Towards a Framework to Situate Assistive Technology Design in the Context of Culture

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ABSTRACT
We present the findings from a cross-cultural study of the expectations and perceptions of individuals with autism and other intellectual disabilities (AOID) in Kuwait, Pakistan, South Korea, and the United States. Our findings exposed cultural nuances that have implications for the design of assistive technologies. We develop a framework, based on three themes: 1) lifestyle; 2) socio-technical infrastructure; and 3) monetary and informational resources within which the cultural implications and opportunities for assistive technology were explored. The three key contributions of this work are: 1) the development of a framework that outlines how culture impacts perceptions and expectations of individuals with social and intellectual disabilities; 2) a mapping of how this framework leads to implications and opportunities for assistive technology design; 3) the presentation of concrete examples of how these implications impact the design of three emerging assistive technologies.

Categories and Subject Descriptors
H.1.2 [User/Machine Systems]: Human Factors

General Terms
Human Factors

Keywords
Assistive Technology, Culture, Autism Spectrum Disorders

1. INTRODUCTION
Our cultures influence the way we perceive the social world. How does culture impact the design of assistive technologies for individuals with social and intellectual disabilities? In particular, what should technology designers understand about culture, and what factors must they take into consideration in their designs? These are questions that we seek to explore in our research.

Our goal is to develop adaptive technologies for individuals with autism. Autism is understood as a spectrum of social and communication disabilities characterized by a triad of differences: difficulties in communication; difficulties in social interaction, and overly focused or repetitive thoughts and behaviors [9]. In our research, we have developed numerous technologies to support a variety of stakeholders linked to autism, but we focus on three particular examples here. The first is a communication system designed to assist young adults in living independently and integrating socially. The second is an authoring system that uses crowdsourcing to assist in designing interactive social problem-solving scenarios. The third technology is designed to support caregivers in the capture of events of interest in natural settings.

We propose that the design of such assistive technologies must be informed by data on the culture of the individual using or being impacted by the technology, since what constitutes appropriate behavior is largely a social construct. In addition, we hypothesize that culture mediates the expectations society has for these individuals. For instance, while living independently is desirable in some cultures, it is not expected, or even acceptable, in others. This is especially important because increases in autism awareness have not occurred uniformly across cultures and societies, and thus these cultural perceptions and expectations will affect the way technologies are adopted.

In this paper, we present the findings of a qualitative study exploring the societal expectations for social and adaptive behaviors for individuals with autism and other intellectual disabilities (referred to as AOID in this document) in four countries: Kuwait, Pakistan, South Korea, and the United States. This study was motivated by the fact that the authors are nationals of these countries. This allowed us the unique opportunity to have the data in each country collected by a native to that culture, and for the data analysis to be done by the multicultural team. This arrangement ensured cultural sensitivity in data collection and data analysis.

Our study indicates that the lifestyle, socio-cultural infrastructure, and monetary and informational resources of each of the four societies were important factors impacting the perceptions and expectations of individuals with AOID in each country. These factors provide a framework within which to frame the design of technologies to support individuals with AOID. There are three key contributions of this work: 1) the development of a framework that outlines how culture impacts perceptions and expectations of individuals with intellectual disabilities; 2) a mapping of how this framework leads to implications and opportunities for assistive technology design; 3) the presentation of concrete examples of how these implications impact the design of three emerging assistive technologies.

This paper is organized as follows: (1) related work from the areas of anthropology, and psychology related to the implications of culture on perceptions of disability, (2) description of our study methodology and data analysis approach, (3) presentation of findings and the resulting framework, (4) implications of these findings on the development of three technologies to support individuals with autism.

2. RELATED WORK
Autism is a phenomenon that has touched the lives of many families around the world, and encompasses individuals with a wide range of needs and abilities [3]. It is considered prevalent in all cultures, races, and social classes [2] and is recognized as being present in at least 80 countries [7]. Researchers have
identified a great need for studying autism in the context of culture [7,11]. A significant exploration of autism across cultures is presented in Grinker's Unstrange Minds [11], which describes his experiences raising his daughter who has autism in the US and the experiences of families living with autism in South Korea, South Africa and India. He notes that autism may not be a "culture" in and of itself, as some suggest, but instead that the way in which people with autism are understood and integrated into a community can differ radically. This is in line with research that has shown that differences in practices and values across societies, cultures, and the socio-economic strata, lead to variations in the experience of autism [25]. In short, it is important to understand both intra-cultural and inter-cultural factors that impact this experience. We seek to explore these factors in our work.

2.1 Diagnosis and Assessment

Culture influences the ways we understand, classify and address autism [11]. Studies have been conducted that compare two or more cultures along one dimension of autism. For instance, a cross-cultural comparison of sensory behaviors in children with autism and typically developing children in United States and Israel revealed that there were significant differences between the typically developing children and the children with autism in each country [20]. The authors indicate that it is important that cultural differences are taken into consideration and that culturally sensitive assessments and interventions to address difficulties in sensory modulation in the autism population be developed. The cultural influences on the behavioral symptoms of autism in Kenya and the US have also been investigated [27]. This work shows that significant differences exist between individuals with autism in these two countries in the three core areas of impairment associated with autism; social interactions, communication, and stereotypical behaviors. Similarly, Daley has studied the trajectory from parental recognition of symptoms to receipt of an official diagnosis, and the way different types of specialists understand and deploy diagnostic criteria of autism in India [8]. Her studies provide effective justification for approaches that look at a range of clinical practices both within and across cultures.

Others have found that screening tools designed for one culture's behavior norms, like eye contact, may not be transferable to cultures where it is not appropriate for a child to gaze directly into an adult’s face [25]. It is apparent that autism diagnosis is largely dependent on social measures, which in turn are framed by cultural factors. Further, these findings have implications beyond diagnosis and impact the expectations that societies have for individuals with autism throughout their lives. Exploring these expectations is one of the goals of our cross-cultural study.

2.2 Perceptions

Research has also shown that the meaning parents attach to their child’s symptoms and their associated beliefs about the causes of symptoms, prognosis, and most appropriate course of care can be described within the context of culture [18]. For instance, researchers found that parents in Japan do not notice social concerns in their children’s behavior as readily as parents in Western cultures, because social behavior in Japan lends itself more to those behaviors going unnoticed [17]. Perception also impact diagnosis. In South Korea, for example, children with autism are frequently diagnosed with a condition called Reactive Attachment Disorder — often associated with child neglect — and among the Efe pygmies in Central Africa, a child who begins exhibiting autistic behavior is understood to be under attack by the family’s ancestors and is sent to another village far away where he will not have contact with blood relatives [11].

Several studies exist exploring how religious practices influence perceptions of autism. Researchers in Kuwait indicate that it is not uncommon for mothers to resort to Allah (God) as a strategy for coping with the stress of caring for a child with a disability [22,1]. This finding is echoed in a study that explores the role of religion in coping in Christian families [23], and in a review of literature on coping strategies used by families of children with autism [18]. Other researchers suggest that in some cultures high levels of functioning are not desired, as people with autism are believed to be closer to the spiritual world [7]. Analogously, the way people view, or appraise, disability is often a function of their cultural values. For example, some Latino mothers view having a child with a severe disability as a way for the mother to sacrifice part of her life and to receive opportunities and blessings or less frequently, as a punishment from God [4]. Similar viewpoints may be common among other cultural, ethnic, or religious groups [17]. In this paper we present findings from Kuwait, South Korea, Pakistan and the US related to perceptions of autism and the influence of religion on these perceptions.

2.3 Education and Services

In a study of educators in selected inclusive education classrooms at sites in the United States and South Korea [14], researchers have examined how educators view the meaning of autism, and how they construct communication and interpret unconventional or undesirable behaviors through interactions with students with autism. It was found that the social requirements and interpretation of communication and behaviors differ between the individualist-oriented culture of the U.S. and a more collectivist-oriented culture of South Korea. In addition to studying individual cultures, researchers have explored multicultural issues in autism and argue that students with autism with multicultural backgrounds are challenged on at least four dimensions: communication, social skills, behavioral repertoires, and culture [10]. This work explored multicultural perspectives on teaching students with autism and present culture-specific strategies for meeting the educational needs of students with autism. Finally, research has shown that eco-cultural approaches that incorporate the components of a family's social and cultural environment create 'best fit' interventions and services that have higher efficacy and that families are more likely to comply with [19,5]. Understanding the educational approaches used, and the availability and appropriateness of services, was an important motivating factor for the work presented in this paper.

3. STUDY DESIGN

Based on this literature review, and our personal experiences, we propose that the design of assistive technologies for individuals with AOID must be informed by data on the culture of the individual using or being impacted by the technology. Furthermore, we hypothesize that culture mediates the expectations society has for these individuals. Following is a description of the study we conducted to explore these notions.

3.1 Data Collection

The first phase of data collection began in 2009. To date, data has been collected from 107 participants at four sites: Atlanta, GA, Kuwait, Lahore, Pakistan, and Seoul, South Korea. The majority of the participants were parents and teachers, but others included administrators, speech language pathologists, psychologists, counselors, and therapists who interact regularly with individuals with AOID (table 1). We recruited participants by word-of-mouth, and chose to expand recruitment beyond only those who work
with children with autism because autism diagnoses are not given consistently across these four societies. We have also begun to interview individuals with AOID, but we believe that data merits separate analysis. Also, we realize that there is an imbalance in the distribution of participants across cultures; however, we were able to interact with at least one participant from each category in each country. In the future we intend to equalize this data.

Table 1. Participant Information

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<td>Parents</td>
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<td>Teachers</td>
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<td>Therapists</td>
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<td>Administrators</td>
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The research was conducted at special needs schools, activity and vocational centers, group homes, autism centers, and adult social skills and special interest groups in each country. A researcher who is native to the culture visited each of the research locations and collected the data via direct participatory observation and contextual inquiry. Researchers began by observing educational sessions, social skills practice, and other activities that make up the daily routines of the participants. Each observation session lasted at least two hours, and each site was observed on at least two separate occasions. Throughout these observations detailed field notes were taken that included photographs.

Semi-structured interviews were also conducted with participants in all four countries. Each interview was audio recorded and varied in length from 40 to 70 minutes. Two classes of questions were asked: 1) individual level, and 2) society level. Individual level questions included questions about the child’s life in general, as well as information about their verbal abilities and level of functioning. Specific questions were asked about the social skills that are required to be successful in each culture. We also asked participants to describe their current instructional practices for social skills, life skills, and vocational skills. Throughout the interviews we focused on understanding the participants’ motivations and practices in their cultural context, in an attempt to identify the impact of their culture on their perception and expectation of socially adaptive behaviors. Society level questions included inquiries related to information gathering practices, technology use, services available, and funding sources. We concluded the interviews by asking the participant what their long-term goal was for their child or students. Most of the research was conducted in-person, but six of the interviews were conducted over the phone. To compensate for this difference, participants who were interviewed over the phone were asked additional questions and provided pictures and other media to enable us to better understand their practices.

3.2 Data Analysis

A researcher who is a native and fluent in the local language collected the data at each of the sites. This allowed for the flexibility of interacting with the participants in the language they felt most comfortable in. This led for data to be collected in English in the US, Korean in South Korea, Arabic and English in Kuwait, and Urdu and English in Pakistan. This data was then translated, and all analysis was done in English.

We used an inductive thematic approach to identify and develop emergent themes. These themes create a framework that outlines the cultural aspects that define the expectations of individuals with AOID and the environments that they must navigate in order to be successful. We drew on analysis techniques described in the *Grounded Theory* approach as it provides a helpful structure for coding the raw transcripts, and a means by which the categories formulated during *open coding* could be developed into richer explanations of the cultural influences on individuals with AOID.

Using an *open coding* approach, three researchers worked together to label instances that were deemed relevant to the lives of individuals with AOID. This inductive process led to seven categories - family structures, linguistic environment, religion, technology and civic infrastructure, programs and services, monetary concerns, and informational resources. Affinity diagrams were also created to help us better understand the relationship between the categories.

*Axial and selective coding* was then used to develop the explanations of each category further. The categories were connected to other concepts following the methods describing causal, contextual and intervening relationships. This process elicited a variety of patterns; each of which we returned to the original transcript and field notes, to find evidence that confirmed or rejected it. This enabled us to identify three central phenomena that encompass all seven categories: *lifestyle, socio-technical infrastructure, and monetary and informational resources.* This hierarchy of concepts creates a framework within which the cultural implications and opportunities for technology can be explored. Following is a detailed description of our findings.

4. FINDINGS

The process described above lead to the development of a framework that allows us to provide a cultural lens onto the AOID communities in the four countries that were studied. This framework may help members of society understand ways they can support these individuals in a greater context, and in particular, with respect to technology design and development.

4.1 Lifestyle

Lifestyle has been defined as “the distinctive pattern of personal or social behavior characteristic of an individual or a group”[24]. Through our data analysis, three categories emerged that fall under the umbrella of lifestyle. These are family structure, linguistic environment, and religion.

4.1.1 Family Structure

Family structure, size, and expected family member roles significantly influence the daily routines of individuals with AOID. We found that family size impacts the distribution of care giving responsibilities, in that it is shared across the family members. In Kuwait and Pakistan the tendency towards large cohabiting families makes it such that care giving and decision-making responsibilities are shared. For example, several parents mentioned that grandparents often had the final say in what treatments and services the child received.

The perception of the desirability of living independently also varied drastically across the four cultures. While participants in the United States reported that independent living is seen as a mandatory part of growing up and living a successful life, this was not the case in the data from Kuwait and Pakistan. In these two cultures it is common practice for all children to remain in the
family home even after they are married. Indeed, moving out is sometimes perceived as unacceptable. Participants from South Korea appeared to have a more flexible attitude towards the importance of independent living. They reported that the individual situation of the person was the deciding factor, such as whether they are they financially stable or whether they just had a child and need help.

In Pakistan and Kuwait, hiring help, such as nannies and drivers, often also support the care of children. This simplifies the coordination that parents are required to orchestrate. We found that in South Korea and the United States parents sometimes struggle to coordinate their daily schedule. Korean mothers indicated that they take on most of these; arranging for things like school and therapy drop-off and pick-up. A Korean teacher reported that at least two mothers she knew were not able to keep their jobs as a result of how demanding both their schedule coordination and housework responsibilities were. American mothers also stressed the difficulties they faced in organizing and providing care for their child.

4.1.2 Linguistic environment
In general, children spend most of their time with their families at home or with teachers at school. We found that the use of language greatly influences not only casual social interactions but also education. Each of the countries studied had at least one official language. In addition, we found that in many instances, other languages are informally introduced into an individual’s everyday life. Participants in South Korea and the United States reported that, for the most part, their children were exposed to monolingual environments. This was not the case in Pakistan and Kuwait, however. Most Kuwaitis and Pakistanis speak the local language at home and in the community (Arabic and Urdu respectively), but most special needs schools in these countries use English language curriculums. In addition, in Kuwait teachers who teach the English curriculums are not always native speakers of English. One parent indicated, for instance, that they believe that their child had not progressed as much this year at school because his teacher’s English was difficult for him to understand.

In Kuwait, the language demands on the individual are further compounded by the fact that many nannies in Kuwait are neither native Arabic nor fluent English speakers, and instead speak a third language. Similarly, in Pakistan, despite using educational materials that are in English, informal interactions at school are mostly conducted in Urdu because many teachers are not fluent speakers of English. Both parents and teachers reported that this inconsistency of language use compounds the communication difficulties many individuals with AOID already struggle with. These findings are similar to those reported for children with AOID with a multicultural backgrounds [10].

4.1.3 Religion
In Kuwait and Pakistan religion plays an important role in defining lifestyle. For instance, many schools cater to religious restrictions arising from a perceived Islamic way of life. Participants from a school in Kuwait reported that they segregated male and female students to classrooms on different floors in the school building, to encourage parents to allow their children to attend the school. Several teachers, in both Pakistan and Kuwait, also reported that they tried to use religion as a means to teach (despite some teachers not being Muslim), in order to relate to the child, and bridge the gap between what they were learning at school and at home. For example, in Kuwait, a Canadian teacher at a special needs school indicated that he was reading and studying the Quran in order to draw lessons from it to use with his students. In addition, religion appeared to play a role in even the simplest activities, like artwork done at school, and music classes.

Participants from both societies also indicated that in many cases, adherence to religious norms was enforced with the individual with AOID (e.g. girls made to wear a head scarf, children expected pray five times daily), and these religious practices were taught as life skills, even though the individual did not always understand the motivation behind them. Lastly, our interactions with the parent participants led us to conclude that sometimes faith leads to complacency. When asked about their goals for their child, our findings were similar to those of researchers studying Indian culture [7], as several of the parents indicated, “it is in God’s hands.” Many Muslims believe that individuals with special needs are blessed (guaranteed entrance to heaven) and that the goal should be to keep them happy and healthy. This is in sharp contrast to the US where it is expected that individuals with AOID should be encouraged to achieve their potential.

The role of religion that emerged in the United States and South Korea was drastically different. Despite the fact that in both societies faith-based schools are not uncommon, participants reported that religion played a minimal role in the educational and clinical services for individuals with AOID. In both societies, public schools and most therapeutic centers strive to remain secular. In the US, the population is very diverse, and several participants indicated the importance of respecting parents’ and children’s personal beliefs while not making them a central part of the educational or clinical services being delivered. For instance, a psychologist at an autism center in the US who’s specialty is sexual health and education, indicated the importance of customizing interventions such that they adhere to the child’s religious and moral values.

4.1.4 Summary
Family structure, linguistic environment, and religion emerged as important cultural factors influencing the perceptions and expectations of individuals with AOID. We found that the level of support provided to individuals with AOID and their caregivers varies based on family structure. The data also suggested that language demands on individuals with AOID may compound communication difficulties. Lastly, it was seen that the impact of religion varies across the four countries, from marginal to dominating most aspects of everyday life. For these reasons, we believe there are opportunities for technology to help balance support across cultures for individuals with AOID and their caregivers, including such tasks as facilitating coordination. There are also opportunities for technology to be used to promote linguistic consistency in the child’s interactions. Finally, it is important for technology to adapt appropriately to reflect the role of religion in the life of the individual. This includes respecting boundaries of appropriate behavior, and understanding how religious morals and values are incorporated into practices, and in turn how they should be considered into the design of technology.

4.2 Socio-Technical Infrastructure
As a member of a community, activities an individual engages in are socially situated. In other words, activities cannot be isolated from the context in which they are occurring. Artifacts, including available tools and large-scale systems such as technologies and civic infrastructure, construct this context. In addition, the milieu, which refers to the individual, caregivers, friends, neighbors and other community members and the home, school and other social settings all frame the social environment of the individual. In our
study, we found that an individuals’ level of functioning was measured by their ability to perform adaptive activities by making use of technological and social infrastructure. Our data indicated that each country had varying levels of infrastructure development, which affected the individual’s activities and goals.

4.2.1 Technology and Civic infrastructure
The importance of knowing how to use the Internet in order to live independently and obtain employment was a notable example of how technology adaptation could influence the individual’s goals. It was apparent that having computer skills and other relevant simple technology competency is important across all four cultures. The need for these skills was largely dependent on the existence of advanced technology infrastructure and the level of access the average person had to the technology. The development of this infrastructure in Pakistan has not occurred as quickly as in the other three countries, therefore the importance of these skills was less emphasized.

In addition, in the United States and South Korea a great deal of educational material has been transferred to an interactive medium. Thus, to access the material, individuals need to understand how to use a computer. In these two countries, many modern jobs require proficient computer skills. To aid in the acquisition of these skills, participants in South Korea indicated that training courses were offered to recent graduates seeking employment to aid in learning to use the Internet, mobile phones, and other ubiquitous technologies. In all four countries job opportunities are directly proportional to level of technical competency. For this reason, our findings lead to the conclusion that the level of independence of the individual is closely related to his or her ability to understand and use technologies, though how much so is dependent on the level of technological development of the country.

We found that besides technology civic infrastructure also impacts the skills an individual needs to be successful. Public transportation systems are an example of complex large-scale civic infrastructures found in modern society [5]. Due to higher centralization of resources to the city, South Korean families tend to move to the capital for better education. This has caused high traffic in the city area that makes the use of public transportation essential. All South Korean parents and teachers indicated that they wanted their children and students to learn to navigate the public transportation system, in order to develop the ability live more independently. The teachers explained that a special curriculum exists to address these skills. It includes practice scenarios to teach students a variety of skills associated with transportation. These range from getting a ticket from a kiosk, to planning their route, and getting off the bus when they get to their destination. The curriculum also addresses relevant social skills, such as how to ask for helps if you get lost.

Despite parents and teachers in South Korea emphasizing the importance of understanding the public transportation system to an individuals’ independence, participants we interacted with in the United States did not mention these skills. We believe that this is due to the fact that the transportation system in the metropolitan city in which our participants reside is not convenient. Instead, participants in the United States stated that learning to drive was important, but very difficult, and often not feasible for certain individuals. This lead to difficulties in scheduling for parents, as it becomes necessary for them to provide all transportation. In Pakistan and Kuwait issues of transportation did not arise as concerns for teachers or parents. This was because in both of these countries it is easy and affordable to obtain hired help (i.e. a driver or a taxi) and there are often other family members around that can provide the individual with transportation.

4.2.2 Programs and services
Community-based activities and services, which arise from grassroots efforts by community members, are an important part of the lives of individuals with AOID. For example, South Korean teachers organized practice sessions where individuals could go through the steps of taking a bus to come to school. Community members like the bus driver, ticket salesperson, and bookstore clerk near the bus stop where the individual was supposed get off were notified about the rehearsal in advance and asked to help if the individual had any trouble. In this way, individuals were able to acquire a set of contextualized skills.

Participants from other countries also reported similar activities. For example, in the United States, we attended weekly social group meetings for adults with autism in which individuals on the spectrum and neurotypical volunteers meet to engage in fun social activities like bowling. This affords the individual with autism the opportunity to socialize in a real, but low stress environment. In Kuwait, one of our participants (a therapist) explained that she hosted tea time for girls with AOID every week. During these meetings the girls would practice the social skills necessary to interact with other women in a culturally appropriate manner, and share their experiences. Many of our participants explained that they believe that the existence of supportive community members is a key factor in the design social and life skills curriculums.

Examples of many additional services arose. In South Korea and the United States participants acknowledged the importance of the family that lives with the individual, and the challenges associated with the care of an individual with AOID. For this reason, in both societies family counseling services are available. In Kuwait and Pakistan, parents often receive this support from family members, rather than counseling services. In addition, a variety of extracurricular activities exist for individuals with AOID in all four countries. These range from Special Olympics (all four), and Challenger Little League Baseball Leagues (United States and Kuwait) to sensory friendly movie screenings (United States) and Rock Climbing (South Korea).

Lastly, curriculum development for academic programs arose as an important differing point between countries. In Kuwait, we found that most special need schools use American, Canadian or British curriculums. This fact makes it such that often, the content of the curriculums is foreign to the students, as they cannot relate to it. This is not the case in Pakistan, Korea and United States, where curriculums are developed locally. Furthermore, in Korea and the United States our data showed that multiple curriculums are often available, and attempts are made to customize them according to the student’s abilities.

4.2.3 Summary
As hypothesized, we found that the expectations and goals for individuals with AOID varied depending on the socio-technological system in their immediate environment, as some societies may require individuals to acquire more complex skills in order to be successful and independent. The data in this section also suggests that in all four countries efforts are being made at the community level to support individuals with AOID. There is a need, however, to facilitate collaboration among community members, and to aid in the process of customizing curriculums for particular individuals and cultures. We believe that there are ways that technology can help promote collaboration among interested stakeholders, and facilitate the customization of curriculums.
adopted from other cultures. There are also opportunities for technology to facilitate the acquisition of complex skills and to help individuals with AOID to live more independently.

4.3 Monetary and Informational Resources

4.3.1 Monetary Concerns
In our work, monetary concerns refer to socio-economic status and the availability of funding sources. In Kuwait the majority of the population is financially stable. Many of our participants indicated having paid out of pocket to travel to the United States or Europe to seek assessment and diagnostic services, and treatments. In addition, we learned that the government funds special education for all nationals. However, non-nationals, which make up half of the population, often struggle to fund education and services. We found that there is great variation in financial status of the population in the other three countries. This leads to the polarization of educational opportunities. Participants indicated that many special needs schools and services in Pakistan, South Korea, and the United States are very expensive and only the wealthy can afford to pay for them.

In Pakistan, teachers indicated that schools are often in need of funding for supplies due to limited government monetary resources. For this reason, donations from affluent locals are a key source of funding. In one of the schools we observed that the fee structure varied from child to child, in that the parents were charged a fee equivalent to what the child’s siblings who attended mainstream schools had to pay.

In Korea teachers indicated putting a great deal of effort towards working on proposals to raise funding. Providing high quality services was very important to them, and this tended to increase the overall cost of education. Participants in the United States also indicated that they are often in need of funding to purchase materials. This money is generally obtained from parents and fundraising in the community.

4.3.2 Informational Resources
In this section we discuss data related to both global and local information gathering of informational resources. Each culture has their own unique way of gathering and sharing the resources used to support individuals with AOID. In Kuwait schools adopt programs from abroad, and Google, Yahoo! Groups and other sites are commonly used for information gathering. This information is then adapted for use locally. In Pakistan Internet accessibility is not as ubiquitous, instead alternative media (e.g. TV programming) and information sessions given by experts are important sources of information. Our data from the United States and South Korea showed that numerous local organizations exist where interested parties meet to share ideas; these include universities and autism centers. In addition, in all four countries local workshops are conducted to keep caregivers informed. These venues provide stakeholders in the community with opportunities to meet and share information. In the United States, in particular, various specialized conferences provide a good source of information.

4.3.3 Summary
We found that socio-economic status and levels of government support leads to polarization in access to services. We also learned that there is great interest in sharing information across the cultures and efforts are made in each country towards the localization and customization of resources. These findings imply that there is a need to provide inexpensive technology that can make use of existing infrastructure to provide services in a more affordable and equitable way. Further, there are ways for technology to ease knowledge sharing and support activism.

5. Implications for Technology Design
Work has been done to identify ways in which the disability studies influence the field of assistive technologies [16]. These researchers indicate that there is a need for work that can connect culture to the use of technology. Our work begins to address this need. In particular, our findings provide a framework within which technology developed for individuals with AOID can be connected with culture.

Great cultural differences exist across the four societies that were studied. The three themes discussed in the previous section provided a framework within which it was possible to understand the nuances present in each of these cultures. In addition to helping members of society understand ways in which they can support these individuals in a greater context, these nuances have implications for the design of technologies and services for individuals with AOID in these societies. Following is a discussion in which we provide a cultural lens onto three technologies developed for individuals with autism. These technologies are impacted by these implications because they address such culturally dependent factors as; life skills and independent living goals, social skills, and data collection in the home environment.

5.1 Supporting Independent Living and Social Integration
As children with autism mature into adults concerns arise as to how this individuals will become integrated into society whether through going to college or getting a job. Regardless of culture, participants addressed the need for services that help them achieve these milestones.

We are developing a prototype that is connected to an online social network service (SNS) to help adolescents practice daily living skills. When an individual feels the need to ask for advice relevant to what he or she is doing at home, the system provides an opportunity to send questions to a trusted set of family, friends, and professionals and receive advice from them via the SNS. This solution may support parents who have been overwhelmed by the responsibility of supervising and supporting their children and facilitate intensive coordination. Thus, the online system will enable the distribution of labor related to caregiving across a set of people who already exists in the individual’s real social environment (e.g. grandparents and other relatives in Pakistan and Kuwait or neighbors in South Korea). The individual with autism will also have access to support at any time from anywhere.

Facilitating the process of making life skills related inquiries in a semi-closed online community benefits not only caregivers in terms of distributing responsibility, but also the individuals with autism, by enabling them to get quick feedback. Inevitably such a system may raise concerns about trust and privacy. Knowledge of regulations that are specific to this population is required to answer the following questions. Who has the authority to control membership in the trusted network? Who do individuals with AOID feel comfortable asking for help? What if questions or advice related to matters that are inappropriately personal are disclosed? The relationship and trust level between the individuals and people in their social environment cannot be generalized. As our data showed, relationships with family members and individuals in the community vary greatly across cultures. For this
The expected level of independence also varied across cultures. The prevalence of hired help in Pakistan and Kuwait alleviates many concerns regarding the acquisition of basic life skills such as those related to household chores and transportation. However, performing daily living tasks is necessary for young adults who move away from home. Money and time management are significantly important as well. Further, more sophisticated life skills—understanding social norms (e.g. etiquette, taboos)—are crucial in enabling the individual to integrate into the social world smoothly. The data we collected implied a number of those social norms are closely related to spirituality in Islamic cultures, but are veiled as hidden rules. To ensure the individual receives culturally contextualized feedback, we carefully design a verification system into the registration process that selectively allows for enrolling trusted people who understand the individual’s culture. For those whom want to give advice, but are unfamiliar with the social norms (e.g. a foreign teacher or relatives living in another country), the SNS can function as a repository of social rules that collects feedback from verified members and categorizes them, providing guidelines to ensure the appropriateness of the advice.

To support the contextualization of advice for an individual, one approach is to share a picture of the problematic moments and the day’s calendar of events that shows what the individual has on their schedule. This disclosure may conflict with perceptions of appropriate behavior in some cultures. For example, sharing pictures with anyone besides immediate relatives is not encouraged in Islamic culture, especially for women. Our work, and that of others [29] indicates, that out of respect for cultural conventions and spirituality, the design of technology should be framed by the religious and cultural values of the proposed user.

5.2 Supporting the Acquisition of Social Problem-Solving Skills

We are developing software to help non-expert authors (i.e. individuals who have little or no experience teaching social skills) to create customized social problem-solving skills instructional modules. These modules are designed to help an individual with autism prepare for a particular social context by presenting them with a social situation in which an unexpected obstacle arises, and guiding them through the process of overcoming the obstacle. It is obvious that, in the real world, many complex social situations exist in which a vast number of obstacles can arise, and each of these obstacles can be overcome in a variety of different ways. Each of these is culturally dependent; the situations, the obstacles, and the appropriate solutions. For this reason, it is crucial that the authoring tool be flexible enough to allow for the incorporation of cultural variations.

When designing software to support the acquisition of social problem-solving skills, it is imperative to understand the social context that the individual must navigate. Our data confirmed that what is seen as appropriate behavior is largely a social construct. The study also provided insight into the different cultural factors that must be considered—such as linguistic environment, religious values, and the social environment in which the individual must succeed to name a few. For instance, who you are expected to ask for help differs across cultures (e.g. mother, aunt, cousin, etc), and learning how to ask for help and what to ask is an important social problem-solving skill.

Our approach enables the author to customize the modules for their child, thereby allowing them to incorporate culture appropriately. However, the technology also uses crowdsourcing techniques to support and guide the author as they create the modules. Crowdsourcing is defined as “the act of outsourcing a task to an undefined (and generally large) network of people in the form of an open call.” [13] As such it is important that several measures be taken to insure that the data that is collected addresses the important cultural factors. For example, it is necessary to determine the cultural perspective of the laborers responding to the open call. One way to do this would be to explicitly ask culturally related questions as part of the task (e.g. what language do you speak at home?). In addition, language is not the only determining factor of cultural variations. It may be necessary to include means by which to determine the cultural biases of the respondent. This may be done by asking additional culturally sensitive questions that will enable us to understand the respondent’s cultural background without explicitly asking for it. Measures such as these will be very important in ensuring the cultural sensitivity of such a crowd-based system.

The tool could enable individuals to receive social skills instruction even if it may not otherwise have access to it because they cannot afford it or it is not available. As such, it addresses one of the other needs that emerged in our findings; the need for inexpensive technology that makes use of existing infrastructure to provide services in a more affordable and equitable way.

5.3 Facilitating the Capture of Problem Behaviors

Children with autism sometimes engage in problem behaviors such as tantrums, biting, and other potentially self-injurious or aggressive behaviors. Behavior assessments used to begin to address these behaviors generally have a long turnaround time. A single limiting factor is the enormous manpower that is required to observe the child in his or her natural environment. As a result, many times treatments must be determined based on parent report, instead of direct observation. Smart video recording technology can significantly reduce this turnaround time. Researchers have developed a new approach to recording called Selective Archiving [12], which, instead of continuously recording, only captures the event of interest when implicitly or explicitly triggered.

In large cohabitating families like those found in Kuwait and Pakistan this technology can be put to use very effectively. There is a wider care giving circle that can make use of the technology to capture videos of the individual with autism exhibiting problematic behaviors. These videos can then be used by a behavior analyst to make an assessment more quickly. In smaller nuclear families like those found in Korea and the United States, with both parents working, extensive use of this technology is limited. Making this technology “smarter” via automatic recognition of problem behaviors, taking the human out of the loop, can alleviate this problem.

As with any video recording, privacy is a major concern. There is no environment in which culture plays a more critical role than the home. People in all cultures have reservations towards the idea of recordings of them being captured in their home, which is generally a private environment. Some cultures, however, are more sensitive to the issue. In Kuwait and Pakistan, some religiously conservative families may not allow video recording at all and others may allow it subject to the condition that no female member of the family can be seen on the video. Civil law may also effect the adoption of technology. For instance, parents in the US are hyperaware of being perceived as being abusive to their
captures systems is informed by information about the privacy cultures. For these reasons, it is imperative that the design of such attitudes towards sharing recorded videos also differs across implications in the US. In addition to limiting the capture of data, having their activities recorded at home would have different nuances that have implications for technology development. Our experiences motivated us to study the expectations and cultural implications and opportunities for technology were explored. We believe this work can be expanded into a broader framework for developers of assistive technologies to use to situate their technologies in the cultural context.

6. CONCLUSION
Our research in technology and autism, and our personal experiences motivated us to study the expectations and perceptions of individuals with autism and other intellectual disabilities (AOID) in Kuwait, Pakistan, South Korea, and the United States. As hypothesized, this study exposed cultural nuances that have implications for technology development. Our findings allowed us to develop a framework, within which the cultural implications and opportunities for technology were explored. Though all 4 countries have strict child abuse laws, US society tends to be more vigilant than the other three countries. Therefore, having their activities recorded at home would have different implications in the US. In addition to limiting the capture of data, attitudes towards sharing recorded videos also differs across cultures. For these reasons, it is imperative that the design of such captures systems is informed by information about the privacy practices, and general cultural values of the particular family by which it will be used.

7. ACKNOWLEDGMENTS
Blank for blind review.

8. REFERENCES