good design practice (Lazar, Feng, & Hochheiser, 2017).

Design Methodology

Two focus groups were held with patients and their primary caregiver(s) in April 2016 to better understand the needs of the DS community. Each focus group lasted three hours and included 4–6 Team MANGO participants and their caregivers. During the focus groups, the MGH group (the researchers/developers) asked questions about if and how nutrition and exercise fit into the self-advocates' lives, what nutrition and exercise goals they would like to achieve, which apps and devices (e.g., pedometers) they already use (if any), and the specific barriers that patients with DS and their caregivers face that directly or indirectly influence their food and activity choices. Additionally, we explored what strategies caregivers have successfully employed (e.g., rewards) to guide individuals with DS toward making healthier choices and elucidate meaningful outcomes for patients and families as well as how they define "success." MGH staff members facilitated the focus groups. Notes were taken during each focus group, and participant responses were noted by their study ID. The sessions were also audio-recorded.

After conducting our two focus groups, we then conducted three cycles of design workshops in May-July 2016. Each design workshop lasted three hours and included 2–3 Team MANGO members and their caregivers. Storyboarding was central to our design workshop methodology. This technique was used to get a sense of the tasks and scenarios that our app will support. Storyboards are much like a comic strip showing what is happening at key points in time, offering a visual representation of flow. In just a few panels, you can convey what the user interface will help a person accomplish. We chose to begin with storyboarding for several reasons: (a) It allowed us to focus on the tasks that the interface will support rather than a particular user interface itself (e.g., buttons), (b) we believed that visually communicating ideas would be much more accessible to our participants with DS (Kumin et al. 2012), and (c) it has proven utility in the design process by helping to get all the stakeholders on the same page in terms of the goal (Kirijian et al., 2007; Snyder, 2003).

The project also included nutrition-related exercises to better understand how individuals with DS make food choices. During the focus groups, researchers went to the nearby Whole Foods Market with participants to better understand the ways that snacking choices are made. Although healthy choices were suggested during these trips, they were not purchased in the majority of cases, most often because a usual snack had already been chosen or a more

desirable, unhealthy choice was spotted at the grocery store. During the design workshops, healthy snacks were instead pre-purchased, and all participants chose one of the dietitian-approved snacks. These exercises demonstrate that people with DS will accept the healthy choices, perhaps, in the absence or limited availability of unhealthy options.

Each design workshop included a 30-minute warm-up period during which our "storyboard facilitator" drew avatars of the self-advocates in real-time as each expressed his or her interests, favorite hobbies, and personal preferences (see Figure 1). This extended and highly visual warm-up period was believed to be essential to help the self-advocates learn about one another using a visual medium with which they are comfortable, as well as to help them get comfortable with the story-boarding process throughout which their verbal comments would be translated into visual representations.

Figure 1. The avatars of the self-advocates drawn by the storyboard facilitator.

Results of Focus Groups

The two focus groups showed that a lot of individual variation exists among individuals with DS in regards to motivators, nutrition and exercise goals, and past knowledge of and experience with nutrition and exercise. However, there were some common themes that shaped app development.

The focus groups affirmed our belief that individuals with DS have strengths in routine and technology. There was a certain excitement when talking about apps, and all families reported that their sons and daughters with DS spent more than 2 hours a day on smart devices. Both auditory and visual components of these apps were appealing to self-advocates. Movies and apps with cartoon characters were generally well-received. "Angry Birds" was one of the favorites. Families provided a list of apps that their loved ones with DS currently use for our designers to review. We had individuals bring their devices to the focus groups to see them use the apps in person.

Caregivers shared that healthy food and exercise choices are common goals of people with DS; self-advocates were more divided on this front. Regardless of the self-advocates' own interest in nutrition and exercise, however, all of our caregivers explained that they are topics discussed daily, requiring frequent reminders and reinforcement. The healthfulness of snacks, portion control, and choices while eating out were the biggest areas in need of improvement shared by participants. Flavor preferences and existing, unhealthy routines were some of the biggest barriers to making healthy choices that were reported. As a design team, we considered both of these facts when considering what behavior change could actually be supported by an app. We decided that portion control, though important and relevant, would be more difficult to target with an app. Similarly, self-advocates reported variable interest in and aptitude for exercise, and caregivers did not report success with personal tracking devices, such as pedometers. As such, we decided to de-prioritize the exercise component of the app.

Independence was a common theme discussed. Families wanted a tool that would help loved ones with DS make independent decisions when caregivers are not there to provide real time support and guidance. Independence was also a big motivator identified by individuals with DS. Families did acknowledge that loved ones with DS have role models who could be leveraged to

guide behavior change. If the right individual were chosen, that individual would not be seen as a threat to independence. The specific role model varied from people within their personal network (e.g., siblings, friends), including professionals who provided care (e.g., support workers, dietitians, and doctors), to individuals in the public domain (e.g., movie or sports celebrities). In the majority of situations, parents did not view themselves, nor did the self-advocates cite their parents, as role models. Both parents and self-advocates believed that too much parent involvement would result in less motivation to use the app. This challenged our team to explore ways we could keep users interested and engaged in the app without a parent promoting app usage or more likely, while enlisting caregiver help in ways that both self-advocates and caregivers found acceptable. Although parents viewed their potential heavy involvement with the app to not be helpful in changing nutritional behavior, in terms of the design process, parents served as important informants to the design as they were often very familiar with the types of nutrition concerns facing individuals with DS. As such, the design team decided to plan for parent or caregiver involvement at the set-up with less involvement from them with the individual's continued use of the app. When explored at future visits, caregivers shared that invisible monitoring could be effective.

In regards to motivators, positive reinforcement was strongly preferred to negative reinforcement. Caregivers and self-advocates said that direct competition with a peer, an oft-used strategy to promote usage of mobile apps promoting behavior change in the general population, would likely backfire in this population. Some families reported excitement about tokens and trophies, particularly if the trophies or reward was based on something real. Verbal praise was noted to be an effective motivator among nearly everyone in the group, especially if delivered from a respected figure or role model which could vary widely depending on the self-advocate's particular interests and hobbies.

We also assessed baseline nutrition knowledge during the focus groups and found that health-related literacy should be a big consideration for app development. The majority of self-advocates could list healthy foods or unhealthy foods, but struggled when probed why a food was healthy or not. It was harder to decide if a meal comprising multiple different foods was healthier than an individual food item. This was affirmed when we sought some more concrete evidence of self-advocates' knowledge of nutrition in our second focus group. We showed the participants with DS different meals and asked them to say if they were healthy or not. Answers did not line up with our expert dietitian's answers. This dissuaded us from including user- or peer-assessment of meals to drive feedback or rewards.

Overall, the focus groups affirmed what our team of experts suspected about the nutritional understanding and goals of individuals with DS. However, speaking to families helped us not only to understand how many families struggle on a daily basis to help their loved ones make healthier choices and identify nutrition topics most important to them, but equally important to more clearly define under what circumstances and how a mobile app could be most effectively utilized.

Results of Design Workshops

The primary goal of Design Workshop 1 was to test two ideas that were born from self-advocates' and caregivers' feedback during the focus groups. The first idea focused on helping self-advocates make healthy choices in an unstructured, sometimes unsupervised, environment—a restaurant. To better understand the experience of someone with DS eating at a restaurant, we had one of the self-advocates explain what happens when they go to a restaurant while one of the MGH team members storyboarded. Other Team MANGO participants were invited to add their own experiences as Drew (our story boarder) narrated. We then did the same activity with our second idea, which was helping self-advocates get into a healthy snack routine while in a more predictable setting—home. A different self-advocate described the process of picking a snack, and the group added feedback.

After our storyboarding exercise, we started to create a paper prototype. Moving from storyboarding to paper prototypes is considered to be a best practice for development (Snyder, 2003). The paper prototypes allowed us to test interaction flow of the application effectively and quickly. The additional benefit of using paper, Post-it notes, and markers was that it was clear

to our participants that nothing in the design had been set in stone, and they could contribute to the design just by picking up a pen.

A member of our team then narrated the two ideas for an app that our interdisciplinary team had brainstormed after the focus groups. While the idea was explained, Drew started to build a large paper prototype on the presentation boards that showed different screens of the app. After reviewing this as a group, each self-advocate/caregiver pair was given Post-it notes and markers. They then went around to the two paper prototypes, adding comments about whether they liked the proposed features and adding ideas of their own. We also gathered feedback about their overall preference for the two ideas.

Of note, both of the proposed apps used the "traffic light" system for describing healthy choices, which is well-documented in the literature as a way to simplify the healthfulness of food choices (Fairhurst, 2012). The healthiest choices are highlighted in green and are the "go" foods that should be chosen daily. The unhealthiest choices are in red and are the "whoa" foods that should be chosen infrequently. Intermediate choices are in yellow and are the "slow" foods that should be chosen "sometimes." Caregivers and self-advocates responded positively to this idea.

Of the two apps employing the "traffic light" system, feedback for the healthy dining concept was more positive in regards to the topic's potential benefit to the DS community and appropriateness for a mobile app. When our team met after Design Workshop 1, we agreed that the app for healthy choices when eating out at a restaurant was the best approach to take. We appreciated that there are some unique barriers for individuals with DS who want to make healthier choices at restaurants, including limited reading ability, feeling overwhelmed by the number of choices on a menu, showing a strong preference for favorite foods—frequently unhealthy ones, and low understanding of which menu choices are healthy. We agreed that an app could be an effective tool to promote independence, self-efficacy, and inclusion in a restaurant setting.

Based on our findings from Design Workshop 1, we set three goals for Design Workshop 2: (a) to see whether the second group of self-advocates and caregivers responded well to the restaurant idea, (b) if so, to go through the storyboarding process again with targeted questions about specific app features (e.g., set-up menu, timing of motivators, range of choices offered, range of restaurants included, etc.), and (c) to better understand motivators and visual preferences of this community. Families responded well to the restaurant idea so we were able to go through our agenda, as planned.

Design Workshop 2 started with a warm-up exercise in which our designer again drew avatar versions of the participating self-advocates. Then, we drew out the concept of dining at a restaurant, again having the self-advocates narrate what that experience is like for them. Participants responded well to the restaurant idea, so we explored more topics related to dining out and learned that self-advocates usually make choices independently at restaurants, though caregivers might help guide their choice if they are present. All self-advocates reported going out with caregivers, but only some reported going out with friends (without caregivers present). Caregivers noted that choices are less likely to be healthy when there is not caregiver supervision.

When we reviewed the concept of the proposed app, in Design Workshop 2, we spent more time exploring each app feature in detail. We focused on possible motivators—some choices discussed included earning stars that could be traded in for a prize and earning virtual clothes for a selected avatar. Self-advocates in Design Workshop 2 were most excited about earning clothes for a personalized avatar. We learned that families go to a combination of chain and local restaurants. For the local restaurants (when nutrition information would not be readily available), we discussed three options: (a) having family members choose red, yellow, or green options themselves; (b) having the family pay a nominal fee for a MANGO dietitian to code red, yellow, or green options for them; or (c) having generic menus available for similar type restaurants (e.g., a generic pizza menu that could be used for a local pizzeria). Families differed in the extent to which they thought they would use options a and b, but all liked the idea of option c. Self-advocates and caregivers were not enthusiastic about making the app a game or offering an option to share progress on social media. We introduced different ideas for the visual design of the app but made limited progress with this in a group setting. We decided to work with individuals one-on-one for some of the more visual features (e.g., avatar, any design

elements to the screen, etc.) in future design stages due to time limitations and the need to finalize the conceptual framework for the app.

We also offered families the choice to add or subtract features from the app. Some families suggested a cap on the number of red or yellow items chosen, an option to "turn off" the dessert or appetizer features, or a feature that limited visible choices to just one or two colors. However, there was not consensus, so we agreed to explore them again in Design Workshop 3. All participants liked the idea of having an option to add an alert bar to the app if someone has a food allergy, is gluten-free, or actually has celiac disease (which is more prevalent in the DS community than in the neurotypical population). The goals of Design Workshop 3 were to (a) revisit any elements of the app's design where there had been a lack of consensus from stakeholders and (b) to prioritize the inclusion of different app features in the first version of the app.

Design Workshop 3, like the previous workshop, started with a warm-up avatar exercise, and then the current design idea was discussed and a new feature was added—a voting exercise. The questions utilized in Design Workshop 3 were more targeted than in past design workshops and concluded with the opportunity for self-advocates and caregivers to identify parts of the app that would be customizable.

One of the big concepts we wanted to investigate in the third design workshop was the way in which the app would motivate behavior change. When asked, families thought the most important motivators were the red, yellow, and green colors as well as the motivational videos. Families suggested that there should be a library of videos that were pre-recorded by people who were important to the self-advocates. They thought the videos would be particularly motivating if the videos were recorded by someone whom the self-advocates respected but did not visit with often, such as a sibling away at college or a family member that lives in another state. Participants in the third design workshop did not think that earning clothes for an avatar would be as motivating as the participants in Design Workshop 2 did, so we decided to hold off on this feature to simplify the app design. As in the previous design workshops, the participants emphasized the importance of constant reinforcement and the need for motivators to pop up at various times during app usage to encourage healthy choices.

We asked about their favorite components of the app. The three pairs (of self-advocates and caregivers) ranked the following components as their favorites.

- Pair 1 chose the red/yellow/green system and videos.
- Pair 2 chose the red/yellow/green system and pre-selecting favorite restaurants.
- Pair 3 chose the red/yellow/green system and picking a support network. This group also liked the allergy warning bar. They were also very supportive of including a paying option in the app to support more independence.

Unlike in Design Workshop 2, the participants were adamant that they did not want to restrict which colored choices were available to their loved ones, as they thought this would be overbearing and would discourage app use.

Lastly, we asked caregivers how involved they would like to be in the app set-up. Caregivers said they were willing to select favorite restaurants and favorite menu items at these places. They again acknowledged that they would need to work closely with self-advocates in the first month of app use, but then they would move towards encouraging self-advocates to use it more independently.

Development of Conceptual Design and Scenarios

The overall goal of the project is to have a better understanding of the needs of people with DS when it comes to nutritional decision making and the conceptual design of a smart phone application to persuade people with DS to make healthier nutritional choices. Because a participatory design approach was used, the individuals with DS (the self-advocates) and their caregivers helped define the conceptual design for the mobile application. It is not possible to strictly separate out which design ideas originated with the users and which ideas originated with the developers due to the nature of this application. This is a persuasive computing application, not designed strictly based on the stated preferences and wants of the users, but

rather an application designed to change the behaviors of the users. Given that reality, it is likely that more of the overall task goals originate with the developers and medical personnel, and more of the design preferences originate with the users.

Goals of the App. Most importantly, we hope that the app will change the food and drink choices that individuals with DS make when dining out at a restaurant or convenience store. Additionally, we hope that our app will promote independence, educate (in a way that is appropriate for the unique learning needs of someone with DS), and support skill building with healthy habits. We want the app to be motivating and fun so that the individual with DS enjoys using the app and gets into the routine of using it every time they eat out.

Educational Accessibility of the App. We are proposing an app that is very visual in nature, which works towards the visual learning strengths seen in most individuals with DS. We plan to utilize the traffic light system that labels foods red, yellow, or green to show the healthfulness of these choices. This simplified model will help the users with intellectual disabilities navigate a situation—dining out—that is already complicated for peers without a disability in our increasingly obese world. Numeracy can be difficult for individuals with DS. So, the app will prompt users to choose from no more than nine different choices for each part of the meal (meaning no more than 9 choices per screen); this is a framework suggested by an expert neuropsychologist who served as a consultant on the project. Lastly, the app will help individuals establish a new routine. The importance of routine for individuals with DS is well documented in the literature and was a common theme during our focus groups with caregivers. Our app will use a logical sequence for making food choices at a restaurant that mirrors the real-life scenario of dining out. We will also use motivators and caregivers to keep individuals with DS engaged in the app. With consistent use, we hope that it will gradually become a new routine.

Interface Usability of the App. The app will be developed using the existing best practices for interface design for people with DS. In general, when most people hear that an application is being designed for someone with a disability, they immediately think of the Web Content Accessibility Guidelines (WCAG), an international standard for making websites and other applications accessible. However, at this point, the WCAG primarily addresses the needs of people with perceptual and motor disabilities. Currently, there is a working group at the Web Accessibility Initiative, called the Cognitive and Learning Disabilities Accessibility Task Force, that is working to develop interface guidelines for people with cognitive impairment, which will potentially be integrated in the future into the WCAG. Since design for DS is not yet a part of the international technical standard, the best practices for interface design for people with DS are based on the research literature and include limiting the number of choices (as described earlier), limiting the use of pull-down menus, minimizing password requirements, making use of familiar icons, making sure that design features are built to be appropriate to the chronological age (i.e., don't use childish design), and designing towards the visual strengths of people with DS.

Primary Caregiver Involvement. We expect that the primary caregivers will be involved when a self-advocate begins using the app. This is necessary to overcome the learning curve that comes with a new piece of technology and to help the self-advocate get into a routine of using the app. In time, we hope self-advocates will be able to use the app independently.

Support Team. Self-advocates will have the opportunity to pick individuals to join their team. Self-advocates can invite whomever they would like, perhaps a family member, friend, healthcare provider, job coach, support staff member, or other respected figure. The primary caregivers might not need to be included on the team, depending on support networks in place and any tension at home surrounding healthy eating. Teammates will be invited to join by e-mail. Individuals who accept the invitation will cheer them on and support them with making healthy choices. The primary mechanism of encouragement will be through scripted videos, detailed below, which will be available through the app. These videos will be recorded when an individual first accepts the invitation to join a self-advocate's team.

Food Establishments Included. For the first version of the app, we will only include food and drinks from chain restaurants and convenience stores. This is because the nutritional information of these items is more readily available to consumers, and we will need this information to code foods as red, yellow, or green.

Illustrative Scenario

Based on the focus groups and design workshops, an illustrative scenario was created, targeted specifically toward adults with DS (rather than developers). Scenarios are useful in development as they allow potential users to understand the potential benefits of an application, as well as what the usage pattern might look like (Rosson & Carroll, 2002). Our full scenario, itself, is very detailed and is 4 pages long. A representative portion of the scenario is as follows:

It's Friday afternoon, and you cannot wait for the weekend to come. The only things standing between you and your Friday night are a morning at your day program and then an afternoon at your job site. Afterwards, it's dinner with your buddies! Tonight, you are meeting up with Chris and Jonah. Like you, they have Down syndrome.

You tell your job coach, Ben, about your plans for the weekend, and he tells you about a cool new app called MANGO that you can download on your phone for when you go out to eat. He kindly reminds you that you've been trying to make healthier choices, and that this app could really help you find the healthier choices at restaurants, learn more about nutrition, and help keep you motivated. Plus, it will be fun and will not take away from the independence that he knows you love and are proud of!

You think it sounds like a good idea. So, you and Ben decide to download the app on your phone and create a profile. You type in your e-mail, create a password, input your name, and specify your gender. The app then asks you if you have any food allergies. Fortunately, you do not. It's good that that feature is there though; your friends, Chris and Jonah, both have celiac disease. Next, the app shows you a set of cartoon characters that you can choose from. You find one that has spiked brown hair and glasses like you, so you choose that one!

Description of Key App Features

Setup Wizard. The setup wizard will walk the user through the basic steps of creating an account and personalizing key MANGO features. It includes a short video that introduces the app to users and explains the "traffic light" system that will be used. Steps in the Setup Wizard include choosing your MANGO portrait, inviting people from your support network to join your team, specifying any food allergies, adding a reward (if desired), choosing favorite restaurants, picking favorite options for each course and for each restaurant, and adding payment information (if desired). These are the most basic features we think users need to successfully use the app. Other features can be personalized using the Settings menu.

Diet Restriction Feature. We have included an option to identify diet limitations for individuals who have a medical need to avoid certain food items. This option is especially important for the DS population, which has a higher prevalence of celiac disease. It is also important because individuals with DS might have difficulty communicating their diet restrictions, putting them at medical risk. The app will help with this by adding a warning label to the top of the screen that a waiter or waitress would see if a self-advocate showed them their order on their phone. The waiter or waitress could then warn them if they were ordering a menu item that was inappropriate for their diet restrictions (see Figure 2).

Figure 2. A scene showing how an individual with DS might show a waiter or waitress what they want to order or any food allergies that they might have.

MANGO Portrait. This will be an avatar created during setup. The goal is to make participating self-advocates feel like they are a part of the app. App users will be able to choose from a library of pre-created avatars. The app designers will give the avatars the typical faces of someone with DS to strengthen the self-identification.

Rewards Feature. For individuals with DS, routine is incredibly important. If someone has a healthy routine, they will likely stay in that routine. If they have an unhealthy routine, it can be difficult to change it. In our focus groups, parents noted that it is easiest to change a routine if there is a motivating reward. Because this reward varies by person, we will offer MANGO users an opportunity to input their personalized reward, add a picture of it, and specify, together with their caregiver, what level of behavior change is needed to earn the reward. The app will keep track of progress towards this goal. Self-advocates or caregivers can track goal progress at any time by accessing the app Settings.

The app will also remind the user of the reward. Teammates will record a video reminding the self-advocate of their reward and the app will send this message after the user makes a healthy choice (to encourage them to keep going) or an unhealthy choice (to encourage behavior change). This will keep the reward present in their minds and strengthen the association between a change in behavior (oftentimes perceived as negative) and a reward (perceived as positive).

Payment Option. In our focus groups, we learned that paying is a considerable obstacle to independence at restaurants for individuals with DS. Limited numeracy, reliance on social scripts, and limited support (if dining with peers with DS) can make eating out a challenge. As such, families were very positive about including a pay option in the app as an optional feature. Those who choose to use it would be able to enter securely their credit card information (see the section below on security). When it comes time to pay, self-advocates will simply hand their phone to the waiter and waitress to pay. In addition to offering a secure payment option, families noted that the ability for the app to "compute" an appropriate tip when needed would be a significantly valuable addition.

Video Library. When a loved one accepts an invitation to be a teammate, they will be asked to record a series of videos. Some of the videos will be scripted videos. For example, all teammates will record a video saying: "Oh no! You chose a red food! Red foods are okay sometimes, but it's better to pick a yellow or green choice because they are healthier. You should think about switching to a yellow or green choice." There will be a variety of videos for different scenarios (e.g., choosing a green food, yellow food, or red food) that might happen in the app. When one of those situations happens, the app will pick the video coded for that scenario to provide real-time feedback to the self-advocate using the app. Other videos will be customizable. Teammates can record a video specific to a self-advocate's reward. They can also record other videos as long as they code them for scenarios where the self-advocate has made a healthy or unhealthy choice.

Progress Bar. The home screen entitled "My Progress" shows a bar graph with the number of red, yellow, and green choices made. This is a way for primary caregivers or teammates to

review progress with a self-advocate in a visual, accessible way. The user can specify the time frame, whether it is on a daily, weekly, monthly, or yearly basis.

Settings Menu. We respect that all individuals with DS are different and might need different types of support to change behavior. As such, we have included opportunities for personalization in the app. Certain settings can be turned on or off. Users can turn off a specific color (for example, you can turn off red so the least healthy choices do not appear as options when making menu choices) or a part of the meal (for example, you can turn off appetizers or desserts if you do not order these at a restaurant). Colors and parts of the meal can be turned off for all restaurants or for just one restaurant.

Nutrition Tips. To promote education and skill building, nutrition tips will be included in the app. For example, if an individual chooses burger and fries, a message will pop up saying: "You chose a main meal with fries. To make it healthier, you could ask for 'light on the fries.'" In another situation, an individual might choose a red food and a screen would pop up that says, "Red choices are the least healthy choices." The goal of these tips is to promote skill building for when a user wants to enjoy a favorite choice that is less nutritious.

Interaction with Social Media. When a user makes all green choices, they will be given the option to share their accomplishment on Facebook. If they choose to share, the MANGO app will generate a post with the user's MANGO Profile character and a message that says: "I made healthy choices using my MANGO app!" This is another way to leverage the user's support network to provide positive reinforcement for healthy choices.

Security. Between having personal health data and having credit card data to help pay for a meal, the potential app would certainly need to have security features. Based on the existing research, we already know that passwords can be problematic for users with DS, and therefore, the best way to handle this in design might be to incorporate Touch ID security or to utilize an existing Facebook or Gmail login if possible. We acknowledge that not all users will have one of those, and therefore a feature to create a password for using the MANGO app would certainly need to be an option. In terms of the logistics of actually paying, existing options such as Apple pay, Android Pay, and Level-up will be investigated to see if they can be integrated with the application.

Wireframes

The first set of wireframes (Figure 3) shows the home screens for a scenario of an adult with DS named John, including "My Restaurants," "My Rewards," "My Team," "My Progress," and "My Profile." Figure 4 shows how John can choose the items at Chili's, a common restaurant chain in the USA. Figure 5 shows wireframes for how users of the smart phone app can recruit people (friends and family members) to be on their "team," helping to monitor their food choices.

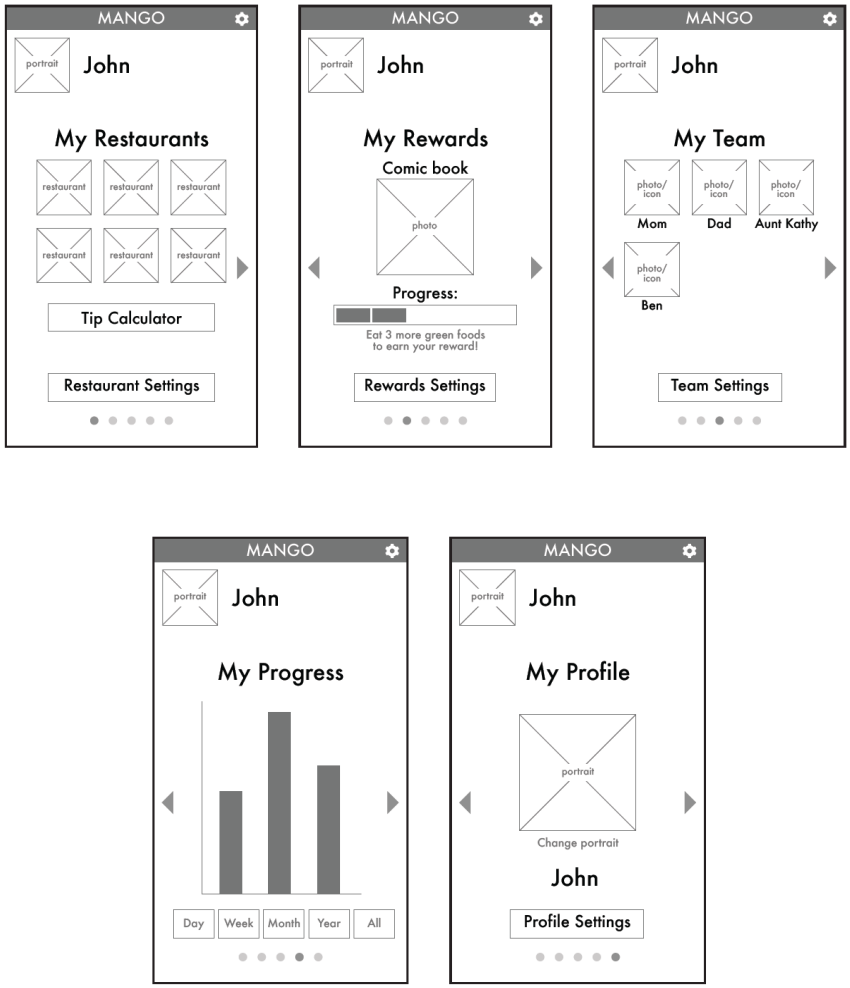

Figure 3. The home screens for a user, including My Restaurants, My Rewards, My Team, My Progress, and My Profile.

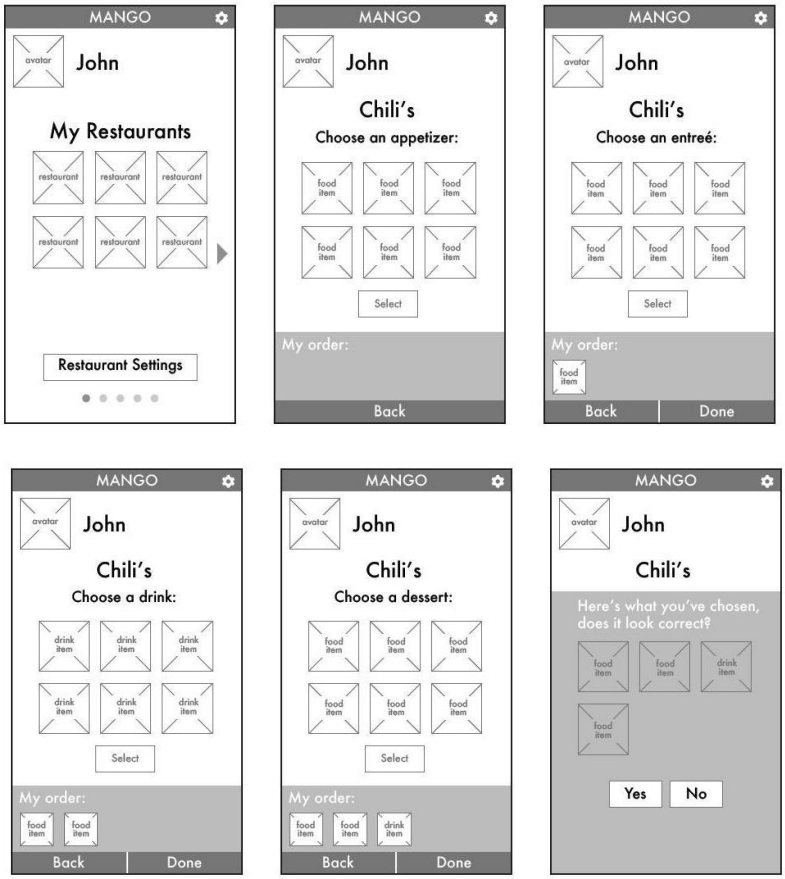

Figure 4. Wireframes showing how users would select food choice options at a common restaurant—Chili's.

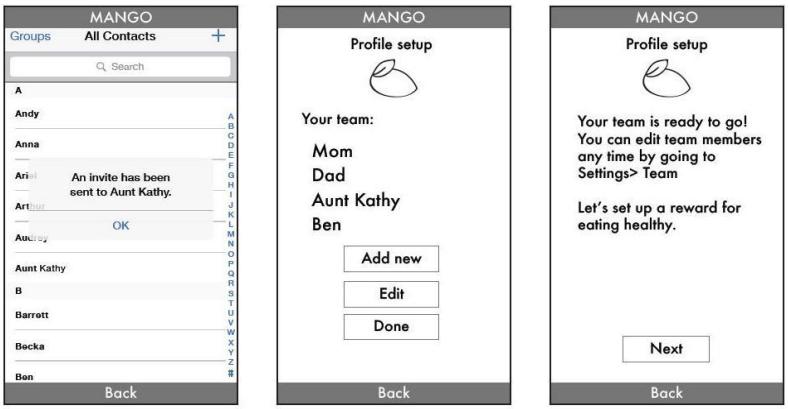

Figure 5. Wireframes showing how users would invite team members who could help monitor their food options.

At this stage, a total of 89 wireframes have been created, covering various aspects of setup and login, home screens, managing your rewards, ordering a meal, calculating a tip, and paying for the meal. From the various wireframes, two illustrated and colored versions have been created to show what the final appearance might look like (see Figure 6).

Figure 6. Two illustrated examples of what final screens might look like.

Conclusion

At this point, the conceptual design for the MANGO application is complete, and the current action is to seek funding to turn this conceptual design into an actual software application. Due to the complex nature of the application, iterative usability testing would be critical throughout the development process before a product launch. The combination of factors (persuasive application, changing eating habits, people with DS navigating health data and financial information) make this a fascinating yet challenging application to complete. In the following sections we have summarized our implications as they relate to user-centered design, designers, and nutritionists.

Implications for User-Centered Design

This project documents how user-centered design (UCD) processes can occur for complex projects involving people with DS and potentially persuasive technology. There were some important differences between UCD involving typical users without intellectual disabilities and the participants in the current project. First, for understanding daily routines, decision making, and health choices, it is important to not only involve the users themselves but also their parents and caregivers who interact with them on a daily basis. While users with some intellectual disabilities may be able to explain their daily schedules, they may not be able to explain the motivations behind their choices (e.g., whether out of habit, ease, or peer pressure). Second, unlike in typical UCD, it was important in this project to understand and document the math skills of participants because they are necessary in both making nutritional choices and in paying for meals at restaurants. Third, in the design workshops, extra time was needed to get the participants comfortable with the surroundings and interactions. The avatars of the self-advocates (see Figure 1) drawn by the storyboard facilitator were a new approach that was very successful in getting the participants comfortable, responsive, and looking at the process as enjoyable. Fourth, because nutritional choices are a key aspect of determining whether this application is successful or not, not only was it important to have a dietitian as a part of the development team, but it was also important to observe the participants with DS in multiple situations involved in making nutritional choices. Finally, due to the documented visual strengths of people with DS, it was important to provide immediate visual feedback in the form of sketches (early wireframes and otherwise) during the design workshops, which helped properly communicate the ideas to the participants. We believe that these approaches will ensure the eventual success of the project.

Implications for Interface Designers

There are a number of potential implications of this project for designers who are aiming to develop applications for people with Down syndrome. First of all, it is important to understand that designing with the Web Content Accessibility Guidelines (WCAG), the international standard for interface design for people with disabilities, will not necessarily make an application any more usable for someone with DS. The needs of people with DS are different and don't generally relate to alternative forms of input or output, as much of the WCAG focuses on. Of the four WCAG concepts (perceivable, operable, understandable, robust), the one that would have an impact on users with DS would be "understandable," ensuring that the content written is easy to understand and appropriate for the average reading level of people with DS. Second, the visual strengths of people with DS have been well-documented over time so it is important to use clear visual cues, such as the stop light system (red-yellow-green) which is easy to comprehend, a metaphor that people with DS understand from daily life, and is also visual. Third, too many menu choices may be overwhelming for users with DS. Typically, in HCI design, it is said that the 7±2 limit applies to recall, not recognition, and therefore, more than 10 menu items (which use recognition) would be acceptable. However, this may not apply to users with DS, where a limited number of menu options might be better. Fourth, due to the challenges that people with DS have with passwords and financial literacy, integration of these aspects with new fingerprint sensing technologies or existing apps (e.g., logins that involve existing Facebook accounts or integration with Apple Pay) may be especially important to ensure that users are not overwhelmed by jumping back and forth between different apps. Fifth, for the population of people with DS, personalization (e.g., using chosen avatars, team members, and specifically, personalization of any rewards [e.g., recorded videos from family members and friends]) may be especially important to ensure continuing interest in and use of the application.

Implications for Dietitians

This project also has implications for dietitians engaging in clinical or research work with individuals with DS. First, it is an addition to a very limited body of evidence on nutrition for individuals with Down syndrome. No other study has taken the time to thoroughly explore and document the ways individuals with Down syndrome make food choices. Future dietitians and researchers can learn from the qualitative strategies employed to better understand the nutrition motivators, behaviors, and attitudes of individuals with DS. Second, this work can help shape research practices when individuals with DS are included. The importance of creating a warm, welcoming atmosphere should not be down-played as it was integral to obtaining rich data in our study. Parents and self-advocates were both very honest that nutrition is a topic that is frequently discussed at home, and sometimes a point of conflict. Third, the study highlights the importance of varying research environments and approaches when evaluating nutrition variables for individuals with DS. The design of the focus groups and design workshops was very deliberate. Focus groups and design workshops included time with self-advocates and caregivers together and apart. Time together allowed shared responses and observations on how self-advocates and their caregivers interact when talking about nutrition. Time with self-advocates without their caregivers allowed more objective measures of nutrition behaviors (such as the trips to Whole Foods) and nutrition knowledge (such as the nutrition quiz). Fourth, the research highlighted the importance of good questions and follow-up questions about nutrition that are appropriate for individuals with Down syndrome. There is a lot of variation in attitudes, behaviors, and knowledge of nutrition. When combined with the diversity in the personalities, support networks, living situations, and intellectual strengths and weaknesses of people with Down syndrome, these variations make it difficult to create a more universal design. A multi-disciplinary team with knowledge of Down syndrome, targeted follow-up questions, and new questions at each stage of design to explore common themes, all helped overcome this challenge.

Tips for Usability Practitioners

The following tips may help usability practitioners conduct similar studies:

- When involving people with Down syndrome in development, it is often useful to not only involve the users themselves but also their parents and caregivers.
- For the development of apps involving nutrition or banking (or in this case study, both), it is important to understand the math skills of participants with DS.
- Don't immediately assume that following the Web Content Accessibility Guidelines (WCAG), the international standard for interface design for people with disabilities, will necessarily make an application any more usable for someone with DS. The needs of people with DS are different and don't generally relate to alternative forms of input or output, as much of the WCAG focuses on.
- The visual strengths of people with DS have been well-documented over time so it is important to use primarily visual cues in both the development process (e.g., the storyboarding), as well as in the actual interface design (e.g., the traffic light system).
- For the population of people with DS, personalization (e.g., using chosen avatars, team members, and specifically, personalization of any rewards [e.g., recorded videos from family members and friends]) may be especially important to ensure continuing interest in and use of applications.

Acknowledgements

We are indebted to the internal funding from Dr. Ronald Kleinman and Dr. Harry Orf at Massachusetts General Hospital. Dr. Kay Seligsohn, a neuropsychologist at Massachusetts General Hospital, provided expert consultation throughout this project. Ben Majewski provided leadership as Captain of Team MANGO. Lastly, we thank all of the participants with Down syndrome.

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