Role of inclusively Designed Technology in Facilitating Communication for Children With Autism Spectrum Disorder

by

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Abstract

Individuals with Autism Spectrum Disorders (ASD) typically have reduced ability to communicate and socialize. This study explores the use of technology in supporting the developmental needs of children with ASD in Saudi Arabia. Specifically, it examines how useful and usable technological educational resources would be for this group of children when they are designed and developed inclusively keeping in mind their cultural needs. An iPad-based learning program called "Sweet Home for Kids" was designed and developed with specific features. The ease of use and cultural relevance of the program was tested with five children with ASD, their parents and teachers at the Jeddah Autism Centre in Saudi Arabia. Results of the study showed that portable electronic devices are very useful in engaging children with ASD, and that multimodal, visually attractive presentation and culturally relevant content make Apps attractive, usable and useful for children with ASD.

Acknowledgements

"Life goes on and history immortalizes the beautiful moments. Some we love, because people like them deserve to be loved and we can't help but love them .. and so we learn beautiful things from them .. and we rebuild many things with them .. and we paint life all over again and we work sincerely to give them some happiness and respect, if not all."

- Gibran Khalil Gibran

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In closing, "Goals are not only absolutely necessary to motivate us, they are essential to really keep us alive." - Robert Schuller.

Thank you all for having helped me keep alive and achieve my goals.

Dedication

For those who draw a beautiful part of my world ...

For those who painted my expatriation days with all the colors of love and giving ...

From the bottom of my heart, I want to thank the person who lit the first candle for me, supported me in my childhood, provided warmth in my life, gave me abundant love. That person is my mother. I also thank my father.

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Chapter 1 – Introduction

My study explores the use of technology in supporting the developmental needs of children with Autism Spectrum Disorder (ASD). Specifically, it examines how useful and usable technological educational resources would be for this group of children when they are designed and developed keeping in mind their cultural needs.

Autism spectrum disorder (ASD) represents a group of neurodevelopmental disorders, the most commonly known being autism. Symptoms are usually apparent before age 3 and last throughout a person's life. Individuals with ASD typically have reduced ability to communicate and socialize. They exhibit a wide range of symptoms and severity and have unusual ways of learning, paying attention, or reacting to different sensations. Experts estimate that 1 out of 88 children up to age 8 will have an ASD, with males being four times more likely to have an ASD than females (CDC, 2012).

Autism in Saudi Arabia

Although ASD is a global disorder, not much is known about its prevalence in Saudi Arabia (Al-Salehi, Al-Hifthy & Ghaziuddin, 2009). Approximately 250,000 children in Saudi Arabia are living with autism, with one out of every 100 children born being autistic (ARTC, 2012). Children with autism face many challenges in Saudi Arabia, such as lack of specialized centers to diagnose and monitor the condition. Social skills groups and other autism treatment facilities are not available in many places and treatment centers to assist those with autism are inadequate. This has resulted in an exodus of children with ASD. Approximately 8,000 autistic Saudi children are receiving treatment outside Saudi Arabia, as informed by the Autism Research and Treatment Center at King Saud University in Riyadh.

Importance of inclusive Technology

Technology has opened up new worlds for children with autism (McIlroy, 2012). Research shows that technology enjoyed by students could improve their motivation to learn, and iPads® are seen to be increasingly used in the education of children with ASD (McGonigle-Chalmers, et al, 2013). However, very few studies, such as by Campigotto, Mcewen and Epp (2012), have empirically examined the effects of iPads® on the behavior of children with autism. More research is necessary to understand the impact of using iPads® on communication and learning by children with ASD.

More than 700 software applications (Apps) for children with autism have been developed and marketed in Apple's App Store, some examples being Proloquo2Go and First Words. However, none of these Apps come with Arabic speech options. Further, the pictures and routines provided are not compatible with the cultural and social practices in Saudi Arabia.

Problem Statement

One of the main reasons why autism treatment in Saudi Arabia is inadequate is because of the time that it takes to adequately treat and care for children with autism. The software currently used in Saudi Arabia, from Boardmaker, is written in English. It takes time to translate this into Arabic. Whereas teachers should be spending more time teaching children the necessary communication skills and essential routines, like how to go to the super market or how to find the nearest toilet, they are having to spend more time on mundane things like translating learning material into Arabic.

Children with autism tend to keep to themselves, that is, engage in their own solitary activities. When they are around other children or adults, this behavior comes to the forefront and they rarely make attempts to socialize. This said, in a setting that involves video games, television or any type of screen, children with autism find these much more entertaining. This is counterproductive because for children with autism to improve their social skills, they need to engage and practice these social skills. The challenge is in their using technology such that their social skills increase.

Research questions

The questions that drive my research, therefore, are:

1. What is the role of technology in helping children with ASD to communicate better?

2. Does culturally inclusive design of technological educational aids help children with ASD engage better with learning?

I examined the first question through a systematic review of literature as in the next section. With regard to the second question, I designed a technological educational aid in both Arabic and English language to improve the social, communication, and behavioral skills of children with ASD, which is what rehabilitation centers in Saudi Arabia lack. My hypothesis is that learning programs that are culturally inclusive could have greater impact on the engagement of children with ASD with learning.

Chapter 2 - Literature Review

Bosseler and Massaro (2003) found that the use of computers could improve the language and vocabulary of students with ASD. Studies reviewed by Yaw and others (2011) point out that computers help significantly decrease behavior problems and motivate students with ASD. In this study, all participating parents confirmed that their children/adolescents with ASD liked using technology and portable electronic devices such as computers, video games, and iPads.

Using portable electronic devices with students with ASD has benefits for students, parents, and teachers. A survey of parents of children/adolescents with ASD (Athbah, 2012) has reported that parents feel using a portable electronic device at home, school, or in daily life activities improves (or would improve) the academic, behavioral, communicational, cognitive, social, language, daily life, adaptive, and recreational skills of students with ASD. Technology and portable electronic devices that are consistently implemented across the home, school, and daily life environments would help to measure the effectiveness in improving students' skills in these different settings.

The Mechling (2011) study supported the use of portable electronic devices across different settings such as school, work, and community. Results of the Mechling study also indicated that students were motivated and entertained when using portable electronic devices, however cost might be a prohibiting factor. The study indicated that

this issue could be addressed by using "generic devices that are designed for the general population in mass quantities" (p. 495).

Children with ASD are strong visual learners and are highly motivated by the use of portable electronic devices (Cihak, Ayres & Smith, 2010; West, 2008). According to Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH) program, trained autistic children learn through structured learning programs that utilize basic visual aids. This is one of the most important means of conveying information in a logical, orderly and sequential manner. This program was designed by Dr. Eric Schople in 1960s at the University of North Carolina. This was one of the first educational programs designed to educate and train individuals with autism. The program teaches important essentials like organizing one's environment and schedules, working individually, using visual aids and visual organization and learning the work routine.

Children with ASD find that they enjoy anything that has a screen; for example watching television or playing video games. With the technological advancements being made, doctors and researchers have learned how to incorporate computers and other technological products in working with children with ASD. They have found that, not only will this new technology help them enhance their ability to read, it increases attention and decreases agitation, but it also can help them in their social learning and communication.¹

ASD is a significantly represented developmental disorder. Effective interventions are needed for students with ASD and the role of parents is critical in those interventions. A

¹ <u>http://www.disaboom.com/assistive-technology-general/assistive-technology-for-autism</u>

survey (Athbah, 2012) confirmed the importance of technology (smartphones and tablets) in helping students with ASD. Respondents indicated that their child with ASD enjoys using and playing with technology. Moreover, parents pointed out that technology such as smartphones and tablets impacted positively on their children's skills. Although respondents considered these portable electronic devices expensive, they also believed the devices can reduce inappropriate behaviors and increase the academic, social, communication, and other skills of children with ASD.

In summary, earlier research points to the fact that portable electronic devices are used increasingly by children with ASD and are found to be helpful in their learning.

Chapter 3 - Method

Introduction

This study has two parts: (i) a theoretical examination of the role of technology in helping children with ASD communicate better; and (ii) the design, development and testing of a technological educational aid (iPad App) involving children with ASD in Saudi Arabia to examine the effect of culturally inclusive design on their engagement with learning.

The first part was done through a review of literature, presented in the previous section, which showed that parents and teachers of children with ASD increasingly used portable electronic devices (PEDs) for education and that software developed for these devices could better engage the children with learning. The results of the review were used for the second part, based on which the following special design features were provided to the developers for incorporation in the software to make it culturally inclusive for children in Saudi Arabia:

- An option to display the written words in English or Arabic.
- An option to have the written words spoken out in English or Arabic as displayed.
- Inclusion of culturally relevant content such as mosque, Koran, and such.
- Inclusion of pictures that are locally relevant.
- Inclusion of daily activities such as washing hands, in steps.
- Use of bright colors and pictures as appealing to local children.

Description of the 'Sweet Home for Kids' App

An iPad App called Sweet Home for Kids was developed with the help of a Saudi Arabian software company with the goal of teaching children with ASD simple things about mosque, school, home, hospital, zoo and mall. An image of the home screen of the App is given in Fig 1.



Fig 1. Homescreen of Sweet Home for Kids App

Screenshots of the iPad App and its Web version are given in Appendix A and Appendix B respectively. The application can be downloaded and used free from the Apple iTunes store from the following link: <u>https://itun.es/us/rz2VN.i</u>.

The Sweet Home for Kids application aims to develop the cognitive, self-care skills of children with autism, in addition to providing them occupational therapy. This application contains six basic concepts of society and includes some practical steps to acquiring the concept of experiencing a specific task such as visiting the dentist, wearing clothes, and

cleaning teeth. Parents, teachers, teacher's assistants, and children themselves can use this application.

This application employs images in delivering a springboard and scientific concept, which develops the ability of children with autism to process optical information and visually understand the relation. It also employs the technology in the education of members of this class that the technical means by which proved to be effective with people with autism.

Accordingly, the application has been designed to contain the following features:

1. Available in both Arabic and English.

2. Uses the globally approved Boardmaker images.

3. Can be used as an educational teaching means for general education teachers in integration programs, special education and with specialist assistants, families with the autistic disorder, and in children themselves.

4. Use as a means of entertainment.

5. Cruise in design and ease of use reduce effort and save time in routine business learning for teachers, coaches and parents.

6. The ability to achieve the goals of private education for children, developing their conversational and communication skills, helping them learn several skills, including the skill of using smart devices.

7. Attracting the attention of the user (child) due to the applicable method being interesting to the child as it is different from the usual education routine.

The App was tested with teachers, parents and students at an autism center in Saudi Arabia to study the effect of the App on the learning and communication experience of children with ASD and their caregivers.

Study procedure

The study was conducted in the Jeddah Centre for Autism Jeddah, Kingdom of Saudi Arabia after obtaining their permission [Appendix 'C']. A letter of invitation (as in Appendix D) was circulated through the school office to the teachers and parents of children enrolled in the school. Teachers who wished to participate in the study, and parents who wished to participate along with their child, were advised to email the researcher within five days from the date of the letter. To such respondents, an Information/Consent form [as in Appendix E] was sent by email. This form contained all details about the study in simple language. The children who participated in the research were minor children with ASD in the age range 5-16. Teachers signed the consent form on their own behalf and parents signed for themselves and also on behalf of their minor child. Upon receiving the consent form back from them, I added their names to the participants list.

Five participant groups were formed, each comprising one child, its teacher and parents. Three children had the same teacher and another teacher was common to the remaining two children. In effect there were 17 participants – five children, five mothers, five fathers and two teachers. I did not directly interact with the children, but only through a parent or teacher. In the consent form, there were options for the respondent to agree to or refuse video/audio recording during the sessions. There were also options for the participants to agree to the use of clips from video recordings featuring them in presentations made by the researcher or results published online. In all cases, the choices made by the participants were respected during the conduct of the sessions.

The consent form contained a section where participants were assured that participation is totally voluntary and that they are free to withdraw from the study at any point without any loss or harm accruing to them. The interview protocol contained a section where participants were assured that they were free to not answer one or more of the questions during the sessions if they feel they should not. None of the participants made a request to withdraw from the study.

Five groups participated in the study each comprising one child, the child's parents and the child's teacher. Each group spent seven days on the study. The group was provided with an iPad for this period with the Sweet Home for Kids App installed on it. Separate sessions were scheduled for each group as per protocol described in Appendix H. Details of activities that happened during the seven days are described below:

On Day 1, a 'start session' of about one hour duration was conducted. I conducted short semi-structured interviews individually with the parents and the teacher for about 10 minutes each, with seed questions as given below:

Q1: How long have you been associated with children with ASD/your child with ASD?

Q2: What is unique about the participating child?

Q3: Are you / is the child familiar with use of iPad-like devices for learning?

Q4: Have you used any learning App on iPad-like devices?

Q5: What resources do you use currently to teach the child?

Q6: Do you think these resources need to be improved in any way?

I then assisted them in learning to use the App on the iPad. Finally, she asked them to help the child interact with the App and observe for about five to ten minutes. I did not directly interact with the child. To gather data for subsequent analysis, I arranged for video recording of the entire session after obtaining the participants' permission. I then requested that the parents and the teacher help the child use the App for one hour every day over the next five days at home and in school respectively. I asked them to keep notes of the child's experiences, reactions and visible progress with the App.

On Day 7, I met the group again for one hour. At the start of the session, I conducted short semi-structured interviews individually with the parents and the teacher for about 20 minutes each, using seed questions given below:

Q1: How long did the child use the App each day from Day 2 to Day 6?

Q2: What were the visible reactions of the child?

Q3: Did the child try to communicate/share with you anything during the time?

Q4: Are there any special observations you wish to share?

Q5: How is this App different from other educational resources you have used?

Q6: How do you think can be done to improve?

Q7: How useful do you think the use of iPad-like devices are for helping children with ASD learn?

I then asked the parent or teacher to help the child interact with the App and observe for about 10 to 15 minutes. The entire session was video recorded, subject to participant consent. The interview was conducted in Arabic in case a parent so desired. I subsequently translated the data extracted from the video into English. Data was analysed through observation to find answers to research question two: does culturally inclusive design of technological educational aids help children with ASD engage better with learning?

Video recording and note-taking during the research was done digitally. The digital video and note files are stored in an encrypted form as password protected files on the computer of the researcher. All files created in the process of data analysis are also protected likewise. Only the researcher has access to the data as well as the participant code file. All data will be preserved for one year, after which time it will be destroyed through electronic/manual shredding.

Results of the research study are presented in the following section.

Chapter 4 - Results

The purpose of this study was to examine

- 1. How technology is useful in helping children with ASD to communicate better; and
- 2. How technological educational aids designed to be culturally inclusive help children with ASD engage with learning.

A review of literature revealed the following points, among others, in relation to item 1 above:

- 1. Children/adolescents with ASD like using technology and portable electronic devices such as computers, video games, and iPads.
- 2. Children with ASD are strong visual learners and are highly motivated by the use of portable electronic devices.

Results of the study conducted with children with autism, their parents and teachers at the Jeddah Autism Centre are reported below, grouped under themes, as emerged from interactions of the researcher on Day 1 and Day 7 with the parents and teachers.

Association with children with ASD

The two teachers who participated in the research had worked for 8 years and 16 years respectively with children with ASD.

Familiarity of children with portable electronic devices

All participants reported that they and their children/students were familiar with iPads. They discussed the Apps they had used. Most of them said there were no Apps in Arabic and that was a handicap. They had used iPads only with English Apps such as AutismApps (which is fairly complicated and takes time to use). One teacher said that she would like to find an educational App in Arabic language to teach ASD children at least the basic words, which has a few games to apply what children gain from it. The second teacher stressed the need for the establishment of an integrated educational training program on the iPad and its adoption in education for measuring the autistic child's progress. A majority of the children enjoyed playing games on the iPad and using Youtube.

Use of learning Apps on iPad

Except for the parents of one child, all parents and teachers had used learning Apps on iPad with their children/students. However, they were unhappy that only English Apps are available in the Apple Store and much time goes in adapting it into Arabic for the children.

Teaching resources used

All teachers, and parents barring one, used Picture Communication Symbols (PCS) from Boardmaker. AutismApps, TapToTalk and Bingo are other software apps used by some. All of these are in English, and a general displeasure was expressed about the time wasted in adapting these for Arabic-speaking children. They felt that the existing resources could be improved in many ways.

Usage of Sweet Home For Kids App by the children

Parents and teachers reported that, during the trial week, children had used the App daily for durations ranging from 2 hours to 4 hours – most common being 3 and half hours.

Visible reactions of children

Every child had reportedly felt attracted to and been happy with the use of colours in the Sweet Home for Kids App although one of the children appeared to have been upset for the first two days before getting used to and enjoying the App. Some children pronounced the name of known things soon after hearing the spoken words. It appeared to a parent that their child enjoyed listening to Arabic speech from the iPad. Parents said they felt happy to see their children express happiness.

One of the children was excited to go through the Restaurant part of the App. Another recognized a doctor in a hospital after having seen the image in the App. Most children repeated after the spoken words. Two of them explored the App by themselves, as it was clear and easy to use, while three sought help in between. One of the children browsed the entire App in one sitting.

Special observations

One of the parents said "It was a wonderful feeling for me to see my child so excited to show me how much he knows of the images and words." Some parents used expressions like: 'Amazing', 'All is good', "It is an excellent work', 'Easy to understand', 'Design is clear to use' and 'Good enough to start'.

The integration of image, voice and written word in the App, making way for multimodal learning, was much appreciated by many parents and teachers. Especially because such features were not available in traditional teaching resources used by them. Another observation was that it would be better if the App could provide "Syrian accent" One of the teachers said 'As a teacher we need more apps like this with even more exercises and games. And I think they need to include more educational clips.' One parent wished to see more verbs and conversational pieces in the app.

All participants used superlative terms to express the usefulness of Portable Electronic Devices (such as iPad) in helping children with ASD to learn, such as 'Magnificent', 'Wonderful', 'Unbelievable', 'Outstanding', 'Premium', 'Excellent' and 'Amazing'. They were appreciative of the language feature and the cultural relevance of the content of Sweet Home for Kids App for the children.

Comparison of Sweet Home for Kids App with other educational resources used

Teachers felt that the App saves more time and effort for them because it provides many of the concepts they need to teach and goals they need to accomplish, that too in Arabic. The time that is saved they will be able to use in the training of the child.

Parents felt that the App is very economical. It was way easier to use than some other apps currently used by them and more fun for the child. The traditional resources had too much information packed into them. Most of them said that their children love the iPad or any other PED and they thought that is the best way for their children to learn without getting bored. Apps on PEDs attract children's attention better and help in achieving the objectives of the traditional learning method much faster.

One of the parents felt that there would be no need to pay for speech therapy sessions anymore if they have such Apps. Another parent said that she found the Sweet Home for Kids App to be a lovely way to start the speech therapy session "My kid & I" with her child. Two parents said that including background music might make the children feel more attracted to the App and enjoy it better.

Suggestions for improvement

During the period of the usability study, teachers and parents worked with their students/children for a week helping them use the Sweet Home for Kids App. On the last day, they were asked to give their suggestions for improving the App. Teachers and parents wanted the following features to be included in the App:

- Educational videos/games (2 comments)
- Stories that describe risks/dangers in daily life (3 comments)
- Writing and coloring Apps (3 comments)
- Steps that describe how to go to pray in the Mosque
- Games and rewards
- Math
- More verbs and conversation
- More lessons on communication skills
- Multiple Arabic accents
- Happy face
- Background music (2 comments)
- Video clips about action steps in the App (such as Washing Hands)
- Lessons about feelings and emotions

In summary, the results of this research show that portable electronic devices are very useful in engaging children with ASD, and that multimodal, visually attractive presentation and culturally relevant content make Apps very attractive, usable and useful for children with ASD. A video report on the study is available at http://youtu.be/gCEHVpztT2k.

Chapter 5 - Discussion

An educational App titled 'Sweet Home for Kids' usable on the Apple iPad® was developed with the objective of helping improve the social, communication, and behavioral skills of children with ASD living in Saudi Arabia. Pictures and routines these children are culturally familiar with were included. Speech was provided in a language they are used to hearing (Arabic) besides English. The design requirements for this App were derived through secondary research of published literature and anecdotal information gathered from the community as well as the researcher's personal experience. Picture Communication Symbols (PCS) from Boardmaker were used; these can be accompanied by any written word/message and tend to be universally understood. The expectation was that this App will help teachers and parents in delivering information to children with ASD in an easy, quick and enjoyable manner and help those children communicate better with them, incidentally also reconfirming the importance of technology in facilitating communication for children with ASD.

Therefore, a weeklong research study was conducted involving children with ASD enrolled with the Jeddah Autism Centre (JAC) situated in Jeddah, Kingdom of Saudi Arabia, together with their parents and teachers. The JAC is a non-profit organization, the first of its kind in the Kingdom, offering good quality educational programs and support for families affected by autism. The study examined the ease of use and cultural relevance of the Sweet Home for Kids App. Results, as discussed in the previous section, indicate

that parents and teachers found the Sweet Home for Kids App to be an "enjoyable, easy and attractive way to learn" and the children engaged better with it than they previously engaged with traditional learning resources. Teachers and parents said that they were looking forward to finding Sweet Home for Kids App in the Apple Store as soon as possible.

Chapter 6 - Conclusions and implications

Autism is a social condition that is highly prevalent in all societies. I hope that my study will help in addressing the void that has been created by the inadequate facilities available in Saudi Arabia for children with ASD. I expect that the App I have created will enable teachers and parents to help children with ASD to learn in an easy, quick and enjoyable manner. I also expect that my study will illustrate the positive role played by technology in facilitating communication for children with ASD. The App will help teachers and parents to deliver information to such children in an easy, fast and lovable way. It will help children with ASD to communicate with their community.

The children, parents and teachers who participated in this study might have benefited to a small degree through the experience of getting to use the Sweet Home for Kids App on iPad for a week, although this cannot be quantified. The feedback provided by the parents and teachers will help in refining the design of educational Apps in Arabic, which could lead to further creation of tablet-based Apps in Arabic, that would benefit Arabic children with ASD. The field of inclusive design will benefit through findings from this research on cultural inclusion, which will help the development of software that are usable by a larger number of people.

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Appendix A - Screenshots from Sweet Home for Kids iPad App



Fig. 2. iPad App - Home screen (English)



Fig. 3. iPad App - Mosque



Fig. 4. iPad App - House



Fig. 5. iPad App - School



Fig. 6. iPad App - Zoo



Fig. 7. iPad App - Hospital

Appendix B - Screenshots from Sweet Home for Kids Web App



Fig. 8. Web App - Home screen (English)



Fig. 9. Web App - Home screen (Arabic)



Fig. 10. Web App - About Application



Fig. 11. Web App - Mosque



Fig. 12. Web App - House



Fig. 13. Web App - School



Fig. 14. Web App - Zoo



Fig. 15. Web App - Hospital



Fig. 16. Web App - Mall

Appendix C – Letter to Jeddah Autism Centre

Date:

The Director, Jeddah Autism Center Jeddah, Kingdom of Saudi Arabia

Re: Research Study support request

Dear Sir,

I am a student of the Master of Design program in Inclusive Design at OCAD University, Toronto, Canada. As part of my course requirements, I am doing a research project on the topic "Culturally inclusive design of educational resources for children with Autism Spectrum Disorder (ASD)." I have the approval from the Research Ethics Board of my University {Ref no.} as well as permission from relevant authorities in the Kingdom of Saudi Arabia for conducting a study as detailed below.

I have designed and developed an educational program for use on iPad, which contains learning material in Arabic and English that is culturally relevant to children in Saudi Arabia. I wish to examine the usefulness and ease of use of the program by engaging children enrolled in your institution in a week-long study. Each child will be grouped with the child's parent and teacher, and I will require five such groups. I need your help in circulating the attached letter of invitation to teachers and parents to participate in my study.

Each group will be provided with an iPad for one week with the program installed on it. On the first day I will spend about one hour with the group talking to them and helping them learn to use the program and engage the child with it. For the next five days, the parent and teacher will help the child use the program for about one hour a day (parent at home and teacher in the school) and keep notes of what happens. On the seventh day I will meet the group again for one hour to know their experience with the child and the program. Your support in conducting the study will help me discover how useful and usable the program is and how it can be improved.

If you need more information, please email me at <u>fatima.m4@live.com</u> or phone me at 00966581403444.

I look forward to your confirmation and hope you will be able to help me with my research.

Yours sincerely, Fatima Mohammad Alghamdi Student, Master of Design Program in Inclusive Design, Faculty of Design, OCAD University, 205, Richmond St. W, Toronto (ON) M5V1V3, Canada. Email: <u>fatima.m4@live.com</u> Phone: +16477735252 [Toronto] 00966581403444 [Jeddah]

Appendix D – Invitation to participate in research study

Date:

Invitation to participate in research study

Dear Teacher / Parent,

I am a student of the Master of Design program in Inclusive Design at OCAD University, Toronto, Canada. As part of my course requirements, I am doing a research project on the topic "Culturally inclusive design of educational resources for children with Autism Spectrum Disorder (ASD)." I have the approval from the Research Ethics Board of my University as well as permission from relevant authorities in the Kingdom of Saudi Arabia for conducting this research.

I have designed and developed an educational program for use on iPad, which contains Arabic speech and culturally relevant content that I believe will be useful to Arabic-speaking children with ASD. I need your help in engaging some children to use the App and also in giving me your feedback about the App.

To take part in the study, you will have to be a part of a group of three consisting of one child, one teacher and one parent. There will be five groups doing the study for one week. Each group will be provided with an iPad for this one week with the program installed on it. On the first day I will spend about one hour with the group talking to you and helping you learn to use the program and engage the child with it. For the next five days, each of you will help the child use the program for a total time of about one hour a day (parent at home and teacher in the school) and keep notes of what happens. On the seventh day I will meet the group again for one hour to know your experience with the child and the program. Your feedback will help me discover how useful and usable the program is and how it can be improved.

If you decide to participate in the study or wish to ask for more information to decide, please email me at <u>fatima.m4@live.com</u> or phone me at 00966581403444. Upon receiving your email to participate, I will send you further details about the study.

Thank you for taking the time to consider my request and I look forward to your reply. I hope you will be able to help me with my research.

Yours sincerely, Fatima Mohammad Alghamdi Student, Master of Design Program in Inclusive Design, Faculty of Design, OCAD University, 205, Richmond St. W, Toronto (ON) M5V1V3, Canada. Email: <u>fatima.m4@live.com</u> Phone: +16477735252 [Toronto] 00966581403444 [Jeddah]

Appendix E – Information / Consent Form

Information / Consent Form

 Date:
 May 10, 2013

 Project Title:
 Culturally inclusive design of educational resources for children with Autism Spectrum

 Disorder
 Disorder

Principal Student Investigator (PSI):

Fatima Mohammad Alghamdi, Student Master of Design program in Inclusive Design Faculty of Design, OCAD University 205 Richmond St. W., Toronto (ON) M5V1V3. Phone: 6477735252 [Canada] 00966581403444 [Saudi Arabia] Email: fatima.m4@live.com Faculty Supervisor: Prof. Jutta Treviranus Faculty of Design, OCAD University 205 Richmond St. W., Toronto (ON) M5V1V3. Phone: (416) 977-6000 Ext. 3950 Email: jtreviranus@faculty.ocadu.ca

INVITATION

Thank you for your interest in participating in my study. I learnt so far in my study that the educational resources currently available for children in Saudi Arabia with Autism Spectrum Disorder (ASD) do not have Arabic speech and also do not include pictures and routines that are culturally relevant to children in Saudi Arabia. I also learnt that children with ASD learn better with touch-screen devices. I have, therefore, designed and developed an App for use on iPad to help children with ASD in learning culturally relevant material in Arabic as well as English. You will now help me find out how easy to use and how useful this App is for children with ASD.

WHAT YOU WILL DO

You will be a part of a group of three consisting of one child, one teacher and one parent. The group will be associated with the study for one week. The group will be provided with an iPad for this one week with the App installed on it. On the first and last days, I will spend about one hour with the group. On the first day I will talk with each of you individually (as a parent or teacher) for about 10 minutes. I will ask you to share information about the current educational resources you are using with the child and your views about how those could be made better. I will also ask you to describe to me the child's level of interaction with such resources. I will then assist you in learning to use the App on the iPad. Finally, I will ask you to help the child interact with the App for about five to ten minutes. I will have a video recording done of the entire session so that I can replay it later and gather necessary information for my research. If you do not wish yourself or the child to be video recorded you are free to say so in the consent form, and I will exclude you from the video recording. Only your speech will be recorded. If you do not wish even your speech to be recorded, you are free to say so in the consent form, and I will exclude so four conversation.

For the next five days, each of you will help the child use the App for a total time of about one hour a day (parent at home and teacher in the school) and keep notes of what happens. On the seventh day I will meet the group again for one hour. I will ask each of you to share information about the child's experiences, reactions and visible progress with the App over the past five days. I will also ask your opinion about whether the App meets any needs of the child that were not met before and how easy you feel it is for the child to use. I will also ask you to help the child interact with the App for about five to ten minutes. I will have a video recording done of the entire session. Here again, I will respect the choice you make in the consent form regarding video or audio recording of the session.

If you wish, you could request at any point for the sessions to be conducted in Arabic.

POTENTIAL BENEFITS AND RISKS

There may be no direct benefit to you as parent or teacher through participation in this study. The children might benefit to some degree by getting to use the App on iPad for a week. Your feedback will help in better design of educational Apps in Arabic, which could lead to further creation of tablet-based Apps in Arabic, that would benefit Arabic children with ASD.

Participating in the study will not cause any harm to you within my knowledge. Also, I will not be interacting directly with the child.

CONFIDENTIALITY

I will be storing the video/audio recordings of our sessions on my computer very safely and securely. Only I will have access to this information. I will destroy the files from my computer at the end of one year. I will not be using the data for any other research nor sharing it with any other researcher. I will be creating a code for each of you and storing all your information with that code so that your name will not be connected with any of the data or results.

VOLUNTARY PARTICIPATION

Participation in this study is voluntary. If you wish, you may decline to answer one or more questions or refuse to participate in any component of the study. Further, if you wish to withdraw from this study at any time, you may inform me before May 31, 2013 after which I would be starting analysis of the data. I will then confirm your withdrawal and I destroy the data collected from you till that point. I wish to assure you that by withdrawing you will not be put to any loss of benefits to which you are entitled and you may do so without any penalty. Please send me an email that you wish to withdraw from the study and I will confirm your withdrawal by reply email.

PUBLICATION OF RESULTS

A short article about the research outcomes will be published in a popular magazine. I will share a copy of the article with you by email. Results of this study may be published in scientific journals or online venues. In any publication, only aggregated or anonymized data will be presented. Quotations from interviews or surveys will not be attributed to you without your permission.

If you agree, I would like to use small, relevant clips from the video recordings while making presentations about this research. Please tick the appropriate box in the consent form to say whether you consent to publishing short video clips featuring yourself/your child as stated. I will honour your choice.

CONTACT INFORMATION AND ETHICS CLEARANCE

If you have any questions about this study or require further information, please contact me, Fatima Mohammad Alghamdi (Principal Student Investigator) or Prof. Jutta Treviranus, my Faculty Supervisor, using the contact information provided above. The Research Ethics Board at OCAD University, Toronto, Canada, has reviewed this study and issued ethics clearance # 2013-16 on May 8.2013. If you have any comments or concerns, please contact the Research Ethics Office through jburns@ocadu.ca or at 416-977-6000 ext.474.

If, after reading and understanding the above, you decide to participate in the study, please fill in the Consent form below except for the signature and email a copy of this document back to me. When we meet, I will obtain you signature on a printed copy of your consent form and also give you a copy to retain with you.

Please use to the "Consent form for teachers and parents" on page 3 if you are consenting as a parent or teacher. Please use the "Parental permission form for minor child participant" on page 4 if you are a parent consenting on behalf of your child.

CONSENT BY TEACHERS AND PARENTS

I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

I agree to have a video recorded of my sessions with the researcher to ensure accurate capture of data for further analysis. I am aware that this material will be treated as confidential.

 NO, I only agree to audio recording NO, I do not want video or audio re 	g of the ses ecording of	sion the session
I agree to the use of clips from video recording □ YES □ NO	gs featuring	me in presentations made by the researcher:
Name:		
Signature:	Date:	
Name of person who explained consent:		(Please print)
Signature of person who explained consent: _		Date:

Thank you for your assistance in this study.

PARENTAL PERMISSION FORM FOR MINOR CHILD PARTICIPANT

I have read the information presented in the information letter about a study being conducted by Fatima Mohammad Alghamdi of the Faculty of Design at OCAD University, under the supervision of Professor Jutta Treviranus. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted. I am aware that my child will participate in the study if he/she agrees to participate and I agree to his/her participation.

I acknowledge that all information gathered on this project will be used for research purposes only and will be considered confidential. I am aware that permission may be withdrawn at any time (by either the parent and/or the child) without penalty by advising the researchers.

I realize that this project has been reviewed by, and received ethics clearance through, the Office of Research Ethics at OCAD U. I was informed that if I have any comments or concerns resulting about my child's involvement in this study, I may contact the Manager, Research, at 416-977-6000 ext.474.

Child's Name:	
Child's Birth Date:	
Gender of Child: Male Female	
I agree to have my child's session video recorded to responses. This material will be treated as confiden □ YES □ NO	o ensure an accurate visual recording of his/her tial.
I agree to the use of clips from video recordings fea □ YES □ NO	turing my child in presentations made by the researcher:
Name of Parent or Guardian:	(Please print)
Signature of Parent or Guardian:	Date:
Name of person who explained consent:	(Please print)
Signature of person who explained consent:	Date:

Thank you for your assistance in this study.

Appendix F – Wait List intimation

Date:

Placed on Wait List

Dear {Name of Participant},

This is to acknowledge receipt of your email indicating your interest to participate in my study. At this point, I have recruited the required number of participants for my study. However, I am placing your name on a wait list. In the event of any participant withdrawing during the study, I will contact people from the wait list, in the order in which the names were entered into the list.

Thank you very much for your interest to participate in my study.

Yours sincerely,

Fatima Mohammad Alghamdi Student, Master of Design Program in Inclusive Design, Faculty of Design, OCAD University, 205, Richmond St. W, Toronto (ON) M5V1V3, Canada. Email: fatima.m4@live.com Phone: +16477735252 [Toronto] 00966581403444 [Jeddah

Appendix G – Acceptance of withdrawal

Date:

Acceptance of withdrawal

Dear {Name of Participant},

This is to acknowledge receipt of your email indicating your intention to withdraw from this study. I confirm that you will not be associated with the study effective from {date}. I would like to assure you that, because of withdrawing, you will not be put to any loss of benefits to which you are entitled and that information collected from your so far will be destroyed and not used in the research.

Thank you very much for participating, and I welcome you to join me in future research opportunities, if any.

Yours sincerely, Fatima Mohammad Alghamdi Student, Master of Design Program in Inclusive Design, Faculty of Design, OCAD University, 205, Richmond St. W, Toronto (ON) M5V1V3, Canada. Email: <u>fatima.m4@live.com</u> Phone: +16477735252 [Toronto] 00966581403444 [Jeddah]

Appendix H - Session Protocol

Before meeting a participant group

- Print out the consent forms received by email from the participants in the group.
- Fill in the participant numbers and session date on the form.
- Keep one iPad ready for the group with the App installed on it.
- Fill in the session information below.
- Check that the video recording device is set up and ready.
- Make a note of the recording choices declared by the participants in their consent forms.

At start of Day 1 session

- Confirm from the participants that they have read and understood the Information/Consent material. If not, read/explain once again and sign the form for having done that.
- Get the participants' signatures on the Consent Forms.
- Ascertain from them if they need the whole or part of the session to be conducted in Arabic.
- Explain to them the setup of the recording device and assure them that their recording choices will be respected.
- Start the recorder and announce the following information.
 - Group number:
 - o Date:
 - Session start time:
 - Whether first day session or last day session

Introduction – read out to participants

Thank you for consenting to help me in my study. Please remember that your participation is voluntary. If you feel uncomfortable with any part of the session or any of the questions, you may request to skip it. You are also free to withdraw from this study at any time. You can feel assured that there will be no negative consequences.

Let us first talk about issues relating to children with ASD and learning resources available for them in Saudi Arabia.

Ask the following questions to teacher / parent (10 + 10 minutes)

- Q1: How long have you been associated with children with ASD/your child with ASD?
- Q2: What is unique about the participating child?
- Q3: Are you / is the child familiar with use of iPad-like devices for learning?
- Q4: Have you used any learning App on iPad-like devices?
- Q5: What resources do you use currently to teach the child?
- Q6: Do you think these resources could be improved in any way?

At the end of around 20 minutes, help the teacher and the parent learn to use the App on the iPad for about 10 minutes each.

Then let the teacher or parent engage the child with the App for 5 to 10 minutes.

Finally, instruct the teacher and the parent to engage the child with the App for one hour each at school and at home respectively for five days, keeping notes about the child's experiences, reactions and learning progress.

Day 1 session Conclusion – Questions / comments

- Is there anything you want to tell me?
- Do you have any other comments or questions?
- Can I contact you later in case any clarification or follow-up becomes necessary?
- Feel free to email or call me if you remember anything you thought needs to be told.
- This concludes our session. Thank you very much for your participation.

At end of Day 1 session

- Turn off the recorder. Check recording.
- Ensure data files are appropriately named with the Group number.

At start of Day 7 session

- Ascertain from them if they need the whole or part of the session to be conducted in Arabic.
- Explain to them the setup of the recording device and assure them that their recording choices will be respected.
- Start the recorder and announce the following information.
 - Group number:
 - o Date:
 - Session start time:
 - Whether first day session or last day session

Introduction - read out to participants

Thank you for helping me over the past five days by engaging the child with the App and noting your observations. Let us now talk about your experiences with that.

Ask the following questions to teacher / parent (20 + 20 minutes)

- Q1: How long did the child use the App each day from Day 2 to Day 6?
- Q2: Did the App meet any need of the child that was not met before?
- Q3: What were the visible reactions of the child?
- Q4: Did the child try to communicate/share with you anything during the time?
- Q5: Are there any special observations you wish to share?
- Q6: What is different about this compared with other educational resources you have used?
- Q7: What do you think can be done to improve the App?
- Q8: How useful do you think the use of iPad-like devices are for helping children with ASD learn?

At the end of around 40 minutes, let the teacher or parent engage the child with the App for 10 to 15 minutes.

Finally, thank the participants, collect the iPad from them and conclude the session.

Day 7 session Conclusion – Questions / comments

- Is there anything you want to tell me?
- Do you have any other comments or questions?
- Can I contact you later in case any clarification or follow-up becomes necessary?
- Feel free to email or call me if you remember anything you thought needs to be told.
- This concludes our session. Thank you very much for your participation.

At end of Day 7 session

- Turn off the recorder. Check recording.
- Ensure data files are appropriately named with the Group number.