

“Wow! You’re Wearing a Fitbit, You’re a Young Boy Now!”: Socio-Technical Aspirations for Children with Autism in India

Sumita Sharma¹, Krishnaveni Achary², Harmeet Kaur², Juhani Linna¹, Markku Turunen¹,
Blessin Varkey², Jaakko Hakulinen¹ and Sanidhya Daeeyya²

¹Faculty of Communication Sciences, University of Tampere, Finland, FI-33014.

²Tamana School of Hope, CPWD Complex, Vasant Vihar, New Delhi, India, 110057.

¹{firstname.lastname, sumita.s.sharma}@staff.uta.fi

²{krishnaveni.achary, blessinvarkey, harmeet0103, sanidhyaranger}@gmail.com

ABSTRACT

In this paper, we build a case for incorporating socio-technical aspirations of different stakeholders, e.g. parents, care-givers, and therapists, to motivate technology acceptance and adoption for children with autism. We base this on findings from two studies at a special school in New Delhi. First, with six children with autism, their parents and therapists we explored whether *fitness bands motivate children with autism in India to increase their physical activity*. Second, with five parents and specialists at the same school, we conducted interviews to understand their expectations from and current usage of technology.

Previous work defines a culture-based framework for assistive technology design with three dimensions: *lifestyle*, *socio-technical infrastructure*, and *monetary and informational resources*. To this framework we propose a fourth dimension of *socio-technical aspirations*. We discuss the implications of the proposed fourth dimension to the existing framework.

Author Keywords

Socio-technical Aspirations; Children with Autism; Autism in India; Technology Acceptance and Adoption.

ACM Classification Keywords

- Human-centered computing~Accessibility theory, concepts and paradigms
- Human-centered computing~Empirical studies in accessibility

Permission to make digital or hard copies of all or part of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for components of this work owned by others than the author(s) must be honored. Abstracting with credit is permitted. To copy otherwise, or republish, to post on servers or to redistribute to lists, requires prior specific permission and/or a fee. Request permissions from Permissions@acm.org.

ASSETS '18, October 22–24, 2018, Galway, Ireland
© 2018 Copyright is held by the owner/author(s). Publication rights licensed to ACM.
ACM ISBN 978-1-4503-5650-3/18/10...\$15.00
<https://doi.org/10.1145/3234695.3239329>

INTRODUCTION

Previous work by Boujarwah et al. [2] defines a three pronged framework for assistive technology design on the basis of culture. This includes, *lifestyle* which incorporates family structure, linguistic environment, and religion; *socio-technical infrastructure*, which consists of technology and civic infrastructure, and program and services available for individuals with autism; and *monetary and informational resources* that individuals and their families have access to. They also discuss the implications of their dimensions towards assistive technology design, development, and adoption for children with autism. Their framework is based on studies in four countries – Kuwait, Pakistan, South Korea, and USA.

To Boujarwah et al.’s framework [2], we propose a fourth dimension of *socio-technical aspirations* of the different stakeholders associated with raising a child with autism. This includes parents, care-givers, educators, therapists, typically developed siblings, and peers. We define socio-technical aspirations as the individual or community driven ambition and desire to own or use a specific technology for either personal benefit or societal acceptance, or both. We believe socio-technical aspirations provide a way to understand expectations and desires towards technology, which are also rooted in the context of culture. Moreover, the context of culture itself is dynamic, and therefore “the assumption that individuals have a single cultural background is problematic, especially in the face of contemporary patterns of globalization and transnationalisms” [13]. Therefore, understanding of socio-technical aspirations provides a snapshot of the dynamic context of culture from a technology perspective.

We propose the fourth dimension, of socio-technical aspirations, on the basis of our work with a special school in New Delhi and previous work on mainstream technology appropriation and adoption in assistive contexts. We focus on technology for individuals with autism. We define autism as a neuro-developmental disorder in which individuals experience varying levels of cognitive, social, and behavioral challenges, hence referred to as Autism Spectrum Disorder (ASD). First, we explored the usage of a Fitbit Flex fitness band for six children with autism. Our findings shows

that several parents were motivated towards using the Fitbit and devised motivational strategies to encourage their child to wear the bands. As the mother of one child proudly reported, other family members appreciated the child wearing a Fitbit (*paper's title*). To further understand what drives and motivates the adoption of mainstream technology, we interviewed five people (two parents, two researchers, and a therapist), three of which were a part of the first study. Lastly, we studied previous research on using everyday technologies, and not custom-made applications or in artificial circumstances, for the benefit of children with autism, in order to derive factors that affect intrinsic motivation towards technology use. From this, we build a case for considering socio-technical aspirations as the fourth dimension in Boujarwah et al.'s framework [2] for assistive technology design. We acknowledge that further work from different cultural contexts is required to fully support this dimension. With this paper, our aim is to set the ball rolling within the ASSETS community.

In this paper, we first contextualize the research within the related work in this domain. This is followed by the description of the first study; its methodology and results, including the distinct experiences that shower light on the socio-technical aspirations of the participants' parents and an occupational therapist (OT). Next, we present thematic analysis of the interviews conducted in the second study. We end by discussing the implications of *socio-technical aspirations* to Boujarwah et al.'s framework [2] and to future work in this domain.

RELATED WORK

Previous research has shown that cultural, social, and economical aspects affect the way autism is perceived and experienced by an individual and the various people that surround them [5]. Therefore, the 'experience of autism' varies largely between different cultures and regions across the world. We first discuss Boujarwah et al.'s framework for assistive technology design [2] and extend it to mainstream technology acceptance and adoption. We then describe the challenges of autism in India and the potential of mainstream technology. We conclude the section by presenting previous work on autism and obesity and the potential of fitness bands.

Extending Boujarwah et al.'s framework

Boujarwah et al. [2] conducted a study with several assistive technologies in Kuwait, Pakistan, South Korea, and the United States for individuals with autism and other neurodevelopmental disorders. Their work provides a firsthand understanding of how culture affects the experience of autism. For instance, the importance of living independently for individuals with autism, and therefore, the importance of designing assistive technologies that support independent living, varied among the four countries. In Kuwait and Pakistan, where it is culturally acceptable, or rather preferable, for individuals to live with their parents in a joint family even after marriage, interventions solely focused on independent living for individuals with autism

were not as desirable as for the participants from the United States. Based on their findings, Boujarwah et al. [2] define a three-pronged framework to understand the experience of autism in order to better design assistive technologies; *life-style, socio-technical infrastructure, and monetary and informational resources*.

This framework covers important aspects of designing assistive technology by situating the experience of autism at the center. In our work, on mainstream technology acceptance and adoption for individuals with autism in India, we experienced a different motivation or drive from the various stakeholders involved - their socio-technical aspirations. Socio-technical aspiration is different from Boujarwah et al.'s socio-technical infrastructure. Socio-technical infrastructure considers current and immediate access to technology as the motivation for technology mediated interventions for individuals with autism. For instance, Boujarwah et al. state that while acquiring some degree of computer skills was important across all the four cultures, "the need for these skills was largely dependent on the existence of advanced technology infrastructure and level of access the average person had to the technology" (ibid). This viewpoint, although an important first step, could potentially limit the way designers and researchers approach technological interventions, by focusing solely on the immediate needs. However, motivation towards technology acceptance and adoption is a more complex blend of various levels of access - immediate, near future, and future aspirations. Therefore, the socio-technical aspirations of an individual with autism and the various stakeholders surrounding them, ought to be taken into account, in addition to the socio-technical infrastructure. In this way, technology does not cater only to immediate needs but also to future aspirations. This shift in thinking from need-based to aspiration-based, according to Toyama [23], is the missing puzzle piece towards sustainable interventions in developing regions.

Autism in India

There is a culturally misguided attitude towards children with disabilities in India ([1],[7],[8]). Studies have shown that without prior acquaintance with a person with disabilities, teachers at mainstream schools meant to integrate children with special needs were unable to understand their needs [18]. Although, there are several schools for children with special needs across India, very few of them employ technology within their classrooms and there is limited research examining the role of assistive technologies. There are several challenges in introducing technology mediated interventions, especially for individuals with autism and other neurodevelopmental disorders, in India ([1],[20]). From resource constraints within the environment, for example, infrastructure and access to electricity, to a huge digital divide, thus communities that can benefit the most from technology have the least access to it. Moreover, inclusivity and integration

among children with disabilities and typically developed individuals is low.

Technologies are too costly, especially for individualized use, and the strong cultural barriers for individuals with autism, and other neurodevelopmental disorders, lead to more pronounced digital exclusion even within the technology-capable communities. For example, economically stable and educated parents might provide a mobile phone to a typically developed child and but not to a child with autism, or vice versa. Using mainstream technology that benefits both individuals with autism and their typically developed peers, can potentially overcome the cost barrier towards technology adoption as multiple people can use the same device. Parents, and other stake-holders, also have certain aspirations and social status attached to mainstream technologies. For instance, rural parents in south India associated computer learning for their children with better social status, one that demands respect [17]. Moreover, appropriating mainstream technologies for persons with disabilities removes the social stigma attached to the usage of assistive technologies that are usually aesthetically and visually different (than mainstream technologies), which in turn can increase long term adoption [21]. Therefore, it is important to consider adoption of mainstream technology for children with autism to assist in their day-to-day activities.

Autism and Obesity, and the Potential of Fitness Bands

Studies suggest several behavioral aspects of autism that can lead to a sedentary lifestyle, and hence increase the chances of obesity ([6],[12]). First, children with autism can have very strong preferences to specific foods, and therefore, be inclined to eat an unbalanced and restricted diet, that could potentially consist of a lot of junk food. Second, individuals with autism face challenges towards social interactions, and this can steer them away from group and social activities, such as playing sports, or playing in the park. Third, the experience of autism is highly dependent on culture, where some cultures are predisposed towards sedentary life-styles, due to the region's climate, infrastructure, or social norms [2]. For instance, within in the Indian context, the motivation for encouraging physical activities is blunted by the social constraints and limited understanding of autism. It can be difficult for children with autism to visit their neighborhood parks every day and run around with their typically developed peers. Therefore, it is important to motivate individuals with autism to be physically active.

Research has shown that technologies that provide social support, goal setting, progress monitoring, and positive reinforcements can motivate physical activity in typically developed individuals ([3],[5]). These technologies include fitness bands, mobile applications, and other wearable sensors, and are increasingly popular among typically developed peers to track their physical activity. Goal setting and positive reinforcement increase physical activity, such as walking, also for individuals with autism [14]. Furthermore, several studies have shown that individual with

autism benefit from physical activity, showing both improved motor and social functions, in addition to better weight management ([15],[22]). Creating routines and habituating children with autism to physical activities can lead to sustainable weight management interventions. Therefore, the focus of our work was to explore the perceptions among the parents and occupational therapist at the school towards physical activity, and study the potential of fitness bands in motivating individuals with autism to increase their physical activity, more specifically walking.

STUDY 1: USING FITBIT TO ENCOURAGE PHYSICAL ACTIVITY

The study was conducted with a special school in New Delhi that is dedicated towards providing individuals with neurodevelopmental disorders support for physical, emotional, and functional wellbeing through customized therapeutic interventions. The school's occupational therapist (OT), who is responsible for interventions that encourage physical activity, kinesthetic learning, proprioception and cephalocaudal proximity, and joint attention skills among others, was involved in the study. Parents accompany students who experience attention deficits and extreme social stress, and display behavioral issues. We used the Fitbit Flex [9] device, which has a 3-axis accelerometer and vibrational motor. Its display consists of five LED lights, which provide the level of progress when the device is tapped twice. The device tracks the number of steps, calories burned, active minutes, and total time spent asleep and awake, where one full recharge lasts between five to seven days. The Fitbit device needs to be synced using the Fitbit application on a mobile phone or computer, via Bluetooth, to retrieve data. Using the application, participants can set goals, connect with friends, monitor their progress, and win badges and awards. The default goal is ten thousand steps per day and was kept the same for the study. Figure 1 (left) shows the Fitbit Flex device and its band. Figure 1 (right) shows a broken band from the one of participants.



Figure 1: (left) Fitbit Flex device, and (right) a band that broke during our study

Procedure

In April 2016, before the school's summer break, a note was sent to parents of forty children with autism to encourage their child to wear a wristwatch during the holidays. The note did not mention the Fitbit fitness band and no other details were discussed with the parents, even if they enquired. Most parents assumed that the activity involved learning the

concept of time, as shared casually by many after the two-month summer break. The summer homework was devised to habituate children to wear a device on their wrist and to identify parents willing to invest the time and effort for doing so. From the forty parents that were sent the note for the summer holiday homework, four decided not to participate. From the thirty-six parents, who made their child wear a wristwatch, sixteen watches were broken or lost.

After the summer holidays, twenty parents, whose children did not lose or break their wristwatch, were invited to be a part of the Fitbit study. Of those, nine parents expressed difficulty in constantly monitoring the fitness band or were not convinced of the benefits of the technology for their child. A total of eleven parents expressed their interest in the study and were given a demo of the Fitbit Flex device and its application by the OT in 20-minute sessions. The OT discussed the features of the Fitbit Flex – of monitoring physical activity and sleep, and showed how to use the device and application. Next, the parents were requested to bring their smart phones or tablets to the school to setup the Fitbit application on their device. However, three parents dropped out because they did not own a smart phone or were not comfortable with technology to participate. The study started with eight parents, but data was only collected from only six participants. One participant relocated and changed schools. The other participant's fitness band stopped working on the first day, which was astonishing for the parents and they decided not to participate further.

From six participants took part in the study, one dropped out after a few days due to health reasons. Therefore, at the end, only five parents were interviewed. We learnt that the parents had devised several successful ways to motivate their child to wear a watch during the summer, and extended these to the Fitbit. Most of the motivational strategies situated the fitness band in cultural metaphors, which created a 'story', which is further discussed in the *Findings* section. The participants were asked to wear the Fitbit for 10 days, preferably consecutively. The OT spent an hour with each participant-parent pair, again introducing them to the fitness band and its application. All six participant-parent pairs visited the school regularly, barring any holidays or sick days. A volunteer assisted the parents with the data transfer, device charging, and answering their queries. A WhatsApp group of parents, OT, researchers, and the volunteer was created to provide immediate solutions to any problems.

Participant Profiles

Six participants (3 Males and 3 Females) took part in the Fitbit study, aged between 8 – 20 years ($M=12$, $SD=4$), diagnosed by the Autism Diagnostic Observation Schedule (ADOS) [16]. All participants were categorized as children with low functioning autism based on the Childhood Autism Rating Scale (CARS $M=33$, $SD=4$) [19] and by the school therapist, as they had low motivation for social interaction and communication (both verbal and non-verbal), and displayed various isolating behaviors and interests. When considering the BMI of the six participants, three are

underweight ($BMI < 18$), two are at healthy weight ($22 < BMI < 24$), and one participant can be considered obese ($BMI > 41$).

Several different stakeholders were a part of the study, including the school's occupational therapist and parents of the participants. Five of the six participants were accompanied by their mothers to the school and one by their father. Table 1 describes all the people involved in the study, their gender, and roles.

Data Collected

Fitbit activity, e.g. number of steps, calories burnt, and sleep data was planned to be collected for each participant, for each day they wore the device. Data was extracted from the Fitbit device using the application by the volunteer when the parents visited the school or by parents sending screenshots of the application to the school researcher via WhatsApp.

At the end of the study, we conducted semi-structured interviews with the parents of the participants and the OT. First, they filled in a questionnaire which asked them to rate their perception of the participants' level of communication (e.g. from verbal to gestures to does not communicate), socialization (isolated to sociable), and physical activity (very active to sedentary / dislikes being active) on a 5-point scale. Then they were interviewed about their experiences with the Fitbit and its perceived benefits. We also asked them to report any behavioral challenges and sensory issues (tactile, auditory, proprioception, visual) previously known or faced during the study. The interviews were audio recorded and later transcribed, and when required translated from Hindi to English. Two raters analyzed the transcribed and translated interviews using thematic analysis. Next, we describe our findings from the data that was collected.

Table 1: People involved in the study and their roles

People in the study	Number (Gender)	Role
Children with Autism	6 (3F, 3M)	Study participants
Parents of participating children	6 (5F, 1M)	Accompanying children to school, involved throughout the study.
Occupational Therapist (OT)	1 (F)	Motivating participants and their parents for wearing the device, and giving demos.
Researchers	2 (2 F)	Planning, execution, and analysis of the study. Interacting with participants and parents.
Volunteer	1 (M)	Data transfer and device charging. Interacting with only the parents.

Findings

Our results include the Fitbit application data, analysis of the questionnaires and interviews with the parents and OT, and our own observations. Together, the results provide a look into the socio-technical experiences of the parents, participants, and the OT during the study.

Fitbit Application and Band Usage

Figure 3 shows the number of days the Fitbit was worn and the average number of steps per day for each participant. The participants wore the device between 4 to 16 days, and five of them averaged over 6000 steps per day. However, one parent, whose child averaged about 2800 steps for the six days they reported the results, did not wish to report the step counts for the first week of use, and therefore that data was not collected. During the interviews, the parent expressed a growing realization of how they were encouraging a pampered but sedentary life-style. This being a sensitive issue was not probed further. Two participants reportedly enjoyed wearing the band, especially because of the blinking lights that flashed up on being tapped.

The participants and their parents faced different challenges during the study. Several participants experienced haptic sensitivity when wearing the fitness band. The OT would gently massage their wrist or use a soft clothes-brush for haptic therapy. Most of the participants did not wear the band while sleeping, and therefore the sleep data is not reported. One participant developed a skin rash while wearing the band due to the hot and humid weather in Delhi. Therefore, the participant wore the device on top of their shirt's sleeve. During the study, one participant started to reexperience seizures, and therefore did not want to participate in the study after a few days of wearing the band. The parent of that participant showed the Fitbit application to their doctor, who was pleasantly surprised to receive the data.

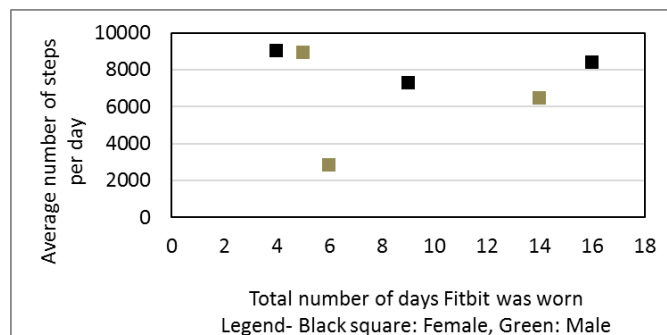


Figure 2: Fitbit data for the six participants

The study required a lot of effort from the parents - from regularly motivating their child to wear the fitness band by providing positive reinforcements, to the continuous monitoring of the band itself as they felt responsible for this 'expensive device'. They feared the child would lose or break the band. During the study, two bands broke due to regular wear and tear (Figure 1, right), and one was misplaced. It was extremely difficult to convince the parents that they do not need to compensate for the misplaced

device, as they felt very guilty about 'losing' it. The device was misplaced at school and was not found.

Questionnaire Analysis

The parents of five of the participants filled in the questionnaire. The OT filled in the same questionnaire for each participant. This allows us to compare the parent and OT's perception of each participant's level of communication, socialization, behavior, physical activity, walking, sensory issues, and sleep. Here, we define perception as the understanding and awareness of a participant's environment, behavior, and challenges. Perception is subjective and thus varies from person to person and situation to situation. For instance, a child who appears difficult for an outsider may not be so for the parent. Furthermore, perceptions of the same child can differ from member to member in a single family and from one educator to another within the same school. For instance, in our study, the OT works with almost one hundred children on a weekly basis, while the parents are only familiar with a few other children than their own. Therefore, their perceptions can be quite different. The rating between the parents and OT for each category were cross-tabulated and the interrater reliability analysis using Cohen's Kappa in SPSS was calculated, as shown in Table 2.

Table 2: Kappa Values of perceptions between Parents and OT

Perceptions of	Kappa Value (κ)	Significance
Communication	0.308	0.149
Socialization	-0.34	0.845
Behavior	0.118	0.626
Physical activity	0.379	0.032
Walking	-0.034	0.851
Sleep	0.077	0.728

Communication, socialization, and behavior

Communication was rated between (i) able to communicate verbally, (ii) uses some words, (iii) communicates using gestures and sounds, (iv) only using gestures, or (v) does not have a specific technique for communication. Children with autism can be verbal or non-verbal communicators and have difficulties with both modes of communication. Four of the six participants did not communicate verbally and used gestures understood by their family and therapists. Socialization and behavior were rated on a five-point scale, from isolated to sociable and from mild behavioral issues to extreme. Socialization includes appropriate behavior and participation as per social and cultural norms. Behavioral issues include repeated behaviors and the need for supervision for day-to-day tasks. Nearly 60% of the parents rated that their child needs supervision due to behavioral issues and whereas the OT rated only 40%. Overall, we

observed a low agreement between parents' and OT's perception of a child's communication and behavioral tendencies, and a disagreement (negative κ value) for socialization. This shows the complexity of the 'experience of autism' within the same community and even between individuals who meet and discuss a child's progress regularly.

Physical activity and walking

Physical activity and walking were rated on a five-point scale, from not active to very active and from no walking to walks regularly. We separated physical activity from walking to obtain a more nuanced understanding of both. Physical activity includes overall physical movements a child makes, due to behavioral issues or their restless nature, such as repetitive movements (hand flapping) and running in the classroom. Parents probably prefer taking their child for walks while the OT is more involved in games, skating, running on the treadmill, and playing in the school playground as a part of physical exercise sessions. From the data analysis, it is seen that the parents and the OT have the highest κ value for physical activity, even though the value indicates only a fair level of agreement ($p < 0.05$). What is surprising though is that the parents and OT have a negative κ value for their perceptions of walking, that is, they do not agree on how much a child walks. This is interesting given our study objective is to encourage children with autism to walk more. On one hand, we have parents who rated their child as engaged in moderate levels of walking, while the OT believes that the children should walk more, in spite of the physical exercise sessions within the school.

Sleep

Sleep was rated on a five-point scale, from interrupted sleep to sound sleep. Again, there was very little agreement between the parents' and OT's perception of the level and amount of sleep of a child. Initially, we planned to compare the parents' and OT's rating to the Fitbit application's sleep data, however this was not possible given the data is limited, and therefore, requires further exploration.

Sensory issues

Children with autism have both hyper and hypo sensory issues. Three participants experienced haptic hyper-sensory issues, which means that they found the sensation of the pressure of touch uncomfortable. The OT helped them become comfortable using haptic therapy and massaging their wrist. In future studies, hyper sensory issues should be taken into account when deciding the right technology for an intervention.

Overall, the questionnaire, and subsequent comparisons, showcase the differences in the experience of autism among different stakeholders within the same environment and culture. For example, a parent did not think much of the sedentary lifestyle of their (obese) child while the OT believed otherwise. This shows the complex social dynamics among the stakeholders that need to be navigated to

challenge incorrect assumptions, which we propose is possible through catering to socio-technical aspirations.

Motivational Strategies

Several motivational strategies were employed by the parent during the summer vacation and the study to convince and encourage their child to wear a wristband. This included comparisons to culturally relevant wrist accessories in India – a *rakhi*, bangles, *moli* (holy thread), and friendship bands. A *rakhi* comes in various shapes and sizes, the most popular one consisting of a large ornament on a thread (Figure 3, left). Bangles, as worn and liked by several female participants, are very popular in India (Figure 3, center). This analogy of considering a Fitbit Flex as a bangle, like jewelry, could potentially explain the 50% female participation in our study. During Hindu ceremonies people wear *moli*, a red holy thread, on their wrist for days or weeks after the ceremony is over (Figure 3, right). Friendship bands are common almost universally among schoolchildren and the participants also made them during their vocational sessions at the school. By suggesting to think of fitness bands as something else more familiar and comfortable, parents were able to motivate their child to wear one. This *motivation* of the parents to *motivate* their child, we believe, is a result of the parents' socio-technical aspiration of *having their child wear a Fitbit*.



Figure 3: An example of a (left) rakhi, (center) bangles, and (right) holy thread with small bells

Personal Narratives and Experiences

Several parents shared their personal experiences with the Fitbit, which although seemingly anecdotal create a picture of their socio-technical aspirations. To protect the identity of the participants and parents, gender-neutral pronouns (they and them) are used to represent individuals (as followed throughout the paper).

“Wow! You’re wearing a Fitbit, you’re a young boy now!”

Parents shared their child's expertise and experience with technology with pride and affection. As the title of this paper shows, one parent exclaimed that their child loved to wear the Fitbit band because of the social 'appreciation' they received, which in turn increased their 'confidence' and made them 'feel happy'. Another parent proudly narrated their child's comfort using a tablet and a web browser for findings songs on YouTube, although in this specific instance, the Fitbit was not mentioned. We gather from these remarks that parents find mainstream technology usage a

way to socially include (*peer acceptance*) and relate to their child within their experience of autism. This provides both the parents, and consequently their child, a sense of accomplishment and acceptance by (typically developed) people in their day-to-day surroundings.

Realization of obesity and need for physical activity

When the data from the Fitbit application was requested for the first time from the parents, one parent showed reluctance in sharing the data as their child's initial step counts were very low. This brought an awareness of the sedentary lifestyle of their child, which was not a cause for concern before the study. It is even more surprising that the parent reported to going on morning walks regularly themselves, however, missed the opportunity to motivate their child to do the same. Here technology motivated a parent to focus on physical activity and helped with the realization of the potential health issues for their child. This was not achieved previously with discussions with school experts, which can be in part due to the additional challenges a child with autism faces, and with parents juggling priorities.

Social and financial responsibilities of parents

Losing devices was an expected outcome of the study the researchers were prepared for and therefore no 'responsibility' towards the bands, for the parents, was explicitly mentioned or stated during the entire study. Moreover, we note there that the devices were not purchased by the school, so there was no pressure from other school staff either. However, several parents mentioned a fear of losing the 'expensive' device, and that if it were lost, it would be 'their fault'. This was because they felt their child does not display a sense of ownership, that is, if someone else were to ask for the Fitbit, they could give it away without raising an alarm or even mentioning the incident. When one band was misplaced, the parent believed they were responsible for the device being misplaced and therefore, should financially compensate (we requested them not to do so). This brings out the responsibilities that parents feel towards their child's behaviors and provides an insight into the social complexities within the cultural experience of autism in India. Here, social and technical responsibilities converge – with the parents being responsible for every action of their child and of the cost of the technology.

Potential of technology to inform and empower

One participant experienced seizures during the study and dropped out. Since they wore the device while sleeping, the parent was interested in analyzing the sleep and activity patterns that lead up to the seizure. The parent showed the Fitbit data to their pediatrician, who was pleasantly surprised to receive this information, as parents would usually retrospectively rate the quality of sleep for their child. The parent narrated this incident with a hint of pride and urged the researchers to consider running a study to map the sleep and activity patterns to the occurrence of seizures, but the parent and child stopped coming to the school shortly after. However, this incident shows the potential of technology to

inform and therefore empower parents of children with autism.

Overall, our results show that the socio-technical aspirations of the parents motivated them to devise culturally situated strategies to encourage their child to wear the fitness band. Moreover, their experiences show several positive outcomes, situated within their socio-technical aspirations of being technically savvy by using a Fitbit.

STUDY 2: PARENTAL PERSPECTIVES TOWARDS TECHNOLOGY

To expand on the experiences of the parents, researchers, and therapist in the Fitbit study, we conducted five interviews at the same special school in New Delhi in July 2016. Three of participants were a part of the Fitbit study and two were not. These interviews are a part of our ongoing work on technology acceptance and adoption in resource constraint environments, such as the special school in Delhi.

Procedure and Participants

Five participants were interviewed at the school with each interview lasting between 40-60minutes. Ten questions were asked. The five participants included two parents (1M, 1F), two researchers (1M, 1F) who are responsible for all technology driven mediations at the school, and the OT (F).

The interview framework consists of economic (school budget, disposable assets, economic responsibilities, contracts), socio-cultural (social practices e.g. between teacher and child, teacher and parent), organizational / political (rules, regulations) and environmental (e.g. infrastructure, architecture, spatial arrangements) perspectives. The different stakeholders bring in their own digital realities and aspirations. Similar categorization of perspectives has been used by e.g. Brewer, who writes about technical, cultural, and environmental challenges in reducing the digital divide [3]. The interviews were conducted in Hindi and English, and transcribed into English for analysis.

Findings

From the interviews, we grouped together the responses to the questions around technology access, desires, and challenges. The findings clearly show that parents, therapists, and researchers working with children with autism aspire to incorporate technology in the child's day-to-day life, even though there are several financial, informational, and infrastructural challenges. We next present the findings with excerpts from the interviews, which are anonymized by not providing a participant reference, since the sample size is too small.

Challenges towards Technology Access

As known previously, the participants mentioned costs and information as two of the main challenges towards technology access;

Price is too high, some parents are not able to afford. [We also should have] community support – therapist take the initiative to ask parents, and each other to find out new apps. Interaction is low. Nobody approaches you, nobody gets to

know, therapists have to take responsibility [of letting the parents know which applications to use].

When asked if one participant believed there was a lack of content that hindered their technology access, they stated;

I wouldn't say lack of content, but a lack of information, there are a lot of applications and content, people are not aware of them. So one can do google searching, YouTube searching.

Current Usage of Technology

We also enquired about current technology use of the participants and their children. Most of them mentioned using one or more online applications for shopping, banking, education, or entertainment. For their children, they said;

Personally, I go for play store, and then I get to know the new apps, and then search out for my kids, whether it will be beneficial for them.

However, technology usage per day was quite limited;

[We use technology for] 5-10 minutes for games every day. Only because the child is special child, so I let him play games coz he enjoys. I also play games with him, like puzzles combing pictures, matching games, ABC games.

School specialists used technology in novel ways to guide parents to provide therapy or follow-ups at home;

Help parents understand how to follow up at home by giving instructions on WhatsApp, taking pictures and videos of the children while they are doing therapy and share with parents via WhatsApp. They get an idea of what to do. Also share new pages/research on Autism on the school Facebook group, and on WhatsApp.

Challenges towards Technology Usage or Adoption

Two prominent challenges towards technology usage were identified; first a tug of war between the parents and school specialists on whose responsibility it is to discover and share new applications for the child. As one parent noted;

Teachers/therapists do not guide, just show us the iPad apps to use.

Second, the therapists lamented on parents' attitude of encouraging technology use over physical activity;

[The children] are using it every day, what I feel like is that children's physical activity level has been reduced and there is more expenditure on technology, on laptop, on iPads.

While from the perspective of a parent, using technology to keep their child busy is an obvious benefit;

[My child] is engrossed in that, and I can do my own work, I don't have to worry about what he is doing, so it is nice. A couple of hours a day, and on the weekends, he also uses. Sometimes he asks for my smartphone.

Another parent was concerned about overuse of technology;

My son plays games on the tabby (tablet), he is improving, but there should be a limit. The child should not forget the world and focus only on the tablet. That is not right. There are now many crimes via internet, kids need to be safe. So there is a bad effect too in kids when using technology.

Moreover, parents were content with technology usage at the school;

School should have technology because technology is monitored then.

But the school specialists noted that to approve any technology intervention, only the school authorities had the power;

The director of the school has to approve. Therapist and educators suggest and discuss...definitely, we are more savvy with technology and getting more ideas, we can work with the kids more [using] technology.

Socio-technical Aspirations

Although, this was not directly asked, we uncovered several desires or aspirations of the participants towards technology usage;

Yes, schools should have technology, iPad, and computers, is great for special kids. We should adopt technology from abroad. Each kid has a level. Even the special kids can do anything, good and bad...Kids are interested in technology. India should also be at par with the world in technology.

One of the parents beamed with pride as they reported;

[My child] is also savvy with technology, [they] can upload and download YouTube videos... [They] are quite techno savvy!

Yet, they also noted;

[I] didn't know what is autism until my [child] had autism. Whereas in the US and European countries they have a lot more awareness, [and support from] the government.

The school specialists stated that they use games as rewards or motivation for children with autism;

...using technology as rewards and for motivations, parents are also impressed that we are using technology. Parents are motivated to use technology and at the same time we also get motivated.

Another participant commented on the dark side of technology aspirations, as they observed;

...as you can see, people who do not have enough to eat, still have laptops, have mobiles. Mobiles are fine to use. India is progressing, but there is also a bad influence... It is expensive, but people who cannot afford food still have mobile phones. It has become an addiction. Girls in villages are using it too much. There is a lot of misuse. Kids who are older, are prone to misusing technology.

The parents and school specialists seem to have a complicated relationship with technology - on one hand they

want to use it for the child and are proud of their child's tech-savviness. On the other, they are also attuned to the potential risks of technology misuse or overuse. We discuss the implications of our findings from study 2, together with study 1, in the next section.

DISCUSSION

Boujarwah et al. [2] define a three-part framework to situate the design of assistive technology within the context of culture; lifestyle, socio-technical infrastructure, and monetary and informational resources. Our work, however, focused on mainstream technology acceptance and adoption within the context of a special school in New Delhi. Moreover, our work is also limited to one culture, that of a middle-class Delhi. Yet, we still propose a fourth dimension of socio-technical aspirations to Boujarwah et al.'s framework [2]. This is because, we find support for studying aspirations within resource constraint environments and HCI for *development* ([17], [23]). Our contribution is mainly streamlining the concept of socio-technical aspirations and proposing it to be situated within the more comprehensive and sustainable design context of Boujarwah et al.'s framework. We believe that an urgent next step is to elicit discussions and further research from different cultural contexts, and with shared resources.

Socio-technical aspirations differ from socio-technical infrastructure, in that, designing for current technology access and infrastructure misses the opportunities provided by the ambitions and desires of the people involved. These desires may or may not be a direct result of access and goals, and can arise in spite of underdeveloped infrastructure and lack of access. Furthermore, the dimension of socio-technical aspiration becomes important when considering acceptance and adoption of mainstream technology for supporting day-to-day activities for children with autism. Children with autism tend to display nonlinear progress, when compared to typically developed peers, which requires stronger motivation from parents and therapists to stay on course with planned interventions [1]. In this case, community driven social aspirations of the stakeholders involved in raising children with autism can provide that motivation. Adding socio-technical aspiration to Boujarwah et al.'s framework allows designers to consider mainstream technology adoption as a potential opportunity in resource constraint environments.

We support this dimension by the findings from the two studies presented in this paper. In the first, we explored the challenges and opportunities in introducing the Fitbit Flex to encourage physical activity to children at a special school in New Delhi. Working with six children with autism, their parents, and their occupational therapist, we found various challenges towards technology adoption and acceptance. These included the financial costs of buying a fitness band, which could be easily misplaced by a child, and the added responsibility of the parents towards monitoring the child and the band. The opportunities presented themselves as praise and appreciation of the child wearing the fitness band

and the realization of the need for physical activity to change sedentary life style behaviors. One thing to note here is the effect of self-selection of the families to our findings, that is, self-motivated and tech-capable families participated in our study, while others parents gradually dropped out. This behavior strongly supports our proposal to designers and researchers to understand socio-technical aspirations for technology acceptance, as there are many reasons to dropout, but only few to continue.

In the second study, we interviewed various stakeholders in the special school to understand the challenges they faced towards technology acceptance and adoption. Parents were proud of their child's tech-savviness and wanted their country to be at par with the developed world in terms of technology and education for children with autism. Tying this to socio-technical aspirations, we posit that an assistive device like Fitbit might have been more motivating for the families to use, given its mainstream appeal and design.

Moreover, within assistive technology design, there is an understanding that technology designed solely for a subset of users, can potentially make them more self-conscious, highlight a particular disability even further, and further isolate an individual [21]. This again brings into focus the dimension of socio-technical aspirations both from the perspective of assistive technology design and for mainstream technology adoption. However, we note that given the limitations of the work presented in this paper, we can only propose this dimension for further discussions.

From the perspective of assistive technology design, as in the case of Boujarwah et al.'s framework [2], understanding the socio-technical aspirations of the culture or community for which the technology is being designed, provides a mechanism to understand overall technology acceptance and adoption. For example, even though our work was carried out with a Fitbit, it is understood that other low-cost solutions can be adopted or designed to achieve the same purpose. In that case, again, it is essential to incorporate the socio-technical aspirations into the design, for example, considering the look and feel of the fitness band and how others perceive it.

Lastly, within the domain of technology for development, researchers are looking to redefine what it means to design for development. Current design practices are unable to support sustainable outcomes, that is, the technology is not always adopted in the long term after the study has ended and the 'researchers have left'. Toyama [23] urges us to think beyond designing for user needs, for that model unknowingly projects designers' or researchers' needs on to their users, to designing for user aspirations. This "shifts the attention from problem solving to people nurturing" (ibid), which can lay the groundwork for positive social change.

CONCLUSION

Given that the experiences of autism are rooted deep within the socio-cultural context, we believe that stakeholder aspirations can motivate the adoption of potentially

beneficial mainstream technologies. Therefore, we extend Boujarwah et al.'s design framework [2] towards technology acceptance and adoption for children with autism and purpose a new dimension of *socio-technical aspirations*. We define socio-technical aspirations, as the individual or community driven ambition and desire to own or use a specific technology for either personal benefit or societal acceptance. We encourage exploration of this concept further by different groups from different cultures and backgrounds.

ACKNOWLEDGMENTS

We thank all of participants and their parents for their valuable time, effort, and feedback.

REFERENCES

- [1] Achray, K. (2009) Autistic Children in India: An Insight. PhD Thesis, University of Delhi.
- [2] Boujarwah, F. A., Hong, H., Abowd, G. D., & Arriaga, R. I. (2011). Towards a framework to situate assistive technology design in the context of culture. In *proceedings of the 13th international ACM SIGACCESS conference on Computers and accessibility* (pp. 19-26). ACM.
- [3] Bravata, D. M., Smith-Spangler, C., Sundaram, V., Gienger, A. L., Lin, N., Lewis, R., ... & Sirard, J. R. (2007). Using pedometers to increase physical activity and improve health: a systematic review. *Jama*, 298(19), 2296-2304.
- [4] Brewer, E., Demmer, M., Ho, M., Honicky, R. J., Pal, J., Plauche, M., and Surana, S. (2006). The challenges of technology research for developing regions. *Pervasive Computing*, IEEE 5, no. 2: 15-23.
- [5] Consolvo, S., Everitt, K., Smith, I., & Landay, J. A. (2006, April). Design requirements for technologies that encourage physical activity. In *Proceedings of the SIGCHI conference on Human Factors in computing systems* (pp. 457-466). ACM.
- [6] Curtin, C., Anderson, S. E., Must, A., & Bandini, L. (2010). The prevalence of obesity in children with autism: a secondary data analysis using nationally representative data from the National Survey of Children's Health. *BMC pediatrics*, 10(1), 11.
- [7] Daley, T. C. (2004). From symptom recognition to diagnosis: Children with autism in urban India. *Social Science & Medicine*, 58(7), 1323-1335.
- [8] Desai, Miraj U., Gauri Divan, Frederick J. Wertz, and Vikram Patel. (2012). The discovery of autism: Indian parents' experiences of caring for their child with an autism spectrum disorder. *Transcultural psychiatry*, 49, no. 3-4 (2012): 613-637.
- [9] Fitbit Flex User Manual. As retrieved on September 2nd 2017 from https://staticcs.fitbit.com/content/assets/help/manuals/manual_flex_en_US.pdf
- [10] Goldsmith, T. R., & LeBlanc, L. A. (2004). Use of Technology in Interventions for Children with Autism. *Early and Intensive Behavior Intervention*, 1(2), 166-178.
- [11] Harrison, D., Marshall, P., Bianchi-Berthouze, N., & Bird, J. (2015, September). Activity tracking: barriers, workarounds and customisation. In *Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing* (pp. 617-621). ACM.
- [12] Hinckson, E. A., Dickinson, A., Water, T., Sands, M., & Penman, L. (2013). Physical activity, dietary habits and overall health in overweight and obese children and youth with intellectual disability or autism. *Research in developmental disabilities*, 34(4), 1170-1178.
- [13] Lilly Irani, Janet Vertesi, Paul Dourish, Kavita Philip, and Rebecca E. Grinter. (2010). Postcolonial computing: a lens on design and development. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (CHI '10). ACM, New York, NY, USA, 1311-1320. DOI: <https://doi.org/10.1145/1753326.1753522>
- [14] LaLonde, K. B., MacNeill, B. R., Eversole, L. W., Ragotzy, S. P., & Poling, A. (2014). Increasing physical activity in young adults with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 8(12), 1679-1684.
- [15] Levinson, L. J., & Reid, G. (1993). The effects of exercise intensity on the stereotypic behaviors of individuals with autism. *Adapted Physical Activity Quarterly*, 10(3), 255-268.
- [16] Lord, C., Risi, S., Lambrecht, L., Cook Jr, E. H., Leventhal, B., DiLavore, P.C., Pickles, A., and Rutter, M. (2000). A standard measure of social and communication deficits associated with the spectrum of autism. *Autism and developmental disorders*, 30(3), 205-223.
- [17] Pal, J., Lakshmanan, M., and Toyama, K. (2007). My child will be respected: parental perspectives on computers in rural India. In *Proceedings of the International Conference on Information and Communication Technologies and Development*, pp. 1-9. IEEE
- [18] Parasuram, K. (2006). Variables that affect teachers' attitudes towards disability and inclusive education in Mumbai, India. *Disability & Society*, 21(3), 231-242.
- [19] Schopler, E., Reichler, R. J., DeVellis, R. F., and Daly, K. (1980). Toward objective classification of childhood autism: Childhood Autism Rating Scale

- (CARS). *Autism and developmental disorders*, 10(1), 91-103.
- [20] Sharma, S., Srivastava, S., Achary, K., Varkey, B., Heimonen, T., Hakulinen, J., ... & Rajput, N. (2016, October). Gesture-based Interaction for Individuals with Developmental Disabilities in India. In *Proceedings of the 18th International ACM SIGACCESS Conference on Computers and Accessibility* (pp. 61-70). ACM.
- [21] Shinohara, K., & Wobbrock, J. O. (2011, May). In the shadow of misperception: assistive technology use and social interactions. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 705-714). ACM.
- [22] Sowa, M., & Meulenbroek, R. (2012). Effects of physical exercise on autism spectrum disorders: a meta-analysis. *Research in Autism Spectrum Disorders*, 6(1), 46-57.
- [23] Toyama, K. (2017) Design, Needs, and Aspirations in International Development. In *IFIP Advances in Information and Communication Technology*, vol 504. Springer.