Published in final edited form as:

J Intellect Disabil Res. 2018 October ; 62(10): 821–832. doi:10.1111/jir.12537.

Mobile Technology Use and Skills Among Individuals with Fragile X Syndrome: Implications For Healthcare Decision Making

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Abstract

Background.—Little is known about how individuals with fragile X syndrome (FXS) and their families use technology in daily life and what skills individuals with FXS can perform when using mobile technologies.

Methods.—Using a mixed-methods design, including an online survey of parents *(n* = 198) and a skills assessment of individuals with FXS (*n* = 6), we examined the experiences and abilities of individuals with FXS for engaging with mobile technology.

Results.—Parents reported that individuals with FXS often used technology in their daily lives, with variations based on age of child, sex, autism status, depression, and overall ability. Parents frequently sought and shared FXS-related information online. Assessment data revealed that individuals with FXS demonstrated proficiency in interacting with technology.

Conclusions.—Mobile technology is a tool that can be used in FXS to build skills and increase independence rather than simply for recreational purposes. Implications for using mobile technology to enhance healthcare decision making are discussed.

Keywords

fragile X syndrome; intellectual disability; mobile technology use; healthcare decision making

Introduction

In recent years, the proliferation of mobile technologies has enabled increased access to information and resources, leading some to call them “the great equaliser.” Apple® released the first tablet computer in 2010; adoption of the iPad® and other tablet devices has grown steadily since then. Among parents with minor children living at home, tablet ownership

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The authors have no conflicts of interest to declare.

increased from 26% to 50% from 2012 through 2013 (Zickuhr, 2013). In 2015, the Pew Research Center found that more than 64% of American adults owned a smartphone; of those, 53% also owned a tablet (Smith, Rainie, McGeeney, Keeter, & Duggan, 2015).

Technology Use Among Individuals with Intellectual and Developmental Disabilities

Historically, individuals with intellectual and developmental disabilities (IDD) have used technological devices primarily for motor, communication, or visual impairments. More recently, technology is used more broadly to support functional skill development as well as general computer use. (Den Brok & Sterkenburg, 2015; Lorah, Parnell, Whitby, & Hantula, 2015; Palmer Wehmeyer, Davies, Stock, 2012). Studies examining access to technology by individuals with IDD have found that computers are widely used in school and work environments and in homes (Tanis et al., 2012; Wehmeyer, Shogren, Palmer, Williams-Diehm, Little, & Boulton, 2012). In one survey, however, individuals with IDD reported that they used computers primarily to access the Internet, mainly for communication via email and recreational purposes, such as games (Tanis et al., 2012). Many software programs have been developed specifically for use by individuals with IDD (Douglas, Wojcik, & Thompson, 2012; Siberski et al., 2015). Mobile applications (“apps”) used by individuals with IDD include both apps that were designed specifically for them and those intended for use in the general population (e.g., grocery lists, timers, and organisers; Douglas et al., 2012; Stephenson & Limbrick, 2015).

Using mobile technologies can provide many benefits for individuals with IDD. Technology can promote greater independence by increasing access to information, supporting social interactions, and enhancing endurance or ability to complete tasks that might otherwise be too difficult (Owuor, Larkan, & MacLachlan, 2017). In addition, technology use can enhance an individual’s sense of control, self-determination, and inclusion (Wehmeyer, Tassé, Davies, & Stock, 2012). Improved outcomes also include literacy; vocational, transition, and employment skills; living skills; and communication (Davies, Stock, King, Woodard, & Wehmeyer, 2008; Davies, Stock, & Wehmeyer, 2002; Hetzroni, Rubin, & Konkol, 2002; Lancioni, Van den Hof, Furniss, O’Reilly, & Cunha, 1999; Schlosser & Sigafoos, 2006; Standen & Brown, 2005; Standen, Brown, & Cromby, 2001; Stock, Davies, Davies, & Wehmeyer, 2006; Stock, Davies, Wehmeyer, & Lachapelle, 2011; Tam, Man, Chan, Sze, & Wong, 2005; Wehmeyer, Palmer, Smith, Davies, & Stock, 2008; Wilkinson & Hennig, 2007).

Despite increased Internet and wireless access in recent years, technology use is not as common in individuals with IDD as in the general population (Carey, Friedman, & Bryen, 2005; Morris, Mueller, Jones, & Lippencott, 2014; Tanis et al., 2012). Barriers to technology use can include costs of devices, lack of information or training on the devices, device availability, and inadequate technical support (Bryant, Seok, Ok, & Bryant, 2012; Palmer, Wehmeyer, Davies, & Stock, 2012; Tanis et al., 2012). Another barrier to the use of mobile devices by individuals with IDD is the lack of universal design features (e.g., simplified content and navigation; Tanis et al., 2012; Wehmeyer et al., 2008).

Technology Use in Fragile X Syndrome

Fragile X syndrome (FXS) is the most common known inherited cause of intellectual disability. Males typically have moderate intellectual disability, although impairment can range from mild to severe, whereas females often have milder delays (Hall, Burns, Lightbody, & Reiss, 2008; Loesch, Huggins, & Hagerman, 2004). FXS is associated with a range of co-occurring conditions, including attention problems, anxiety, hyperactivity, and autism (Bailey, Raspa, Olmsted, & Holiday, 2008). Individuals with FXS also have a higher prevalence of certain medical conditions such as seizures, gastrointestinal disturbances, and sleep problems compared with typically developing peers (Kidd et al., 2014).

Few studies have examined technology use in individuals with FXS. Interviews of speech-language pathologists who work with children with FXS reported use of assistive technology devices among children who were nonverbal or minimally verbal (Mirrett, Roberts, & Price, 2003). A pilot study of an electronic reminder system to improve daily living skills in an adult female with FXS showed positive results (Riley, Bodine, Hills, Gane, Sandstrum, & Hagerman, 2001). Another single-subject study design for three boys with FXS showed decreases in hand mouthing using assistive technology (Stasolla, Perilli, Damiani, & Albano, 2017).

Use of Mobile Technology in Health Care

Several recent studies have shown measurable benefits emerging from the adoption and use of mobile technologies in healthcare (Buntin, Burke, Hoaglin, & Blumenthal, 2011; Free et al., 2013). Concurrent advances in health policy, adoption of health information technology by providers (e.g., electronic medical records), and development of health-focused mobile apps have created ideal conditions to enable expansion of tablet-based assistive technologies and interventions. According to the 2015 Mobile Technology Survey from the Healthcare Information and Management Systems Society, 47% of responding organizations said that one of their top priorities was mobile service implementation as a way for patients and caregivers to access information (Healthcare Information and Management Systems Society, 2015).

As of this writing, more than 165,000 mobile health (“ml·lealth”) apps are available for consumer download through Google Play™ and Apple iTunes® stores (IMS Institute for Healthcare Informatics, 2015). Use of electronic tools and services has created new opportunities for individuals to participate actively in monitoring and directing their healthcare; the body of evidence that supports use of such strategies to improve health outcomes continues to expand (Singh et al., 2016). This is especially true for individuals with special health care needs. A study examining the use of mobile technology among individuals with diabetes, for example, found improvements in self-rated wellness scores and several quality-of-care metrics (Bovbjerg, Lee, Wolff, Bangs, & May, 2017). Reviews of health care management apps for asthma (Tinschert, Jakob, Barata, Kramer, & Kowatsch, 2017) and bipolar patients (Nicholas, Fogarty, Boydell, Christensen, 2017) showed promise for monitoring symptoms and providing condition-specific information.

For individuals with FXS, health technology represents a potential tool to enable independence through the management of health symptoms and other co-occurring conditions. The use of a behaviour management app, for example, could lead to improved outcomes for children as well as result in lower stress in parents or other caregivers. However, little is known about how individuals with FXS and their families use technology in daily life and what skills individuals with FXS can perform when using mobile technologies. To address this gap, we examined the following four research questions:

1. What types of technology do individuals with FXS and their families use?
2. How do individuals with FXS and their families use technology?
3. What technological skills do individuals with FXS possess?
4. How engaged are individuals with FXS when using technology?

Methods

Study Design

We used a mixed-methods design to address the four research questions. We used data from a large survey of parents of individuals with FXS to assess technology use and conducted in-person assessments to gain a better understanding of the skills and engagement levels of individuals with FXS when using technology.

Participant Recruitment and Characteristics

Parent survey participants.—We recruited parents to participate in the technology use survey through *Our Fragile X World* (OFXW), a research registry housed at RTI International. We invited 758 families of individuals who had a child with FXS to participate in the survey. A total of 185 parents of individuals with FXS (24% response rate) completed the technology use survey. Most respondents (90%) were female; the average age was 53.1 years (range: 31.880.9 years, 9.3 standard deviation [SD]). The majority were White (93%); the remainder were Black (2%), Hispanic (3%), Asian (1%), or some other race or ethnicity (1%). Most respondents reported a family income of $75,000 or more (64%), had at least a college education (71%), and were married (84%). We conducted a non-responder analysis and found that those who responded to the survey were more likely to have higher education ($p = 0.01$), income ($p = 0.02$), and be older ($p = 0.005$) than those that did not take the survey. There were no differences by gender of respondent ($p = 0.35$), employment status ($p = 0.18$), or race ($p = 0.61$).

When families had more than one child with FXS, we used a sampling algorithm to select the child whom the parent should think about when answering the survey items. The individuals with FXS were predominantly male (81%), with a mean age of 24.1 years (range: 12.0–56.0 years, 9.4 SD). We asked parents to report whether individuals with FXS had been treated or diagnosed with any of a variety of co-occurring conditions. Most reported that their children had attention problems (84%) and anxiety (77%), 42% had a co-diagnosis of autism, and 19% had depression. Parents rated their children’s overall thinking, reasoning, and learning ability as very good or good (17%), fair (53%), or poor (30%).

In-person assessments with individuals with FXS.—In addition to the survey, we conducted in-person assessments with a convenience sample to examine the technology skills of individuals with FXS. We identified these persons through their participation in a larger study on healthcare decision making in adolescents and adults with FXS. Eligibility criteria included having FXS and being able to communicate verbally with the research assistant during the assessment. The study team completed recruitment and screening by telephone with parents of participants. All parents were the legal guardians of the participants. The cognitive, behavioural, and social-emotional development of these individuals was also assessed.

We completed a total of six assessments; five participants were male (83%). Their average age was 22.3 years (range 16–28 years). Two participants met diagnostic criteria (based on IQ and adaptive behaviour) for a mild intellectual disability, one for a moderate intellectual disability, and three for a severe/profound intellectual disability. One participant (16%) met the diagnostic cutoff for anxiety (using the Adolescent [Gadow & Sprafkin, 1998] or Adult Symptom Inventory [Gadow, Sprafkin, & Weiss, 1999]); two met criteria (33%) for attention deficit hyperactivity disorder (ADHD; using the Adolescent or Adult Symptom Inventory); and two (33%) for autism (based on both the Autism Diagnostic Observation Schedule [Lord, DiLavore, & Gotham, 2012] and the Social Communication Questionnaire [Rutter, Bailey, & Lord, 2003]).

Instruments and Procedures

Parent survey.—The survey included closed-ended items and covered the following topics about their children: (a) Types of technology used (e.g., a desktop or laptop computer, tablet, cell phone, gaming console, e-reader); (b) Hours per week the technology was used; (c) Types of websites frequently visited (e.g., educational, games, weather, news, health and lifestyle); (d) Types of activities the Internet was used for (e.g., watch videos, play games, listen to podcasts, engage in social media, send and receive email); and (e) The child's typical level of engagement (no interaction with technology, moderate engagement, active engagement, and overly engaged or difficult to disengage). Parents answered questions about their own use of technology for seeking health-related information, including information about FXS. We asked parents to identify what types of health-related information they searched for online, what sources of information they trusted, and whether they shared information online. Survey items are available upon request.

The survey was completed online. Each family received an email invitation along with reminders that contained a unique ID to access the survey. Data collection was open for approximately 6 weeks. All procedures and materials were approved by the supporting organizations' institutional review boards. Parents were asked to read and sign a consent form prior to participating.

In-person assessments.—We conducted the in-person assessments in either an office conference room or the participant's home, depending on preference. Participants were asked to assent to the assessment before we began; parents signed consent forms as the legal guardian. Parents were encouraged to observe their children during the assessments. We developed a semi-structured assessment guide that included general questions and prompts asking the participants to interact with an iPad tablet computer. Assessments lasted approximately 45–60 minutes. During the visit, a research assistant introduced participants to the iPad and then guided them through the iPad apps, depending on time and interest level. Participants were asked to demonstrate specific skills of interest (Table 1). None of the participants had prior experience with any of the selected apps.

Assessment apps were publicly available game and story apps, which we selected because we considered them to be of interest to individuals with FXS and required the skills we were interested in assessing. To gather additional information about their abilities, we used free-play apps related to interests of the participants that their parents had indicated in the screener. These included popular games, sports, books, local news, and weather apps. In total, we used six assessment apps and seven free-play apps.

All participants with FXS saw the assessment apps in the same order based on the complexity of skills being evaluated, from least to most complex. We used fourth-generation iPads (model number A1458) running iOS™ version 7.0.1 for all assessments. The research assistant assessed each participant’s level of engagement when interacting with the assessment and free-play apps. Each participant was rated on a 5-point Likert-type scale, developed by the study team: (1) refused to interact with the app, (2) limited engagement, (3) moderate engagement, (4) active engagement, and (5) overly engaged or difficult to disengage. Example behaviours were developed to assist in scoring each participant and to train the research assistant who completed the assessments. For example, a score of 3, moderate engagement, would apply if the participant was willing to focus and interact with the app appropriately but may have required some prompting by the research assistant.

Data Analysis

All analyses were conducted using the Statistical Analysis System (SAS, Version 9). First, we calculated percentages to generate descriptive data on categorical survey items. To account for missing data at the item level, we based percentages on the numbers of respondents who completed each question. Next, we conducted tests to examine potential differences by sex, age, co-occurring conditions, and level of intellectual disability. To test differences, we used the Cochran-Armitage trend test for ordinal by binary variable cross-tabulation tables and the Mantel-Haenszel test for two ordinal variables. A general linear regression was used for two continuous variables. We calculated means for summary variables and conducted follow-up *t*-tests to determine differences. For assessment data, we report frequencies.

Results

Parent Survey

Types of technology used.—Families reported that they owned a variety of electronic devices. Most participants owned a cell phone (96%, with 77% reporting it was a smartphone), laptop computer (82%), tablet computer (78%), desktop computer (73%), or iPod/MP3 player (63%). Other common devices in the home were gaming consoles (55%)

and electronic book readers (41%). No respondents reported owning none of these devices. Most people in the household accessed the Internet from a tablet (78%), laptop (73%), smartphone (65%), or desktop computer (63%). Only a handful used gaming consoles (22%) or the television (17%) to access the Internet.

How parents of individuals with FXS use technology.—Almost all parents (92%) reported that they looked up information about FXS online. About one-half (48%) said they also searched online for information about clinical trials or drug safety and recall information (41%) or consulted online reviews about specific drugs (49%). Other common health-related online searches were for information on medical treatments or procedures (90%), doctors or other healthcare professionals (79%), health insurance (55%), and medical test results (38%). Fewer sought information about long-term care online (14%). Parent advocacy organizations, such as National Fragile X Foundation or FRAXA (92%) and FXS clinics (45%), were common trusted sources of information about FXS. Other sources included the National Institutes of Health (24%), WebMD (25%), and Google or other search engines (45%). More than one-half of parents had shared health-related information on a social networking website (59%) or an online discussion group or electronic mailing list (58%).

How individuals with FXS use technology.—When asked about their children's amount of technology use for work, school, or play, parents were most likely (43%) to say that the children used technology 5 to 20 hours per week; another 33% reported use of 5 or fewer hours per week and 24% reported 21 or more hours per week. Amount of technology use differed by age, $\chi2$ (96.37) = 4.47, $p < .001$. Children who used technology fewer than 5 hours a week were older (29.7 years, 11.5 SD) than those who used technology between 5 and 20 hours (21.1 years, 7.5 SD) or 21 hours or more per week (21.9 years, 6.2 SD). Individuals with FXS who also had a diagnosis of depression were more likely to use electronic devices either infrequently (< 5 hours, $p < .01$) or for high amounts of time (> 21 hours, $p < .01$), $\chi2$ (1, 109) = 4.47, $p < .001$. Individuals with both FXS and autism were more likely than those without autism to use technology for fewer than 5 hours a week ($p = .03$). Technology use did not differ for individuals with FXS by sex, attention, anxiety, or overall ability.

Parents reported that, when their children with FXS accessed the Internet, they most often watched videos from a variety of sources (65%), followed by watching video or listening to audio of news reports and podcasts (39%). The following four activities were reported with almost the same frequency: playing interactive games online (29%), emailing (29%), communicating on social media sites (27%), or doing other activities (e.g., listening to music; 27%). Only a few individuals with FXS read the news online (17%). When we summed the number of different types of Internet activities (maximum of seven based on the aforementioned list). Our statistical analyses revealed an inverse relationship between age and total number of activities on the Internet; younger individuals with FXS participated in more activities ($p < .01$). On average, females (2.8 activities) were more likely to participate in more Internet activities than males (2.8 vs. 1.8 activities, $p < .01$). Also, individuals with FXS who did not have autism engaged in more activities than those with autism (2.3 vs. 1.5,

$p < .01$). Individuals with very good or good overall ability did more activities on the Internet (2.6) than individuals who were rated as having poor (1.9, $p < .01$) or fair (1.8, $p < .02$) overall ability.

The websites or apps that individuals with FXS used most frequently included games (57%), educational (37%), weather (31%), social networking (27%), and sports (23%). Less frequently visited websites were news (19%), photography (8%), and health and lifestyle (5%). Other types of websites (e.g., YouTube) were also visited often (47%). When we considered the total number of websites or apps used, we found an inverse relationship between age and number of websites or apps used; on average, younger individuals with FXS used more than older individuals ($p = .002$). Females with FXS visited more types of websites and apps than males (2.6 vs. 1.8, $p = .02$). Individuals with FXS and autism used fewer websites and applications than those with FXS only (1.5 vs. 2.2, $p < .01$). The total number of different websites and apps used did not differ by anxiety, attention problems, depression, or overall ability.

When asked about the child’s level of engagement when playing with electronic devices, parents generally reported (47%) that the child was actively engaged. However, one-fifth of parents reported that the child was overly engaged (20%), so much so that the child had a hard time stopping use of the device. Another 29% reported moderate engagement, 13% reported limited engagement (13%), and 3% responded that the child refused to interact with technology.

In-Person Assessments

All six participants had some prior experience with a computer (i.e., desktop or laptop). Of these, four had prior experience with Apple products (i.e., iPad). Other technology used included smartphones (n=2), video game consoles (e.g., Xbox™ or Wii™, n=2), and other types of tablets (e.g., Kindle Fire™), MP3 players, and smartboards (each n=1).

Overall, all six participants demonstrated the interactions that each of the assessment apps required; they did this either independently or with minimal prompting by the assessor. Prompting took the form of verbal instruction and modeling of the task by the assessor. The interactions are grouped together for discussion here by those that focus on fine motor control, customization, and exploration.

Simple interaction skills.—Simple tapping was an interaction that individuals with FXS performed either independently (n=3) or with prompting (n=3). Dragging was also an interaction that most participants (n=5) could perform independently. However, touch and hold was an interaction that required prompting and modeling for all six participants.

When asked to demonstrate the ability to turn a page within an app using the swipe feature, individuals with FXS were evenly split between independently performing the skill or needing prompting. In addition, most individuals (n=5) could independently tap the screen to turn the page rather than swiping, if required within an app. Last, five of the six individuals independently used the forward and back arrows to turn pages. When the arrows were visible, they required less prompting from the research assistant and enabled participants to navigate the app more independently.

Advanced interaction skills.—Individuals with FXS demonstrated a variety of skill levels when asked to demonstrate advanced interaction skills with the apps. The six participants differed when asked to customise the app settings using a menu: two participants could not access the menu at all, two could with prompting, and two demonstrated the skill independently. When asked to customise other features of the app (e.g., change the appearance of an avatar), three of the six could do this independently. We also assessed whether individuals with FXS could type on the iPad’s virtual keyboard when prompted. Three participants used the keyboard successfully and the other three did not demonstrate this skill even when prompted.

Exploration skills.—Three apps included hotspots (i.e., an area within an app that performs an action when selected) with varied design and required interactions. Some hotspots were more noticeable than others; they included text, audio, images, or a combination of these. Three participants explored these text and image hotspots independently and the other three required prompting. Hotspots that were less obvious and inconsistent from page to page were more difficult for the participants to find and explore. These hotspots required more frequent prompting for four individuals, but the other two individuals interacted independently with them.

Level of engagement.—All participants were willing to interact with the assessment apps. The average engagement scores for individuals with FXS on the assessment apps ranged from 2.7 to 3.3 (see Table 2), indicating limited to moderate engagement. Participants were most engaged in apps that allowed them to explore hotspots or that included narration or avatars. Participants were least engaged with overly simplistic apps that didn’t require much interaction.

Individuals with FXS selected free-play apps with which they were familiar, including weather, sports, or game apps. Engagement during the free-play apps was much higher, withan average score of 4.4 across five of the six participants; one participant ended the assessment session early. Two participants displayed overly active engagement during the free-play apps.

Discussion

Parents Access to and Use of Mobile Technology

Parents of individuals with FXS reported high rates of ownership of mobile technology and other devices. These rates are higher than those recently reported in the general population (Smith et al., 2015). This may be due to the non-representativeness of our survey sample as the majority of our respondents were from higher education and higher income families. A survey from Pew Research Center (Anderson, 2015) also found that smartphone, tablet, and computer ownership is skewed to younger, more affluent, and more educated individuals but mobile phone ownership is common cross all demographic groups. Although we did not ask about ownership among individuals with FXS, previous research shows that individuals with disabilities had similar rates of device ownership as those reported in the general population (Morris et al., 2014). These findings suggest that, at least among the families who participated in our study, access to mobile technology or other electronic devices was comparable to the general public.

Parents commonly looked online for health-related information about FXS, including medications and clinical trials. Trusted websites were parent advocacy organizations, WebMD, and Google. Similarly, in one national survey, about four out of five Internet users looked online for information about various health topics, including specific diseases or treatments (Fox, 2011). Moreover, about one-quarter of the Internet users in that survey consulted online reviews of drugs or medical treatments. Another survey of individuals with multiple sclerosis reported that the most common source for general health information was the Internet, followed by their physicians and then the National Multiple Sclerosis Society (Marrie, Salter, Tyry, Fox, & Cutter, 2013).

Although we did not ask parents to report on their use of mHealth apps, studies of the public indicate that these apps are common. In a national survey of mobile phone users, over half had downloaded and used an mHealth app (Krebs & Duncan, 2015). Although approximately two-thirds of mHealth apps are for fitness, lifestyle and stress, or diet and nutrition, the next largest subset are disease-specific apps (IMS Institute for Healthcare Informatics, 2015). Mental health apps comprise about one-third of the disease-specific mHealth apps, including commonly addressed conditions such as autism, anxiety, depression, and attention deficit hyperactivity disorder. The use of mHealth apps by families or individuals with FXS may provide promising ways to access, record, or communicate health-related information.

Parents of individuals with FXS commonly shared health information online. Although about one-third of general Internet users reported reading about someone else’s health or medical issues online, less than 1 in 10 shared their own health information online (Fox, 2011). However, this percentage rises significantly for health information sharing *within* specific disease populations. For example, a survey of members of PatientsLikeMe, an online personal research platform for individuals with life-changing illnesses, found that use of the site was associated with increasing levels of comfort in sharing personal health-related information online (Wicks et al., 2010). Other research has shown that individuals with rare diseases often use online communities for sharing or seeking health-related information as well as social and emotional support (Lasker, Sogolow, & Sharin, 2005). Our study found similar results, with more than half of parents of individuals with FXS reporting the use of social networking websites or discussion groups. For families or individuals with FXS, the Internet and social media may offer ways of connecting with others, especially for those who have never met another person with the same genetic condition (Raspa, Bailey, Bann, & Bishop, 2014).

Mobile Technology Use and Skills in Individuals with FXS

Most individuals with FXS used technology for 5 to 20 hours per week. Reports show that, on average, the general population spends about 5 hours a day interacting with mobile technology (Perez, 2017) and up to 10 hours a day of screen time (Howard, 2016).

Individuals with FXS used technology in similar ways as their typically developing peers, including to email, access news, sports, or weather information, for entertainment, and social media. This reflects the growing use of technology in everyday life and the transition from use of adaptive or assistive technology for communication or mobility purposes only.

Technology use by individuals with FXS varied by age, autism, and depression; younger individuals, those without an autism diagnosis, and those with depression used technology more often. Similarly, among the general population, individuals ages 18 to 29 have the highest rates of Internet access (Pew Research Center, 2017). This also is in keeping with previous work showing higher rates of technology use among younger individuals with intellectual disabilities (Carey et al., 2005; Morris et al., 2014; Palmer et al., 2012). Although other studies have examined overall rates of technology use by type of disability (e.g., cognitive disability, physical disability, deaf or hard of hearing) (Dobransky & Hargittai, 2006; Morris et al., 2014), our study was the first to examine variations among individuals with a specific disability.

Most parents of individuals with FXS rated their children as actively or moderately engaged with technology, with about 20% rated as overly engaged. The in-person skill assessment corroborated these findings. Overall engagement scores were moderate, with higher scores for free-play apps. Most participants also were able to demonstrate simple interactive skills with little to no prompting. More advanced interactive skills were harder, with about half of the participants needing prompting or a demonstration. Exploration skills, such as clicking on hotspots, often were difficult for some participants; one-half required prompting or support. Although assistive technology has been used to improve skills in individuals with disabilities (Wehmeyer, Palmer, Smith, Parent, Davies, & Stock, 2006), very few studies have assessed computer or mobile technology skills or investigated ways to improve them with training. Deaf and hard-of-hearing students who attended middle or high school, for instance, had computer skills rated in general as “good,” with better abilities reported for those individuals who had higher rates of access to technology (Luft, Bonello, & Zirzow, 2009). Although we did not investigate this in our study, it may be that individuals with FXS who owned their own devices or had higher rates of technology use could demonstrate better skills or interact with technology in more complex ways (e.g., for emailing rather than entertainment).

Study Limitations

We note the following limitations to this project. First, our survey sample of parents with a child with FXS comprised a non-representative population. Most participants were female, white and with higher education and income than people in the general population. This was particularly this case given the differences between the responders and non-responders. Although this sample is consistent with other FXS survey research, we caution that our findings may not generalise to all families who have a child with FXS. Second, the online survey used parent-reported measures of anxiety, attention problems, depression, co-occurring conditions, and overall ability, whereas the in-person assessments used standardised measures. The inperson assessments used a small sample size of convenience. Participants were mostly male. Although these individuals ranged in overall functioning level, all could take part in an in-person skills assessment. Finally, we did not link the survey and in-person samples, so were unable to draw conclusions about skill use and technology access.

Implications

Mobile technologies can provide a useful platform for both parents and individuals with FXS beyond use for entertainment and social networking. Tablet computers and mHealth apps can improve outcomes for individuals with FXS and enable them or family members to record or share health-related information. Additional research is needed to examine the use and quality of specific mHealth apps geared toward intellectual and developmental disability populations. Apps used by individuals with FXS or other intellectual and developmental disabilities should be designed to follow universal design principles (Assistive Technology Act of 2004), which are likely to decrease cognitive demands and frustration levels and increase the enjoyment of the interactive experience. For individuals with FXS, certain design features may be more acceptable than others. Future research should examine the amount of content that individuals with IDD can understand, the optimum balance between text and auditory material, and different strategies for promoting interaction. Finally, investigations should focus on how mobile technology, and mHealth apps in particular, can be used to promote informed decision making related to health outcomes for individuals with FXS or other IDD.

Acknowledgments

This study was funded by a grant from the Eunice Kennedy Shriver National Institute for Child Health and Human Development (R01HD071987–01A1). The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the National Institutes of Health. The authors thank the individuals with fragile X syndrome and their families who participated in this research study as well as Don Bailey at RTI International for his review of earlier drafts of the manuscript..

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Table 1.

Types and Description of iPad Skills Performed During In-person Interviews

Type of skill[a]	Example and description of skill
Simple interaction	*Tap:* Touch the screen briefly with one finger to select something
	Drag: Touch the screen with one finger and drag around the screen *Touch and hold:* Touch the screen with one finger and hold it *Turn page:* Move from one screen to the next by (1) swiping the screen [e.g., left-to-right, top-to-bottom), (2) tapping anywhere on the screen, or (3) tapping on right or left arrows.
Exploration	*Hotspots:* Find pronounced areas or features to tap as a means of interacting further with the app content (e.g., bolded words or outlined images that play audio when tapped)
Advanced interaction	*Change settings:* Use a menu to manipulate app settings (e.g., change the speed of movement) *Type:* Type words on a virtual keyboard

[a] Skills appear in ascending order of complexity (least to most challenging).

Table 2.

Engagement Scores With Apps During In-Person Interviews

Participant ID	Average engagement score: Assessment apps	Average engagement score: Free-play apps
01	3.7	4.0
02	3.3	—
03	2.7	5.0
04	3.7	4.0
05	3.0	4.0
06	2.2	5.0

Note. Engagement scores are based on a 5-point scale: 1 = Refused to interact; 2 = limited engagement; 3 = moderate engagement; 4 = active engagement; 5 = overly engaged, difficult to disengage.