

Software and Technologies Designed for People with Autism: What do users want?

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ABSTRACT

Software developers, designers and researchers have been looking to technology for solutions to help and educate people with autism for over two decades. There are many examples of seemingly successful technology-based products and prototypes, yet very little is known about how well these solutions are currently integrated into lives of children and adults with autism and their families. This paper reports on results from an anonymous on-line survey intended as a first step to elucidate information about software and technology use. Additionally, data was analyzed to aid creation of future technology-based products for people with autism that are not just effective, but that also meet important user goals and align to their interests and strengths. Major findings included: (1) very few respondents (25%) had any experience with software or technology designed for people with cognitive disabilities; (2) when asked an open-ended question about what they desire in technology design, respondents reported three major goals (social skills, academic skills, and organization skills), and many suggestions for improvements to software and hardware design; and (3) technology was reported as both a major strength and interest for people with autism.

Categories and Subject Descriptors

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

General Terms

Design, Human Factors

Keywords

User-centered design, autism, software and technology design

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1. INTRODUCTION

In the last two decades we have seen an increasing number of software and technology solutions focused on helping and educating people with autism in both the research literature and the marketplace. Software in this category has been designed for use on multiple different platforms including personal computers, assistive technology devices and PDAs. While many researchers report on successful software/technology-based products and prototypes, very little is known about how well, or if, these solutions are currently integrated into the lives of the targeted users; the user group includes children and adults with autism, their families, teachers, and other professionals who focus on people with autism.

Creating effective and useful products from a user-centered perspective begins with a focus on user goals, attitudes and behaviors [8, 18]. 'You are not the user', is an often heard mantra of individuals who purport the effectiveness of user-centered methods. Keeping this in mind is even more important when designing products for audiences with special needs [11]. This paper reports on results from an anonymous on-line survey intended as a first step to elucidate information about software and technology use from the user's perspective. Additionally, data was analyzed to aid creation of future technology-based products for people with autism that are not just effective, but that also meet important user goals, and aligns to their interests and strengths.

Research questions first looked to the past and first asked users to report what types of software and technology designed for people with cognitive disabilities had users tried and next to describe their experience with those products. The survey found that while experiences were generally good, relatively few users (25%) had ever tried technology designed for people with cognitive disabilities; and only 7% of respondents had used technology products designed specifically for autism.

The survey questions then focused on information for future development, first asking what do users report as desirous in software and technology. Next, the survey asked what are end-user's attitudes and behavior toward technology, in other words, do respondents report technology related interests and strengths in the domain when asked about strengths and interests generally? And finally questions were asked about what other common proclivities, interests, behaviors and talents might also help future design efforts.

When asked an open-ended question about technology design, respondents reported three major goals (social skills, academic skills, and organization skills) and multiple suggestions for software and hardware improvements. Other major findings included positive attitudes toward technology-related domains when asked open-ended non-directed questions about their strengths and interests.

1.1 Background

The following sections provide a brief description of autism, a discussion of technology and autism, and the research questions motivating this investigation.

1.1.1 Autism

Autism is a spectrum disorder, typically diagnosed by the age of three. Because it affects each individual to different degrees, autism is considered a spectrum disorder with three general areas of impairment, often referred to as the ‘triad of impairment’ (a) communication, (b) socialization, and (c) repetitive, unimaginative and stereotyped patterns of behavior, play and interests [27]. Autism is one of five disorders categorized as a Pervasive Development Disorder (PDD); the other four disorders categorized as PDD are Aspergers syndrome, Childhood Disintegration Disorder, Rhett’s Syndrome, and PDD, Not Otherwise Specified (PDD-NOS). In common usage, Aspergers syndrome, PDD-NOS and autism are diagnoses that are collectively referred to as Autistic Spectrum Disorders (ASD).

People are intellectually impacted by ASD in different ways. Some have severe learning disabilities while other function academically at a very high level. It is estimated that as many as one-half of people diagnosed with ASD fail to develop any form of functional language. Often those that do develop language tend to be delayed in their linguistic milestones. For example, delays in verbalization of first words or communicative phrases are common [7]. On the other end of the spectrum, people with ASD have written eloquent memoirs of their lives detailing their experiences [13, 3]. While there is huge variability in how ASD affects each individual there are some strong similarities in the population.

Many of the similarities people with ASD share manifest inwardly through their interaction with the world or outwardly through their behavior. Inward examples include reported strengths in the visual spectrum; these individuals excel in response to visual interventions [26]. Additionally, 80-90% of children diagnosed with ASD suffer from sensory dysfunction [25], which can manifest in several ways including a lack of both fine and gross motor control and oversensitivity to noise and physical sensations [2]. Reported behavioral similarities include an expressed need for predictability and the related tendency to repeat actions and/or to become obsessed with a particular object or subject area [23]. Additionally, a fundamental difficulty with social interaction is common to many people with ASD [21]. Many researchers feel that some of the strong similarities in the population predispose people with ASD to accept and excel in the use of software designed for computer and related technology products [14, 23].

1.1.2 Technology and ASD- a seemingly good fit

Several studies have demonstrated that not only are software and technologies well received among participants with

ASD, but research also supports the effectiveness of computer-based training for teaching a variety of skills to children with ASD [5, 7, 17, 30]. Some reasons for this easy acceptance and effectiveness given by researchers investigating technology solutions designed for people with ASD include:

- Software programs accommodate the ASD need for sameness by being predictable and familiar [30].
- Tasks can easily be repeated with very little change from one exercise to the next. In other words, software does not get impatient with repetition [30] and can be implemented to provide prompts and reinforcement consistently [29].
- Most software and technologies are delivered through a visual medium, for example, desktop computers, which capitalizes on what many consider a strength of the audience [26, 29].
- Much of software delivered in computer-based training eliminates the social complexities of interaction with others and allows users to work at their own pace [23].
- Educational software for the personal computer platform can deliver a one-on-one structured learning environment which is often required for children with ASD to effectively learn a topic [30].
- Software delivered on technology devices may provide readily available and affordable teaching tools which augment off-line learning that children and adults can access at home or school, thereby addressing the shortage of instructors needed for intensive one-on-one teaching.

The aforementioned are reasons developers, designers and researchers cite when explaining why technological solutions make sense for people with ASD; however, a few negative issues are also mentioned in the literature. For example, some fear that working on computers will further isolate users that already have difficulties with social interactions [6], or the computer will become a focus of obsessive compulsive behaviors [23]. The generality of computer-assisted instruction is another area of expressed concern.

Two types of generality are a concern: will a lesson learned while interacting with a computer translate to off-line situations or other environments, and will success with one participant translate to a wider group. The latter concern arises because research is typically limited by small sample sizes and common use of single subject designs. Additionally the wide range of abilities found in the audience compound this concern. Acknowledgment of the skepticism and concerns of generality are important considerations as the range of technological-based solutions for people with ASD is constantly expanding.

A wide range of experimental and shipping products (currently for sale) have been designed for people with ASD. Many software and technologies in the educational and entertainment domains that can benefit people with ASD actually target a wider range of cognitive disabilities. Products and prototypes designed specifically for people with autism range from web-based instruction [29], language related skill acquisition [30], robots [24], virtual peers [28], facial recognition instruction [12], virtual reality simulations [16, 21, 19],

cooperative games [22], video modeling [15], play support [20], activity schedules [9] and assistive technology devices.

1.1.3 Research questions: understanding the user

While investigations and products listed above do not represent an inclusive list of every effort undertaken in this domain, it does provide a strong indication that enthusiasm surrounding technology related products for people with ASD is growing. The literature also includes a few scattered reports on user discontent surrounding technology products designed for people with cognitive disabilities. For example shortcomings were found in software used in the classroom for children with ASD [4], and a low adoption rate of assistive technology devices was reported for people with cognitive disabilities [10]. However, there has been very little investigation into the proliferation of software and technology products in the ASD population. Additionally, there is very little discussion about creating useful technologies aimed at user goals that also align to end-user's attitudes and behaviors. In summation, the research questions motivating this investigation are:

1. What types of software and technology have users already tried?
2. What has been their experience with those products?
3. What do users report as desirous in software and technology?
4. What are end-user's attitudes and behavior toward technology?
5. What other common proclivities, interests, behaviors and talents might also help future design efforts?

2. METHOD

The following sections describe the participants who responded to the anonymous on-line survey, the survey design, and the procedures used to analyze the data. The survey is available for review on a University of Washington server at <https://catalysttools.washington.edu/webq/survey/cyputnam/34194>.

2.1 Participants

Between October 1 and November 15, 2007, 120 respondents completed the anonymous on-line survey. Two submissions were rejected because the responders were not at least 18 years old; an additional four were rejected because the answers were given for children with a cognitive disability other than ASD. The remaining 114 submissions included 12 from adults diagnosed with ASD who completed the survey for themselves and 102 submissions concerning a child with ASD.

A majority of these submissions concerning a child were from parents (79%); the remaining submissions were from family members, special education teachers, and other professionals who work with children diagnosed with ASD. Ages of the focus children ranged from 0 to over 18 years old; diagnosis was reported as Aspergers syndrome, autism, or PDD-NOS. See Figure 1 for distribution.

Males dominated the sample, 75% of the 114 submissions were from male adults or about male children. The ratio of

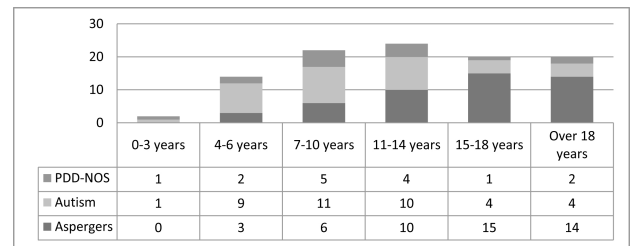


Figure 1: Distribution of focus children from adult respondents

males to females in the ASD population ranges from 4:1 to 2:1 [1]. Consequently, the survey sample is possibly more male dominated than the population.

2.1.1 Distribution

Respondents were recruited by utilizing a snowball sample technique that began from links located on three known sources:

1. The fall 2007 newsletter for the northern California chapter of FEAT (Families for early autism treatment).
2. The DO-IT (Disabilities, Opportunities, Internet working and Technology) listserv at the University of Washington that serves a variety of people with disabilities at the university.
3. An Asperger support website for the Seattle area located at <http://seattleaspergers.org/research.aspx>.

The finished survey did not request information about how the respondent heard about the survey in order to maintain anonymity; therefore, origin of respondent's knowledge of the survey is unknown.

2.2 Procedure

2.2.1 Survey Design

The survey contained a branching design, so that, responders only saw questions relative to their previous answers. For example, if the respondent had not tried any type of software or hardware designed for people with cognitive disabilities, the survey skipped to demographic and open-ended questions located at the end. Following an introduction page, the survey sequence began by asking the responder if he/she was 18 years or older; if the responder was under 18 they were branched to the thank-you screen and no information was gathered.

Next, the relationship to the person or child with ASD was ascertained; if the respondent was answering for himself he saw an identical set of questions, but they were written directly to the responder rather than referencing a child. Responders answering questions about a child were instructed to only answer the survey for ONE child (they were encouraged to take the survey again for different children) so that inferences might be made about relationships between responses and other information such as age and diagnosis that might help future design efforts.

The survey then targeted the first two research questions asking about types of software and technology users tried and about their experience with those products. The survey asked if they had ever used (or the focus child ever used)

software that was designed for people with cognitive disabilities on a PDA, computer, cell-phone or assistive technology device. If no, the survey once again skipped to demographic and open-ended question section. If yes, the survey asked how many types of software they had used in the last three years, up to the three most recent. The next nine questions asked about each software package.

To explore user experiences the next questions asked: (a) the purpose of the software; (b) type of device it was designed for; (c) brand name if applicable; (d) if the software experimental and (e) was the software specifically designed for people with ASD. The survey then asked the respondent to rate the software on a five point Likert scale to determine if they felt the software effective, easy to set-up, and easy to use.

Next, demographics were collected to probe possible correlations between age, verbal abilities, diagnosis and gender to answers to the other questions. Finally, the survey ended with open-ended questions intended to probe user goals, attitudes and behaviors that were targeted at answering the last three research questions: what do users report as desirous in software and technology; what are end-user's attitudes and behavior toward technology; and what other common proclivities, interests, behaviors and talents might also help future design efforts?

2.2.2 Data analysis procedures

Open-ended questions were analyzed by identifying and categorizing key phrases and words. For example, if a parent respondent mentioned their child needed 'help in reading' in relation to what they would find desirous in software, this was categorized first as a goal, then in the educational domain, and specifically in reading. After agreeing upon categories the authors independently analyzed the data to assess intercoder reliability. Reliability was calculated at 94%; the reliability rate was determined by dividing the number of agreements by the number of agreements plus disagreements. Additionally, correlations with demographic data, interests, and verbal ability were generated to evaluate the possibility of identifying predictors of future software use through logistic regression, and to determine if goal categories pertaining to software and technology use and common attitudes and behavior categories were shared by similar groups in significant and meaningful numbers.

3. RESULTS

The survey results were evaluated for proliferation and user experience with software and technology products designed for people with cognitive disabilities and information about users to benefit future development.

3.1 Past user experience

Only 29 of 114 (25%) responders reported experience with software and technologies designed for people with cognitive disabilities. Eight responders reported multiple experiences creating a total of 45 software and technology experiences to evaluate for this report. A majority of the software (55.5%) was designed for the PC and to teach skills in the educational domain. See Figure 2. Eight of the 45 software and technology products (18%) evaluated were reported as designed specifically for the ASD audience; the remaining 37 products were designed for people with cognitive disabilities in general.

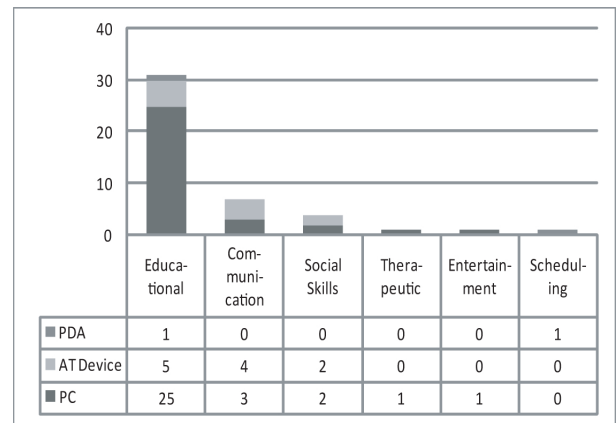


Figure 2: Software distribution by domain and hardware device

Users reported somewhat positive encounters with the software and technology they had experienced. When asked on a scale from 1-5 if they felt the software or technology was effective in its intended purpose, most respondents were in agreement, ($M = 3.44$, $SD = 1.14$). Users also reported a positive experience when asked on the same scale how easy the product was to set-up, ($M = 3.89$, $SD = 1.01$), and for the end-user to understand how to use, ($M = 3.89$, $SD = 1.11$).

Verbal ability, diagnosis, and age were not significantly correlated or associated with current use; therefore, the study did not find a linear set of variables that might predict a segment of the population more likely to use technology-based products in the future.

3.2 Future design considerations

The survey asked, 'In a perfect world, what type of software or technology (if any) do you think your child (or you in the case of the self responders) would really benefit from?' to investigate what users desire when considering software and technology. A total of 136 comments were evaluated from 83 (72% of 114) individual respondents. An additional nine comments from eight unique respondents not included in the total above could not be relegated to a shared category; therefore are not discussed in this paper. Answers to this question fell into three categories, goals (62%), access concerns (5%) and design suggestions (33%). Goals were further subdivided into three domains, (a) social/communication; (b) academic/school help; and (c) scheduling/organization. See Figure 3 for goal distribution by diagnosis.

3.2.1 User Goals

Social and communication goals were expressed by 32% of the responders. Twenty-eight submissions (21%) mention the phrase 'social skills' explicitly, for example, respondent 21 wrote:

Something that engages him to communicate more, teach him on social skills by modeling that he can pick up quickly.

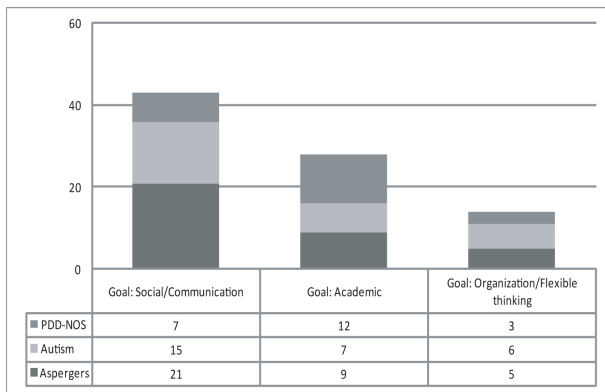


Figure 3: Goal distribution by diagnosis

Eleven (8%) submissions mention help in communication more generally; respondent 2 suggests:

Since he understands language, a device that would allow him to use that vocabulary without large amounts of planning and setup time.

The academic domain also received many goal-oriented suggestions; 27 of the 136 analyzed comments (20%) discussed a need for help in writing, math, reading, and general classroom and academic help from 24 unique submissions. Thirteen comments pertained to writing help that included the need for tools to aid organization of thoughts, for example respondent 29 wrote:

He would also benefit from software that helped him generate, organize, and write his thoughts and ideas.

Another common writing goal (five responses) were directed towards the act of handwriting, for example respondent 100 answered:

His handwriting is weak and illegible; He shortens his writing because of it.

Math was another important skill area mentioned in seven responses. Math concepts taught using multiple modes was mentioned in three cases, for example respondent 66 expressed a need for:

...an upper math program with audio and visual explanations.

Answers categorized in the organization and flexible thinking domains were mentioned in 14 (10%) of the 136 analyzed responses from 11 unique submissions. Eight submissions mentioned scheduling and organization explicitly, for example respondent 24 wrote:

Helping him cue his life (how to move forward and structure time without numerous adult prompts!).

Respondent 94's submission also mentioned critical thinking promotion:

...something that helps develop organization and critical thinking.

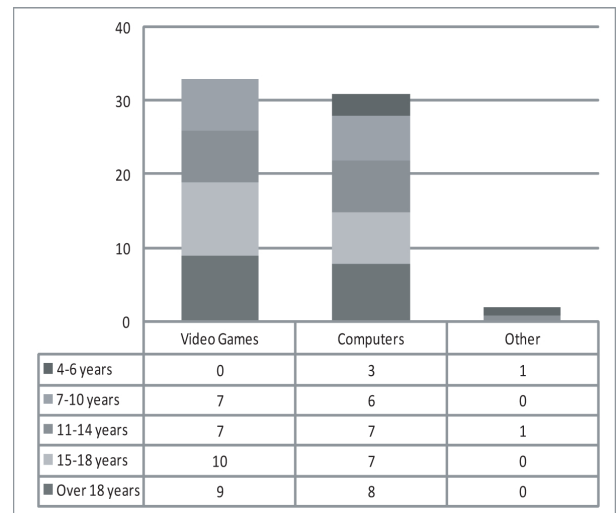


Figure 4: Technical Interests by Age

No meaningful significant correlations or associations were found between end-user information (gender, verbal ability, diagnosis, and age) and social/communication or scheduling/organization goals; however a significant correlation was found between academic goals and diagnosis, $\chi^2(2, N = 102) = 19.24, p = < .01$. Academic goals were disproportionately expressed by parents of children diagnosed with PDD-NOS.

3.2.2 Access concerns and design considerations

Fifty-two (38%) of the submissions responding to the open-ended question above described concerns about a lack of access to computers and technology (5%) and design considerations (33%). Design considerations included suggestions to consider sensory integration issues, make products portable, make input devices easier to use including multiple suggestions regarding voice activation. Additionally, 22 responders (19%) requested software designed with fun in mind; the responders felt developers should consider creating learning experiences as games. For example respondent 36 wrote, 'games to teach him that he enjoys.'

3.2.3 Attitudes and behaviors toward technology

Many responders wrote of positive attitudes toward technology-related domains when asked open-ended non-directed questions about their strengths and interests, see Figure 4. Fifty-two responders (46%) wrote of reported interests related to video games, computers and other related technology; their 66 responses comprised 21% of all analyzed interests. Additionally, 14 unique submissions (14%) from responders answering the survey about a child identified computers as one of their focus child's strengths.

3.2.4 Other strengths and interests that might help future design efforts

The survey asked, 'What are your child's strengths?', from respondents answering for a child to evaluate end-users strengths that designers and developers might consider in future products. A total of 207 comments from 94 unique submissions were analyzed. Common strengths include:

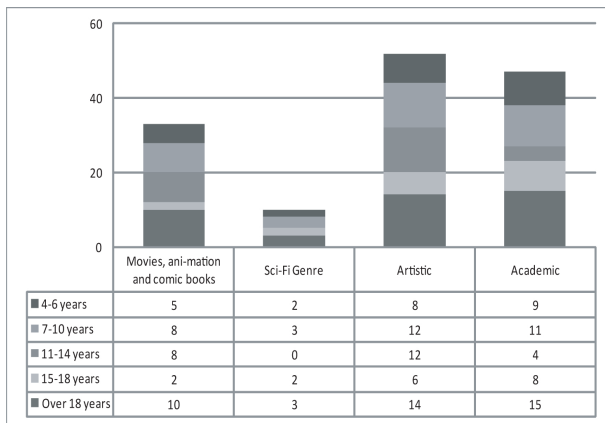


Figure 5: Common Interests by Age

- Twenty-nine respondents (28%) specifically note that their focus child has strengths in reading and math; this was especially noted for children in the 7-10 age range.
- Twenty-three respondents (23%) note that their focus child had a particularly good memory.
- Fourteen responders (14%) claim their focus child had a strong desire to be social which aligns to the most common goal area as well; additionally, this strength was disproportionately mentioned for younger school-age children.

The survey asked, ‘What are your (or your child’s) interests?’, to investigate end-users interests that designers and developers might consider in future products. A total of 307 comments from 112 unique submissions were analyzed from respondents answering a question about their own (12 responders) or their child’s (100 responders) interests, see Figure 5. Common interests include:

- Thirty-three responders (29%) indicated a strong interest in movies, animations and comic books.
- Eight respondents (7%) specifically mention the science fiction genre in relation to both reading and movies.
- Forty-one responders (36%) wrote of a strong interest in artistic pursuits that included writing, music and art; this interest was disproportionately mentioned for females.
- Thirty-five responders (31%) had interests in academic pursuits; again reading and math dominated this category comprising 44% of the comments.

Other common interests that designers might consider incorporating in their software were animals (17 responders), transportation (15 responders) and a desire to understand mechanical and electrical devices (8 responders).

4. DISCUSSION

The results of this anonymous on-line survey provide a preliminary understanding of user experience, goals and concerns when considering software and technologies designed

for people with ASD. Additionally, the results provide an illustration of common perceived strengths and interests that influence attitudes and behaviors; these attitudes and behaviors may be used to guide future product design and development. This paper represents an initial step in utilizing user-centered design methods to create effective and useful technology that that are integrated into user’s lives.

4.1 User experience

The results indicate that excitement expressed in the literature about a seemingly good fit between technology and people with ASD does not translate to a high proliferation of products in user’s homes; only 25% of responders had any experience with software and technology designed for people with cognitive disabilities and only eight of the 45 reviews were about products specifically designed for people with ASD (three of those were about the same product and two were about experimental products that are not available to most users). Products reviewed by responders for this paper were primarily in the educational domain and designed for the personal computer. However, it was encouraging to find that while exposure was limited, responders were somewhat enthusiastic about experiences and reported a moderately high level of satisfaction.

Verbal ability, diagnosis, and age were not significantly correlated or associated with current use or interest in software and technology products designed for people with cognitive disabilities. This finding indicates there is no clear, focused segment of the end-user population that developers and designers should consider in future product design.

4.2 Design Considerations

Open-ended questions were used for the exploratory portion of the survey in order to generate goals, attitudes and behaviors that might help future product development. Answers to the question, ‘In a perfect world, what type of software or technology (if any) do you think your child (or you in the case of the self responders) would really benefit from?’ were related to concerns about access and design considerations in 38% of the analyzed submissions; 62% of the submissions described goals associated with software and technology. The number of goals generated by the responders was especially surprising since the question was entirely open-ended.

4.2.1 User Goals

Goals fell into three domains, (a) social/ communication; (b) academic/school help; and (c) scheduling/organization. Social/communication goals were expressed by 32% of the responders, academic/school help by 20% of the responders and scheduling/organization by 10% of the responders. Interestingly, the large portion of responders indicating social/communication goals is not proportional to the type of products currently used; only 9% of the products users had tried were designed to address social skills. Conversely, 69% of the products users had tried were in the educational domain. However, the concern with social skills is aligned to what most consider the ‘core deficit’ in autism.

No meaningful significant correlations or associations were found between user information (gender, verbal ability, diagnosis, and age) and social/communication or scheduling/ organization help; this indicates these goals are shared equally in the ASD user population. However, 42% of the responders

relating goals pertaining to academic/school were diagnosed with PDD-NOS, a significant difference, indicating that this segment of the ASD population is disproportionately concerned with academic related goals when considering software and technology for people with ASD.

4.2.2 Access concerns and design considerations

Lack of access to technology was a concern for five responders, and design considerations and improvements were suggested by 38 respondents. Hardware design suggestions including making products more portable and input devices easier to use including multiple suggestions regarding voice activation. Design considerations for software included suggestions to consider sensory integration issues by allowing users to set color and sounds.

Twenty-two responders (19%) specifically requested that software be designed with fun in mind; the responders felt developers should consider creating learning experiences as games. This suggestion was significantly disproportionately made by parents of children diagnosed with autism (vs. PDD-NOS and Aspergers) indicating that developers interested in creating educational games for people with ASD should strongly consider the needs of this segment of the population.

4.2.3 Analyzing reported strengths and interests for behaviors and attitudes

This study also asked questions pertaining to end-user's interests and strengths to further probe attitudes and behaviors that might help future design efforts. Many responders had positive attitudes toward technology-related domains. Fifty-two responders (46%) wrote of reported interests related to video games, computers and other related technology. Additionally, fourteen responders answering the survey about a child identified computers as one of their focus child's strengths.

While effective product designs support user's goals, motivation to buy and use products also comes from a strong alignment to their strengths and interests. Many of the strengths and interests collected in this survey are particularly helpful for software and technology design considerations.

Strengths designers and developers might consider are: strengths in reading and math (this was especially noted for children in the 7-10 age range); (b) good memory; and (c) fourteen responders reported that their focus child had a strong desire to be social which aligns to the most common goal area as well.

Interests that designers and developers might consider in a technology product were: (a) strong interest in movies, animations and comic books; (b) the science fiction genre in relation to both reading and movies; (c) artistic pursuits that included writing, music and art (this interest was disproportionately mentioned for females); and (d) interests in academic pursuits (again reading and math dominated this category). Other common interests that designers might consider incorporating in their software were animals, transportation and a desire to understand mechanical and electrical devices.

5. CONCLUSIONS AND FUTURE WORK

This paper reported results from an anonymous on-line survey that was intended as an initial step to elucidate in-

formation about software and technology use from user perspectives. Additionally, data was analyzed to aid creation of future products for people with ASD that are not just effective but also meet important user goals and align to their interests and strengths. While many of the findings are interesting and may help future product development; the results are limited by the sample.

First, the snowball method used to recruit the sample is not random and favored respondents in two geographical areas in the United States (Seattle and northern California) whose economies include many technology-based companies. Secondly, since both the survey and distribution methods were on-line, the sample clearly had access to computers and would probably be more inclined toward high enthusiasm when considering technology design for people with ASD. Finally, since the survey was about software and technology use, the sample was probably more interested in the area of research, and consequently shared more strength in these domains than what one would expect in the entire population.

5.0.4 Next steps

This study points toward several viable technologically-based product concepts that might be both effective for people with ASD and meet their goals. Additionally, this study provides an idea of who might be interested or inclined to use particular products. Moving forward, this investigation is interested in the bigger question, of what types of modifications and adaptations are required in user-centered design methodologies when considering the ASD audience. Toward this end, a few targeted product concepts based on these results will be developed to explore these research questions. It is hoped that this information will help developers, designers and researchers create more meaningful, useful and usable products for this important, growing segment of the general population.

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