

**Community-Based Participatory Research to Develop a Client-Centred Virtual Reality  
Program for Children with Autism: An Integrated Knowledge Translation Approach**

by

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The following individuals certify that they have read, and recommend to the Faculty of Graduate and Postdoctoral Studies for acceptance, the dissertation entitled:

# Community-Based Participatory Research to Develop A Client-Centred Virtual Reality Program for Children with Autism: An Integrated Knowledge Translation Approach

submitted  
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the  
degree of   Doctor of Philosophy

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## **Abstract**

**Background:** Autism spectrum disorder (ASD) is a disorder that affects socio-emotional skills. As there is no curative therapy for ASD and traditional interventions are costly, introducing possible complementary programs is warranted. Low-cost gaming programs (e.g., Kinect games) can enable users to communicate with characters on the screen through intuitive ways such as gestures or speech. However, current studies did not tailor the Kinect games to address individual needs of children with ASD.

**Purpose:** The **objective** of this five-phase study was to design and develop a Kinect program using an integrated knowledge translation approach and participatory design.

**Method:** The **first and second phases** involved studies that gathered perspectives of 26 stakeholders on: (a) barriers to social participation and priorities for the focus of the Kinect program; and (b) factors that can make virtual reality programs effective to use, employing interviews and focus groups. The **third phase** was developing and validating the social stories for the content of the program via the modified Delphi method, with 63 stakeholders. The **fourth phase** was developing and debugging the program in an iterative process with 10 children/youth with ASD and their parents. The **fifth phase** aimed to uncover barriers in adoption of the technology, helping us to plan for the knowledge translation activities during dissemination.

**Results:** In the first two phases, stakeholders identified the ability of perspective-taking in socio-emotional situations as a critical element to enhance social participation, and highlighted the importance of mirroring real world, addressing heterogeneity, and incorporating teaching strategies in a virtual reality program. In the third phase, they

suggested explaining social scenarios and incorporating calming strategies. Adjusting the audio-visual features and strategies to engage users were expressed in the fourth phase. In the last phase, barriers to technology uptake were identified, such as personal belief, suitable technology, and external resources to implement.

**Implications:** This study introduces the development process of a novel program for children with ASD in collaboration with stakeholders. Involving stakeholders during all stages of the development help meet end users' needs. Future studies are required to provide evidence on the efficacy of this program in improving socio-emotional functioning.

## **Lay Summary**

Autism spectrum disorder (ASD) is a childhood developmental condition. Virtual-reality programs are affordable alternatives that can be used to improve social skills among children with ASD. Despite the importance of developing a user-centred technology, there is a lack of literature to describe the process of incorporating stakeholders' ideas during the co-development.

In this project, we involved over 120 stakeholders including youth/children with ASD, their parents, clinicians, and administrators of ASD organizations during the development of a motion-gaming Kinect program to address social participation of children with ASD. We describe the process of developing the technology during five phases while incorporating end users' opinions.

Stakeholders offer valuable perspectives that should be considered in research and practice. By involving stakeholders during development, there will be an increased likelihood to meet end users' needs and enhance the uptake of the program.

## **Preface**

The research studies and phases of this project were conducted in the community and at the Department of Occupational Science and Occupational Therapy at UBC, in Vancouver, British Columbia, Canada. The five studies of this research were designed and developed by Parisa Ghanouni in consultation with Dr. Tal Jarus (supervisor), and Drs. Jill G. Zwicker and Joseph Lucyshyn (supervisory committee members).

Ethics approval for the work described in Chapters 2 and 3 was obtained from the Behavioural Research Ethics Board of the University of British Columbia (H16-01806). My involvement included study design, development of the research projects, participant recruitment, data analysis, writing the manuscript and disseminating findings. Versions of Chapters 2 and 3 will be submitted for publication.

The protocol for the work described in Chapter 4 was approved by the Behavioural Research Ethics Board of the University of British Columbia (H14-01173). I was responsible for study design, participant recruitment, survey development, data analysis, writing the manuscript, and dissemination. This chapter has been submitted for publication.

Ethics approval for the work described in Chapter 5 was obtained from the Behavioural Research Ethics Board of the University of British Columbia (H16-02904). My role included concept formation, participant recruitment, acting as a liaison between programmers and study participants, trialing the program, data analysis, writing the manuscript, and dissemination. A version of this chapter has been submitted for publication.

The study described in Chapter 6 was approved by the Behavioural Research Ethics Board of the University of British Columbia (H16-02911). I was responsible for study development,

recruitment, data collection, data analysis, authoring the first draft of the manuscript, and dissemination. A version of this chapter has been submitted for publication.

Tal Jarus (T.J.) supervised all research projects and provided ongoing guidance and support in concept formation, study design, development of research projects, data analysis, and interpretations. She edited all the documents and manuscripts that are based on this dissertation. Jill G. Zwicker (J.G.Z.) contributed to the design of the studies, recruitment and partnership with BC Children's Hospital and Sunny Hill Health Centre for Children, and provided constant support in refining the project. She provided feedback and assisted in editing all manuscripts and chapters of this dissertation. Joseph Lucyshyn (J.L.) contributed to study design of the project, gave feedback and edited all chapters of this dissertation.

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## Glossary

**Client-centred approach:** This approach emphasizes that clients or patients have both the right and ability to be involved in the decision-making process. It acknowledges that clients are aware of their needs and can prioritise their goals to optimise health care outcomes (Directorate, 1991; Law, Baptiste, & Mills, 1995).

**Content analysis:** Systematic analysis of spoken or written texts in qualitative studies that involves developing codes, categories, and themes (Hsieh & Shannon, 2005).

**Empathizing-systemizing cognitive style theory:** This theory suggests that people can be categorised based on the scores on two dimensions of empathizing or systemizing. Those with high empathizing have greater interest in empathy, and those with high systemizing score have greater interest in systems and rules (Baron-Cohen et al., 2005; Baron-Cohen, 2009).

**Embodiment theory:** This theory indicates that there is a strong link between sensory-motor and cognitive systems. It reflects that feeling and thoughts are grounded in bodily interaction with the environment. Embodied learning offers an intellectual way of thinking while involving physical movements, leading to more effective learning (Kiefer & Trumpp, 2012).

**Flow model:** This model describes perceived challenge of the task and the level of skill during the learning process. Based on this model, if the challenges are too much or too little, the users might get anxious or bored, respectively, which reduce the learning. To optimize learning, the challenge should be adjusted based on the skill set of learners (Boutsika, 2014).

**Interpretive description approach:** This is an inductive analytic approach designed to create ways of understanding phenomena (Thorne, 2016). According to its philosophical

underpinning, interpretative description emphasizes contextual and constructed human experiences that create multiple realities. This approach values subjective knowledge and attempts to inductively generate interpretations of a phenomenon that can be applied in clinical practice.

This constructivist and interpretive positioning help researchers to consider alternative perspectives and potential biases during interpreting findings.

**Knowledge translation:** All the activities to facilitate moving the research from academia to the hands of stakeholders to put the findings into practice. The Canadian Institutes of Health Research (CIHR) defines this dynamic and iterative process as synthesis, exchange, dissemination, and ethically sound application of the findings (Graham, 2007).

**Participatory design:** This approach actively involves stakeholders during the design of a product to ensure meeting end users' needs (Kujala, 2003).

**Perception-action model:** This model explains that there is a shared representation for perceiving and performing a behaviour. According to this model, perception of a behaviour will automatically represent the respective repertoire in the brain that consequently outputs the shared experiences of that behaviour. This circuit will be provided by mirror neuron systems (Preston & De Waal, 2002; Preston, 2007).

**Perspective-taking:** The ability to interpret others' mental states and predict social behaviours (Flavell, 1992).

**Repertoire:** Internal model or mental representation of an output behaviour (Preston & De Waal, 2002).

**Social behaviour:** Behaviour that is observed among two or more entities (Sanchez Puerta, Valerio, & Bernal, 2016).

**Social participation:** The extent of everyone's involvement in social activities (Law, 2002).

**Social skills:** The competence of social interaction and communication (Sanchez Puerta, Valerio, & Bernal, 2016).

**Socio-emotional skills:** The ability to understand, express, and manage emotions in social situations (Sanchez Puerta, Valerio, & Bernal, 2016).

**Virtual reality:** A simulated three-dimensional image or environment generated by computers that allows players to manipulate objects in the virtual settings and/or interact with agents (Parsons & Cobb, 2011). Virtual reality is the term used to describe when users are part of the virtual world or when they are immersed within the environment. However, the degree of embodiment and immersion vary in different devices (Dautenhahn, Ogden, & Quick, 2002; Dautenhahn, 2003).



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Finally, from bottom of my heart I thank all children and youth with ASD, their parents and clinicians, and administrators of ASD organisations who participated in the project and volunteered to share with us their wisdom. I truly appreciate all your significant contributions.

## **Dedication**

I dedicate this work to my family, who has been truly supportive of me intellectually, emotionally, and mentally, for every day, minute, and second of this project when I was miles away from them, living and studying. My heartfelt thanks for everything to my family, because of their patience, tolerance, and insight. This work and everything I have in life would not have been possible without them.

## **1. Introduction**

### **1.1 Importance of Socio-emotional Skills**

Human-beings as social creatures communicate with each other and send messages through various modes (Cozolino, 2006). Verbal and non-verbal interactions help humans to share their ideas, thoughts, and feelings. Being considerate of other people's feelings, responding to them appropriately, and expressing personal needs are all social skills that affect the quality of social interaction (Cozolino, 2006; Sanchez Puerta, Valerio, & Bernal, 2016).

Socio-emotional skills refer to a wide array of abilities that act as integral parts of communication and help build other skills. Socio-emotional skills, such as recognising emotions, enable children to build relationships with peers and learn through play. It has been shown that children who are emotionally and socially adjusted have a greater chance of success in school-related activities (Raver, 2003; McClelland & Morrison, 2003). Appropriate social interactions with children will increase their self-esteem and confidence to keep their connections and further communicate with others.

Children typically learn socio-emotional skills during development by experiencing interpersonal interaction. Multiple brain areas, such as the temporal regions, fusiform area, and limbic system primarily contribute to the understanding of socio-emotional cues (Soto-Icaza, Aboitiz, & Billeke, 2015). As children grow, these areas of the brain get more fine-tuned and mature to function appropriately. However, children with developmental disorders, such as autism spectrum disorder, might have difficulty to learn socio-emotional skills

naturally or might demonstrate a delay in or difficulty with these skills compared to their typically-developing peers.

## **1.2 Autism Spectrum Disorder and Prevalence**

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental condition affecting social interaction and reciprocal communication (American Psychiatric Association, 2013). These symptoms are present from early in development and last throughout life (Baron-Cohen, 1989; Baron-Cohen, Wheelwright, Hill, Raste, & Plumb, 2001; Kuusikko et al., 2009). Although there is no psychopharmacological therapy to treat this lifelong disorder, interventions, education, and compensatory strategies may help to reduce the symptoms.

This social function disorder is one of the most prevalent childhood disorders in the world, with about 1 out of 59 children diagnosed with ASD (Baio et al. 2018). This disorder is observed more often in males than females with the ratio of 3:1, and the prevalence is on the rise (Wingate et al., 2014). Although the precision of diagnostic tools and increased awareness may contribute to this growth, the possibility of true increased incidence rates of autism cannot be ruled out (Ouellette-Kuntz et al., 2014). It is expected that this prevalence will continue its upward trend; therefore, appropriate planning and resource allocation should be taken into account.

## **1.3 Socio-emotional Difficulties in Individuals with ASD**

Problems in communication skills and impaired social interaction, both in quality and quantity, are the core symptoms in children with ASD. These children have fewer social

interactions and spend less time interacting with others (Hilton, Crouch, & Israel, 2008). They also show heightened anxiety in social contexts compared to their typically-developing (TD) peers (Corbett, Schupp, Simon, Ryan, & Mendoza, 2010; Corbett et al., 2014). This hyper-arousal and social anxiety in children with ASD can be the result of poor adaptive social skills and coping strategies to respond appropriately. Enhanced anxiety can also reflect a greater awareness of their own limited social skills in preparation for appropriate social interactions (Corbett et al., 2010). As children with ASD get older, they gain more insight about their limited social competencies and they experience more stress in social contexts (Corbett et al., 2010; Kuusikko et al., 2008; Lopata, Volker, Putnam, Thomeer, & Nida, 2008).

Children with ASD show delay and difficulty in perspective-taking, that is, the ability to interpret others' mental states and predict social behaviours. According to the theory of mind (Baron-Cohen, 1990; Baron-Cohen, 1997), children with ASD have problems in understanding that other people have different viewpoints, leading to dysfunction in inferring others' emotions, desires, and intentions. Deficits in intention-reading and not being capable of understanding the desires, feelings, and emotions of others contribute to the challenges children with ASD face with social interactions (Baron-Cohen, 1990; Moran et al., 2011). The ability to attribute behaviours to various intentions and emotions, and understanding what is in the mind of others are parts of empathy. To empathize with others, it is necessary not only to understand others' mental states or emotions (cognitive part), but also to respond to them appropriately (affective part) (Aan Het Rot & Hogenelst, 2014). As perspective-taking, cognitive empathy, and affective empathy are linked together and difficult to separate (Bensalah, Caillies, & Anduze, 2016), children with ASD show difficulty in all these aspects,

which profoundly affect their ability to empathize and display socio-emotional reciprocity (American Psychiatric Association, 2013; Baron-Cohen, 2002; McIntosh, Reichmann-Decker, Winkielman, & Wilbarger, 2006; Minio-Paluello, Baron-Cohen, Avenanti, Walsh, & Aglioti, 2009; Pasalich, Dadds, & Hawes, 2014).

Since the human face is central in communication and expression of emotion (Golan, Baron-Cohen, & Hill, 2006), most studies have examined emotional face recognition in children with ASD; however, these studies yielded mixed findings in regards to the ability of children with ASD to recognise specific types of emotions. Although some studies demonstrated that there is a deficit in all types of negative emotions (Ashwin, Chapman, Colle, & Baron-Cohen, 2006), others showed that the deficit is confined to special negative emotions, such as disgust (Golan, Baron-Cohen, & Hill, 2006), anger (Gioia & Brosigole, 1988), sadness (Boraston, Blakemore, Chilvers, & Skuse, 2007), and fear (Howard et al., 2000; Pelphrey et al., 2002). Some studies reported that individuals with ASD have impaired emotion recognition both in static stimuli (Deruelle, Rondan, Gepner, & Tardif, 2004) and in dynamic stimuli (Yirmiya, Sigman, Kasari, & Mundy, 1992). Other studies showed that these deficits become apparent when complex emotions (e.g., embarrassment and intimacy) compared with basic emotions (i.e., happiness, disgust, sadness, anger, fear, and surprise) are used (Baron-Cohen et al., 2001; Golan et al., 2006). This inconsistency may be due to demographic variables (e.g., age, IQ, severity of disorder, and comorbidity), experimental stimuli (e.g., static vs. dynamic stimuli, colourful vs. grey stimuli, basic vs. complex emotions, fixed vs. adjusted intensity levels of emotion), and the methodology of the assessment (e.g., matching or identification vs. labelling emotional tasks, accuracy or reaction time vs. threshold) (Harms, Martin, & Wallace, 2010; Tracy, Robins, Schriber, &

Solomon, 2011; Uljarevic & Hamilton, 2013). Therefore, future studies need to take advantage of various types of experiments and sample characteristics to investigate socio-emotional functioning in children with ASD.

### **1.3.1 Reasons for Socio-emotional Difficulties in Individuals with ASD**

Socio-emotional difficulties in individuals with ASD may be due to problems in attending and orienting to relevant social stimuli. Difficulties in rapid shifting of attention between social stimuli and the inability to share attention with others result in profound social problems in individuals with ASD (Dawson, Meltzoff, Osterling, Rinaldi, & Brown, 1998; Dawson et al., 2004). As the nature of social stimuli is variable and unpredictable, individuals with ASD have difficulty processing social stimuli and drawing attention to them (Dawson et al., 2004). Also, individuals with ASD may not find social stimuli intrinsically motivating and rewarding, which result in reduced attention to faces (Chevallier, Kohls, Troiani, Brodtkin, & Schultz, 2012). People with ASD tend to focus more on objects rather than faces, and typically avoid eye contact (McPartland, Dawson, Webb, Panagiotides, & Carver, 2004; Swettenham et al., 1998; Wallace, Coleman, & Bailey, 2008). The inability to detect and respond precisely to social stimuli, such as eye gaze and emotional faces, hinders the development of socio-emotional competences in people with ASD (Dawson et al., 2004).

When focusing on the face, individuals with ASD process emotional faces differently than their peers. Some studies show that individuals with ASD tend to focus more on the lower parts of the faces (i.e., the mouth) than the upper parts (i.e., the eyes), which result in difficulty processing negative or complex emotions (Joseph & Tanaka, 2003; Langdell, 1978). Although attending to the mouth may obtain better verbal information for individuals



with ASD, lack of attention to the eyes may result in difficulty understanding the mental states conveyed through the eyes (Klin, Jones, Schultz, Volkmar, & Cohen, 2002). Bal et al. (2010) showed that increased attention to the eye regions led to higher accuracy of emotion recognition in individuals with ASD. Individuals with ASD adopt a more feature-based or detail-focused processing approach rather than a configural face-processing approach used by their TD counterparts, which also contributes to difficulty in recognizing emotions (Lahaie et al., 2006). According to weak central coherence theory, individuals with ASD over-rely on details and extract local information (Happé & Frith, 2006). This atypical visual processing and increased local bias in individuals with ASD interfere with their ability to interpret emotional faces, a task that mostly requires holistic processing of the whole face (Behrmann, Thomas, & Humphreys, 2006).

Impairment in facial emotion recognition in individuals with ASD may derive from deficits in underlying functional and structural brain systems (Harms et al., 2010; Ghanouni & Zwicker, 2018). Neuroimaging studies have shown that hypo-activation of the fusiform gyrus and dysfunctions in the superior temporal sulcus and limbic regions (such as the amygdala) are associated with problems in the processing of emotional faces (Harms et al., 2010). Abnormal structure of the amygdala and deficits in functional connectivity between the amygdala and the fusiform gyrus in individuals with ASD prevent development of cortical face specialization. Thus, the amygdala appears to be a key brain region interpreting emotions, especially negative emotions such as fear and sadness, which are particularly observed to be impaired in individuals with ASD (Ashwin et al., 2006; Grelotti, Gauthier, & Schultz, 2002). The Causality Model of Social Perception helps to explain why dysfunction in the amygdala may be associated with autism (Schultz, 2005). See the next section.

### 1.3.2 A Causality Model of Social Perception in ASD: Theoretical Foundation

Social cognition and social perception are presumed to mature during development; however, children with ASD have abnormal or delayed developmental patterns. Schultz (2005) proposed a model to explain how impoverished face perception and social skills are formed in a child with ASD. Based on this model, ASD is probably due to amygdala dysfunction that leads to the lack of children's interest in attending to faces. Because the child does not look at faces, s/he cannot experience facial processing, which precludes development of the fusiform area (see Figure 1). When the fusiform area is underdeveloped, it gradually becomes dysfunctional, preventing scaffolding social skills and social knowledge in children with ASD (Glezerman, 2012). According to this model, looking at a face automatically activates the fusiform area and primes the observer for having social interactions (Glezerman, 2012; Schultz, 2005). Although this model has not been tested yet, it is assumed that providing the opportunity of being exposed to social stimuli and attending to faces in a controlled environment, such as a virtual reality or video game program, may facilitate learning social skills.

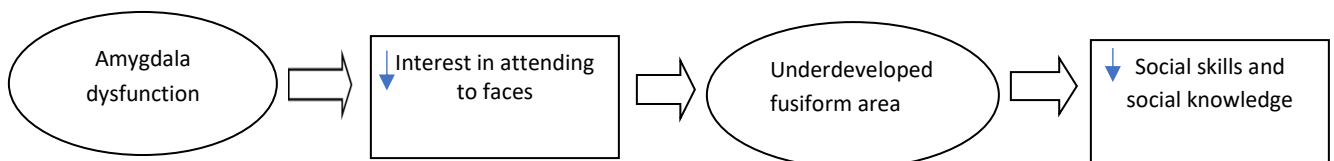


Figure 1.1 The Social Perception Deficiency in Individuals with ASD

### **1.3.3 Empathy and Emotion Recognition as Predictors of Adaptive Social Skills**

Empathy is one of the most important skills in social interactions (Eisenberg, 1990; Salovey, Mayer, Caruso, & Yoo, 2002). As children get older, they develop this skill through experiencing different social contexts (Eisenberg, 1990). Humans' ability to share their emotional experiences and empathize with others play a pivotal role in interpersonal communication (Riggio, Tucker, & Coffaro, 1989). Lack of empathy and difficulties in recognizing others' emotions and affective responses to them interfere with social interactions, which consequently affect participating in everyday life (Law, 2002; Combs & Slaby, 1977). Social participation and involvement in activities also promote a diverse range of social skills (Law, 2002). In other words, participating in various activities may help children to develop social and emotional skills.

Finding the indicators that predict and facilitate adaptive social skills may govern the direction of therapeutic interventions (Izard et al., 2001; Oakland & Harrison, 2011; Trentacosta & Fine, 2010). Emotion recognition, as a component of empathy, is associated with communication skills and is a predictor of adaptive social skills (Trentacosta & Fine, 2010; Williams & Gray, 2013). The ability to detect and recognize emotional cues may reinforce communication skills, leading to positive and adaptive social interactions (Boraston et al., 2007; Izard et al., 2001). Therefore, consistent misinterpretation or misperception of emotional cues, which is usually observed in children with ASD, is likely to impede the advancement of their socio-emotional competences (Izard et al., 2001; Williams & Gray, 2013).

#### **1.4 Interventions and Assistive Technologies in Individuals with ASD**

Early intensive behavioural and educational interventions are applied in clinics or at children's homes for 20 to 40 hours per week for multiple years, depending on severity, to address socio-emotional symptoms as well as other symptoms of ASD (Eikeseth, 2009; Matson & Smith, 2008). Such one-to-one behavioural teaching is necessary and effective for children with ASD (Eikeseth, 2009; Matson & Smith, 2008). However, it has been estimated to cost approximately \$40,000 to \$75,000 per child per year (Motiwala, Gupta, Lilly, Ungar, & Coyte, 2006; Amendah, Grosse, Peacock, & Mandell, 2011; Moldin & Rubenstein, 2006). As there is still no curative therapy for ASD, and as traditional intervention is costly, introducing complementary tools that are effective, practical, motivating, and affordable is warranted.

In recent years, there has been an increasing trend in using low-cost technology to promote social and emotional skills of individuals with ASD. Using humanoid or cartoon characters in computer-based intervention programs has been shown to significantly improve emotion recognition in individuals with ASD (Golan et al., 2010; Hopkins et al., 2011; Tanaka et al., 2010). Increased perspective-taking and a higher level of social interaction within short-term usage of the computer-based interventions show that these methods might be considered as fruitful tools for individuals with ASD (Hughes, 2014; Golan et al., 2010; Moore, McGrath, & Thorpe, 2000).

Additionally, virtual reality as a type of three-dimensional computer program has been used as an intervention tool for children with ASD (Parsons & Cobb, 2011; Moore et al., 2000; Parsons & Mitchell, 2002). Virtual reality allows players to manipulate objects in

virtual settings and/or interact with agents. Virtual reality is the term used to describe when users are part of the virtual world or when they are immersed within the environment. However, the degree of embodiment and immersion vary in different devices (Dautenhahn, Ogden, & Quick, 2002; Dautenhahn, 2003). Most virtual reality technologies among children with ASD use low degrees of immersion by using desktop devices compared with headsets to prevent potential negative sensory experiences (Josman, Ben-Chaim, Friedrich, Weiss, 2008). Previous studies showed that children with ASD enhanced their social skills via a virtual environment that represented a virtual café or a bus aimed to teach finding a seat (Mitchell, Parsons, & Leonard, 2007). They also showed some improvements in emotion recognition and social perception after using a virtual reality training intervention (Kandalaf, Didehbani, Krawczyk, Allen, & Chapman, 2013). However, these studies usually did not incorporate emotions in the context of daily social situations for children with ASD; thus, further investigations are needed.

One type of virtual reality games among children with ASD is based on motion-gaming systems (e.g., Kinect, Wii) that allow players to interact with avatars via body movements (Boutsika, 2014; Zhang, 2012; Ge & Fan, 2017). Given the higher resemblance of these motion-gaming programs to the real world compared to other types of games, they have been used to improve social skills in children with ASD. Previous studies showed that using these commercial games can bring behavioural and cognitive benefits (Anderson-Hanley, Tureck, & Schneiderman, 2011), increase levels of peer interaction (Bartoli, Corradi, Garzotto, & Valoriani, 2013; Hillier, 2013; Ge & Fan, 2017), and improve learning and attention (Bartoli et al., 2013; Bartoli, Garzotto, Gelsomini, Oliveto, & Valoriani, 2014; Chia et al., 2013). However, previous motion-gaming programs developed for commercial games

did not consider the special needs of individuals with ASD. Therefore, , it can be assumed that by designing a program tailored for needs of individuals with ASD, their socio-emotional difficulties can be better addressed.

#### **1.4.1 Why Gaming Programs and Tele-rehabilitation Might Be Effective for Use in Individuals with ASD?**

Socio-emotional problems in individuals with ASD appear to be pervasive and permanent (Baron-Cohen et al., 2001; Kuusikko et al., 2009), and the costs of current interventions are high (Moldin & Rubenstein, 2006). Therefore, inexpensive suitable complementary interventions are a valuable supplement. Although older children with ASD that show higher social interactions (compared with younger children with ASD) would likely benefit more when they are taught in direct face-to-face social skill training in natural settings (Bauminger, 2002), younger children with ASD that show more withdrawn social behaviours and reduced motivation in learning may benefit more from treatments that rely on less face-to-face interactions, such as virtual reality games (Corbett & Abdullah, 2005; Corbett et al., 2010). Motivation, as one of the key elements in learning directs children towards particular goals and reinforce behaviours (Dweck, 1986; Pasch, Bianchi-Berthouze, van Dijk, & Nijholt, 2009). It is assumed that keeping children engaged and maintaining their motivation would enhance their ability of learning new skills (Linnenbrink & Pintrich, 2002; Pasch, Bianchi-Berthouze, van Dijk, & Nijholt, 2009)

Virtual reality or computer games seem to be a suitable means of providing treatment because of the special interest of individuals with ASD to systems with fixed rules, such as computer or virtual reality games (Golan et al., 2010). According to Empathizing-

Systemizing cognitive style theory, individuals with ASD have superior abilities in systemizing, which is the drive to analyze systems and predict rules (Baron-Cohen et al., 2005; Baron-Cohen, 2009). To keep children with ASD motivated in long-lasting interventions, their special interests in systemizing and following rules should be harnessed. Virtual-reality programs provide the opportunity of practicing in a rule-based environment, which allow individuals with ASD to use their systemizing ability to learn socio-emotional skills and compensate for their difficulties in empathy (Golan et al., 2010). Therefore, interventions that aim to increase socio-emotional skills in individuals with ASD should take advantage of their systemizing ability to enhance the effectiveness of the therapy (Golan et al., 2010; Tanaka et al., 2010).

Using virtual reality games in the domains of education and neuro-rehabilitation offer the opportunity of practicing in a safe and controlled environment (Chia et al., 2013; Garzotto, Valoriani, & Bartoli, 2014). Behaviours and skills can be rehearsed in a context that is similar to the real world but within modified settings. The difficulty of the task can be adjusted to provide sufficient challenges to facilitate acquiring new skills. Based on the flow model, if the challenges are too much or too little, the users might get anxious or bored, respectively (Boutsika, 2014). Virtual reality games enable the users to focus on a task adjusted to their age and competency. The level of verbal and non-verbal feedback can be manipulated to sustain motivation (Parsons & Cobb, 2011). Individuals with ASD understand virtual environments as being representative of reality and do not show negative sensory experiences when playing with virtual reality games (Parsons, Mitchell, & Leonard, 2004; Wallace et al., 2010). All of these are key elements to position virtual reality as a

complementary therapeutic environment for individuals with ASD in gaining experience through active, engaging, and independent learning (Kandroudi & Bratitsis, 2012).

Gaming technologies such as motion-gaming systems may help individuals with ASD to form the repertoire or internal model that is necessary to perceive and act appropriately (Crowder & Merritte, 2013). According to the perception action model, perception of a behaviour will automatically represent the respective repertoire in the brain that consequently outputs the shared experiences of that behaviour (Preston & De Waal, 2002). This circuit will be provided by mirror neuron systems in the brain, which are activated both in perception and execution of a behaviour (Cameirão, Badia, Oller, & Verschure, 2010).

Gaming programs also have the potential to be applied as tele-rehabilitation as an alternative and promising way to improve the accessibility of health services. Tele-rehabilitation provides access to therapy for individuals who cannot attend regular therapy sessions due to living in remote areas or having difficulty affording therapeutic costs (Winters, 2002). This also allows continuation of the therapy, which is a necessity for managing the life-long nature of ASD.

#### **1.4.2 Rationale for Using the Kinect Motion-based Systems: Unique Features**

Kinect motion-based virtual reality facilitates learning and engages users by integrating kinaesthetic interactions (Hsu, 2011). In line with embodiment theory, there are strong links between sensory and motor systems on the one hand and cognition on the other hand (Kiefer & Trumpp, 2012; Gutman, Raphael, Ceder, Khan, Timp, & Salvant, 2010). Embodied learning offers an intellectual way of thinking while involving physical movements, leading to more effective learning (Kiefer & Trumpp, 2012). Kinect games



enable embodied learning through involving body movements to reinforce motivation and level of engagement as central elements in promoting and sustaining learning (Pasch, Bianchi-Berthouze, van Dijk, & Nijholt, 2009; Pintrich, 1999).

In addition, in human-human interaction, integrating auditory and visual signals is an essential part of communication, thus simulating this type of environment is needed to enhance learning outcomes. Multi-modal interfaces can provide multiple channels of communication, including auditory, visual, affective, and gestural channels, that resemble real life interactions (Jaimes & Sebe, 2007; Teófilo, Nogueira, & Silva, 2013). Likewise, motion-gaming Kinect platforms can enable users to communicate with the systems through intuitive natural ways, such as gestures, body movements, or speech, resembling real-life contexts (Catuhe, 2012; Tashev, 2013). Kinect motion sensors can track body movements and display it on the screen (Francese, Passero, & Tortora, 2012; Zhang, 2012). It can also be integrated with a speech recognition engine, making verbal commands possible (Catuhe, 2012). Therefore, Kinect seems to be an appropriate platform to develop a multi-modal gaming program with auditory and gestural channels. However, there are two important factors that need to be considered to potentially increase the efficacy of the program for children with ASD. This includes the generalization of learned skills (via the use of general case training) and incorporating the voice of the end users (guided by client-centred approach).

## **1.5 General Case Training**

There are concerns about the degree of transferability of learned skills in virtual environments to real-life settings and dependency of children with ASD in using these

technologies (Bölte et al., 2010; Pennington, 2010). While some technologies have shown effectiveness in skill acquisition among children with ASD (Moore et al., 2000; Pennington, 2010), most of behavioural studies lack evidence of generalization; that is, the transfer of learned new skills to non-trained contexts or real-life scenarios (Parsons & Mitchell, 2002). If a person is only able to perform a task in controlled settings, the benefit of the therapy is not sufficient.

To enhance generalization, the “general case training” method is recommended (Chezan, Drasgow, & Marshall, 2012; Day & Horner, 1986). This method identifies natural variations of stimuli (such as social skills) and then selects adequate numbers of stimuli based on their natural variation in order to teach the skills, which can result in correct responses [generalisation] to all of the stimuli of its kind (Horner, Sprague, & Wilcox, 2005). This teaching method, based on applied behaviour analysis, has been effective in teaching generalisation of skills in individuals with developmental disabilities (Day & Horner, 1986; Sprague & Horner, 1984; Steere, Strauch, Powell, & Butterworth, 1990; Walters, Holborn, & Ediger, 2007). General case training suggests that generalisation is affected by instructional design that includes six steps: (1) defining the instructional universe; (2) defining the relevant stimuli and response variations; (3) selecting examples that sample the range of variations, (4) sequencing examples; (5) teaching examples; and (6) testing with non-trained examples and analysis of patterns (Horner et al., 2005). The goal of generalization is achieved by detailed and precise stimulus control (Horner et al., 2005). In this project, I used the general case training approach when designing a virtual reality program to address perspective taking in children with ASD. I explain our stimuli and variations (i.e.,

instructional universe) and the procedures in detail in the Methods section in Chapter 4. The process of developing various stimuli was guided by a client-centred approach.

## **1.6 Importance of Client-centred Approach**

Using a client-centred approach is a key tenet in occupational therapy interventions, and considers clients or patients being at the centre of the health care. This approach moves away from the idea that clinicians are experts and supports a mutual partnership between clients and clinicians (Directorate, 1991; Law, Baptiste, & Mills, 1995). Clients are more aware of their needs and can prioritise their goals (Lucyshyn, Albin, & Nixon, 1997). They have both the right and ability to be involved in the decision-making process that enables them to develop or maintain functional skills (Law et al., 1995).

In this approach, clients play an active role in defining the goals and desired therapeutic outcomes (Directorate, 1991; Law et al., 1995). To optimise the efficacy of the program and maintain its sustainability among the end users, we used this client-centred approach by integrating the ideas and perspectives of relevant stakeholders. To do so, we considered a participatory design approach to incorporate stakeholders' input.

## **1.7 Participatory Design Approach and Integrated Knowledge Translation**

Community-based participatory research is a collaborative approach to create a partnership between researchers and stakeholders in order to engage them in all phases of the project (Viswanathan et al., 2004). This will help partners share their expertise, mutually exchange their ideas, and have equitable roles in contributing to the project. Thus, stakeholders gradually develop a sense of ownership that enhances application of the research findings and promotes tangible outcomes (Minkler & Wallerstein, 2011). In this

project, we involved stakeholders, including parents of children with ASD, youth/children with ASD, and clinicians working with individuals with ASD, from the initial stages of the project throughout the study to share their ideas. We formed a steering committee of stakeholders who could commit to the project timeline, including one youth with ASD, two parents of, and two clinicians working with children with ASD. They took part in discussions related to the focus, direction and progression of the project, and guided us throughout the study. While the steering committee was not involved in the initial phase of forming the research questions, other stakeholders who took part in the first study shaped the formation of the research questions. Stakeholders' involvement was at various stages including data collection, identifying the main issues and elements, developing, trialing, dissemination, and launching the program.

This community collaboration is a critical element for integrated knowledge translation, because co-creation of knowledge with knowledge users and knowledge producers is emphasized (Gagliardi, Berta, Kothari, Boyko, & Urquhart, 2015). This dynamic and respectful approach eliminates power differentials and expands the capacity to bridge the know-do gap to overcome delayed implementation of effective practices (Jull, Giles, & Graham, 2017). Technology acceptance and its uptake are pivotal factors for implementation in practice. With the rapidly growing studies in developing novel technologies, the issue of technology adoption still remains. Usually huge investments are made by institutes and organisations to develop and introduce novel technologies; however, these investments will not yield any impact if the technology is not adopted (Sharma & Mishra, 2015). Valuing stakeholders' perspectives during the development phase and

mitigating barriers to implementation allow for easier and faster uptake of knowledge and products that are generated by research.

Using a participatory design approach, we incorporated feedback and ideas shared by clinicians, parents, and children and youth with ASD during the design and development of the program. According to international standards for user-centred design, there are four underlying principals during the design of a product (Earthy, Jones, & Bevan, 2012). This includes identifying the context of use and users needs, specifying the requirements and users' goals, creating design solutions, and evaluating the design (Earthy, Jones, & Bevan, 2012). We considered these elements throughout the project in various chapters (see Section 1.9). This iterative process of gaining users' input during the development can enhance the efficiency of the final product and ensure that key informants' needs and priorities are incorporated (Kujala, 2003).

## **1.8 Summary and Rationale**

Children with ASD show difficulties in perspective-taking and emotion recognition, affecting their social interaction. Virtual reality programs can be used as mediums to enhance these functional skills. Existing literature on Kinect systems in individuals with ASD demonstrated behavioural and cognitive improvements (Bartoli et al., 2013; Chia et al., 2013). However, the therapeutic benefits and the ecological validity of these studies were limited since these studies used commercially available video games that are not tailored to the specific needs of children with ASD. Most individuals with ASD are slow at information processing, may be distracted easily, and may not sustain their attention on a specific task (Gepner & Féron, 2009). Their difficulties in understanding social situations and in

intentionally disengaging and switching attention between various tasks should be considered when applying an intervention (Casas, Herrera, Coma, & Fernández, 2012; Gepner & Féron, 2009; Landry & Bryson, 2004). As far as we know, no study has developed a Kinect platform, using audio and visual features that resemble real-life social contexts, with the approach of community-based participatory and general case training to enhance perspective taking functions and social participation among children with ASD.

## **1.9 Research Objectives**

In this project, we considered the user-centred design process in different stages. The objectives of this multi-phase research project are addressed in the following chapters.

First, we aimed to illuminate barriers of social participation of individuals with ASD (Chapter 2). Participants prioritised their needs and identified pivotal components that can facilitate social participation of children with ASD. This phase helped to pinpoint the focus of the gaming program and addressed the first component of the user-centred design process.

Second, we aimed to uncover factors associated with making virtual reality programs effective for use with children with ASD (Chapter 3). This phase addresses the second component of the user-centred design process by specifying the requirements and users' goals. We asked stakeholders from the previous phase to pinpoint their opinions on how to maximise the outcomes and quality of the program. This phase helped with the design of the game.

Third, we developed and validated the content of the virtual reality game, targeting perspective-taking in children with ASD (Chapter 4). We describe the procedure of creating

a panel of experts and incorporating their suggestions during multiple iterative rounds of refinement. This phase shaped the content of the game.

Fourth, we developed the Kinect game in collaboration with stakeholders (Chapter 5). Using participatory design, we obtained iterative feedback from participants to debug the program and to enhance the usability of the game. This phase addressed the third and fourth components of the user-centred design by creating design solutions and evaluating the design.

Lastly, we aimed to determine components that affect the uptake of a novel technology by stakeholders in the field of ASD (Chapter 6). Participants shared factors that are involved during the decision-making process. This phase will assist in designing knowledge translation activities to increase the uptake of technology in general, and the developed game in particular.

## **2 An Exploratory Study of Perceived Barriers and Existing Challenges in Participation of Children with Autism Spectrum Disorders: “He Did Not Understand and No One Else Seemed to Understand Him”**

### **2.1 Introduction**

Social impairments have been central defining characteristics in ASD. A wide spectrum of difficulties in acknowledging others, persistent deficits in verbal and non-verbal social communication, challenges in socio-emotional reciprocity, and misinterpretation in socio-emotional contexts are usually observed in individuals with ASD (American Psychiatric Association, 2013; Sperry & Mesibov, 2005). These impairments affect their relationships and suppress their ability to sustain their social networks and friendships. This, in turn, compromises their social participation and makes them vulnerable to additional social and psychosocial difficulties (Kawachi & Berkman, 2001).

Focusing on improving social participation in individuals with ASD is consistent with the World Health Organization, which identifies participation as a necessity in children’s development, health, and well-being (Lollar & Simeonsson, 2005). Social participation allows children to learn how to communicate, build friendships, find their strengths and weaknesses, and develop the competencies and skills they need in interpersonal relations (Law, 2002; Law, Petrenchik, King, & Hurley, 2007). In addition, social participation can affect emotional well-being, life satisfaction, and psychological development (Mactavish & Schleien, 2004). It has been shown that through participation in various activities, emotional and behavioural problems can be reduced (Law, Petrenchik, Ziviani, & King, 2006).



Children with disabilities usually experience restricted or limited social participation as a result of interactions between individual and environmental factors (King et al., 2003; Law, 2002; Law et al., 2007). These children are often considered as being less competent and may be of a lower or more unstable social status than their peers without disabilities (Law et al., 2006). Many children with disabilities have few friends, engage in less diverse activities, and have fewer opportunities to engage in out-of-home or at-home activities with peers. Previous research has shown that among children with disabilities, those with behavioral or cognitive problems have fewer peer interactions than those with physical impairments (Geisthardt, Brotherson, & Cook, 2002). Many parents of children with developmental disabilities report that other parents are usually reluctant to encourage their children to interact with a child with disability, as it may require extra supervision (Geisthardt et al., 2002; Solish, Perry, & Minnes, 2010). This further limits the opportunities for social interactions and participation, which exacerbates the issue, especially for children with socio-emotional difficulties, such as ASD.

Research has shown that children with ASD participate in activities less frequently and with less variety than typically developing children and even children with other developmental disabilities (Hilton, Crouch, & Israel, 2008; Little, Sideris, Ausderau, & Baranek, 2014; Potvin, Snider, Prelock, Kehayia, & Wood-Dauphinee, 2013; Taheri, Perry, & Minnes, 2016). Profound and pervasive problems in social interactions, verbal or non-verbal communication, and development of peer relationships in individuals with ASD limit the opportunities of being engaged, acquiring new skills, and learning from social groups (Orsmond, Krauss, & Seltzer, 2004; Reynolds, Bendixen, Lawrence, & Lane, 2011). These difficulties are observed early in childhood, and often continue throughout life. Previous

studies demonstrated that adults with ASD usually experience social isolation and depression, as the majority of them do not have friends, and even when friendships occur they do not seem to be supportive (Liptak, Kennedy, & Dosa, 2011; Orsmond et al., 2004; Orsmond, Shattuck, Cooper, Sterzing, & Anderson, 2013). Furthermore, it was shown that children with ASD usually tend to participate in more structured and less recreational activities where their parents or caregivers are involved rather than peers (Potvin et al., 2013; Solish et al., 2010). Given the personal and environmental factors as the predictors of social participation, individuals with lower functional skills and with less familial or environmental support are more likely to have lower levels of participation (Rosenberg, Bart, Ratzon, & Jarus, 2013; Law et al., 2006).

Although the literature is generally consistent in describing social problems and factors associated with decreased social participation of individuals with ASD, previous studies usually used pre-defined questionnaires and parent-reported checklists to examine dimensions of participation. Gathering stakeholders' ideas, including from parents, clinicians, and youth with ASD, may provide additional insight to the challenges and support they need. As far as we know, no study has examined the perceived barriers in participation of individuals with ASD from the perspectives of these stakeholders. Additionally, with respect to the various social problems in ASD, it is not obvious which one(s) play a significant role in restricting participation, from the stakeholders' viewpoints.

This study aimed to add to the literature by involving stakeholders to highlight barriers that are pervasive and most challenging, and hinder social participation of children with ASD.

## **2.2. Methods**

### **2.2.1 Research Design**

This qualitative inquiry adopted an interpretive description approach. This is an inductive approach designed to create ways of understanding a phenomenon (Thorne, 2016). According to its philosophical underpinning, interpretative description acknowledges the contextual and constructed human experiences that create multiple realities. This approach values subjective knowledge and attempts to inductively generate interpretations of a phenomenon that can be applied in clinical practice.

The interpretive description approach is underpinned by a constructivist epistemology, where perception and experiences are socially constructed. This approach emphasizes the co-construction of meaning within the everyday social contexts and highlights the complexity of subjective experiences (Thorne, 2016). This constructivist and interpretive positioning helps researchers to consider alternate perspectives and recognize how knowledge is always co-constructed.

As this study explores barriers of social participation from the viewpoints of stakeholders, we used the interoperative descriptive approach. We collected data by conducting focus groups and interviews with stakeholders to have a better understanding of factors that affect social participation.

### **2.2.2 Participants**

The participants consisted of three groups of stakeholders: youths with ASD (aged 13-17 years), parents of children or youth with ASD, and service providers (clinicians from various disciplines and teachers). Recruitment criteria included: (1) parents/guardians of

children diagnosed with ASD; (2) service providers with a minimum of one year of experience working with children with ASD; or (3) high functioning youth between the ages of 13-17 years diagnosed with ASD who are able to verbally communicate with the research team.

Using convenience sampling, participants were recruited from the community through email and posters sent to public and private clinics and organizations who support children with ASD and their families. Snowball sampling was also used in order to reach a broader base of relevant stakeholders. No incentives were provided for participating. The goal of recruitment was to have an even distribution of participants across the stakeholders; however, due to challenges with recruiting youth, the majority of participants were parents/guardians and service providers.

### **2.2.3 Research Procedure**

Semi-structured focus groups and interviews were conducted with participants from three stakeholder groups, lasting between 45-90 minutes. Focus groups were the preferred method of gathering data as they could facilitate discussion and generate ideas among participants, especially youth with ASD who might experience anxiety or lack of confidence to share ideas. In addition, due to scheduling challenges, the researchers offered to conduct interviews with participants who could not attend the focus groups. Three interviewers, who were graduate students and were trained on how to communicate with participants and ask questions, conducted the interviews/focus groups. There was no relationship between interviewers and participants prior to the study. Prior to the focus groups and interviews, stakeholders gave written consent to participate in the study.

We conducted four focus groups, three of them with service providers (n=3, n=2, n=2), and one with parents (n=2). Eleven interviews were completed with parents of children with ASD, two interviews with service providers, and four interviews with youth with ASD. The study was approved by the University of British Columbia Behavioural Research Ethics Board and all participants provided consent prior to the focus groups and interviews.

We involved participants in an interview or focus group at a time and location of their choosing. Three participants attended remotely (one over phone, and two via Skype) due to travelling challenges. We developed semi-structured interview guides to facilitate discussion through open-ended questions and related probes (Appendix I). Follow-up questions were also used to allow for the exploration of unanticipated topics during the discussion. The interview guide was evolved through data collection. After initial data collection, the interview guides were altered slightly to better explore stakeholder perspectives in subsequent interviews and focus groups. We audio-recorded all focus groups and interviews and transcribed verbatim. One researcher listened to all the recorded files and double-checked transcripts to ascertain accuracy.

Interviewers also took field notes and memos to better reflect on the discussions. We replaced all participants' names with pseudonyms to maintain confidentiality.

#### **2.2.4 Data Analysis**

The data collection and data analysis of the project were based on a constructivist approach, in which researchers believe that there are multiple realities and perspectives on a phenomenon. Data analysis was an iterative process, and it started at early stages during data collection. Thematic analysis was used to classify the data based on units of meaning. First,

we reviewed a few transcripts to understand the main concepts identified by participants. Then, by reading and re-reading the ongoing transcripts, we looked for common ideas shared by participants. Using NVivo computer software, the first several focus groups and interviews were coded by three researchers individually. Then, they discussed their codes in a meeting to resolve any disagreements, and proceeded to code the rest of the transcripts. Then they came together to group the codes into categories based on similarity in concepts. Finally, the researchers merged the categories together to come up with overarching themes (Thorne, 2000).

#### **2.2.5 Trustworthiness Strategies**

We used two main trustworthiness strategies, namely reflexivity and triangulation (Creswell & Miller, 2000). Prior to the data collection and analysis, we wrote our assumptions and ideas on potential responses that might be given to the interview questions. This helped us identify our unconscious thoughts that might prevent us to accept participants' ideas. Throughout the data analysis, we reflected upon our assumptions. We considered triangulation by involving various stakeholders, multiple researchers, and repeated interviews to increase credibility of the study (Morgan-Ellis et al. 2006). We did not use triangulation for confirmatory purposes, but rather to provide complementary perspectives and enhance the richness of the analysis. During data analysis, four members of the research team shared their viewpoints during group discussion to enhance the understanding of the concept.

## 2.3 Results

**2.3.1 Demographic of Participants:** We recruited 26 participants in total: 13 parents/guardians (12 female), four youth with ASD (male), and nine service providers (seven female clinicians and two female special educators). Twenty of the participants were Caucasian, two were Hispanic, and four were Asian.

Parents were aged between 30-65 years, with an average of 46.5 years (SD: 9). The ages of their children ranged from 8-17 years [mean (SD): 12.4 (3.3) years]. Among their children, 44% did not have any co-occurring conditions, while the rest had either one or multiple co-occurring conditions. This included 44% with learning disorders, 56% with attention deficit hyperactivity disorder, and 33% with anxiety.

Of the service providers, four were occupational therapists, three were behavioural consultants, and two were special educators. They ranged in age between 30-57 years [mean (SD): 40.1 (11.3) years]. Service providers' experiences working with children with ASD varied between 1-20 years, with an average of 8.7 (6.8) years.

All four youth participants with ASD were male with a mean age of 14.1 (1.9) years. Only one of them reported having a co-occurring condition (attention deficit hyperactivity disorder).

**2.3.2 Themes:** The information gathered from the interviews and focus groups from youth with ASD and parents and service providers of children with ASD yielded three themes with regards to barriers of social participation. These were: (a) understanding social situations; (b) maladaptive behaviours; and (c) limited services. These three factors act in a vicious cycle, which exacerbate and further restrict social interactions in children with ASD.

## Understanding social situations: “It’s hard to pick up cues”

Social situations are, in and of themselves, complex and conditional. Participants identified that this complexity is intensified for children with ASD with delayed social development or social deficits. Harvey, a youth with ASD said: *“I find it a little bit difficult to get to know someone just from the start”*. Mary (clinician) described that the difficulty children with ASD have is more with understanding subtle social nuances: *“There’s the underlying social rules that we all get. The unspoken ones. And [children with ASD] don’t get them.”* In addition, it can be a challenge for children with ASD to apply different social rules in different social situations, as described by Louise (parent of a son with ASD):

*“He [son with ASD] felt that there was this massive list of rules that everybody else knew and he didn’t. And he was supposed to remember them all, and select the correct rule in every situation, which, as you know, every situation is subtly different, and there are all these little cues that he was supposed to be picking up and like analyzing very quickly and then spitting out the right response.”*

Parents also shared stories of their children’s challenges with reading and understanding emotions in others. For example, Mandy (parent), said: *“If people are angry, he [child with ASD] kind of just looks at them and is like ‘pff what’s your problem?’ He wouldn’t know how to calm somebody down, he would just walk away...when he sees frustration in people, he doesn’t understand that”*. A few parents shared specific challenges with subtle emotions, with Shar (parent) stating, *“When there’s subtle changes in other people, he doesn’t always pick up on them, like if someone is a little bit sad or lonely”*. A similar account was shared by



Pamela (teacher), *“Yeah I think it’s hard for them to notice other people, like they can’t really read other people’s facial expressions or like if you’re upset or something, they can’t necessarily read that...it’s more like subtle expressions they can’t [read] I find, it’s harder for them to grasp”*. These quotes highlight the importance of being able to read subtle cues to others’ emotions when socially interacting with people.

Participants also described the difficulty children with ASD have in taking the perspective of others as one of the biggest problems. Jessica (parent) identified how an inability to understand others’ perspectives can lead to negative social interactions:

*“I would say perspective-taking [is the biggest challenge]... When you can't put yourself in someone else's shoes or have that automatic thought 'how would I feel if that was said to me in that way' or whatever, or if someone hit me like that or whatever, if you can't do that, it's just going to snowball every time.”*

Brenda, a clinician, stated, *“What is difficult [for children with ASD] is taking the perspective of [the] other person, it’s like ‘why would you feel upset about that’. It’s more the perspective-taking rather than the not recognizing emotions”*. Similarly, Shar (parent) shared the story of her son when he could not understand his peer’s feelings and others could not understand her son’s frustration: *“so he [child with ASD] didn’t understand what was going on, like why she [the peer] was upset, and at the same time no one else seemed to understand why he [child with ASD] was so angry and frustrated”*. Likewise, Marni (parent) shared this challenge by stating, *“He [son with ASD] doesn’t realize sometimes that other people have feelings and feel a certain way, he thinks everybody is feeling the same way he is feeling”*. Gavin, one of the youth participants, was able to articulate his experience with

regards to other children being mad at him for cheating during a game of tag, *“I wouldn’t recognize [their reaction to my cheating], [I] don’t see why someone is looking at them that way...and [I] don’t know how to respond”*.

As an example of not being able to take others’ perspectives, parents and clinicians reported children with ASD as having a strong affinity to win and not understanding that peers may also want to win, for a game to be mutually enjoyable. Louise (parent) said: *“He [her son] would try to change the game rules to make it so he would win.”* Katrina (clinician) added that it is *“hard for [children with ASD] to understand that if they always win and their friend always loses, then it would be not that fun to [play] with the same peer again... they always want to be the winner, and it’s hard to maintain friends when you’re always the winner.”* So, improper perspective-taking and an inability to infer others’ feelings interfere with social reciprocity among children with ASD.

These quotes demonstrate that, although there is a wide range of difficulties observed in children with ASD, perspective-taking might be one of the biggest challenges. Having difficulties in understanding others’ emotions, feelings, and thoughts, and problems in exhibiting appropriate responses to the social cues, prevent children with ASD from fully participating.

### **Maladaptive behaviours: “He didn’t know when to put the brakes on”**

Many of the barriers to positive social experiences described by participants related to the obsession and maladaptive behaviours of children with ASD in social situations. For

example, children with ASD often have a particular or fixed interest, as described by Nicole (clinician):

*“A lot of time kids [with ASD] tend to be so fixated on those interests that when they socialize with another child, they keep talking about that one interest and it’s hard for them to move on from that.”*

Likewise, Brenda (clinician) related, *“I had this one boy [with ASD] who would keep going and going ...he was on a roll and he needed someone to put the brakes on, he didn’t know when to put the brakes on”*. Similar stories were shared by parents, *“It’s all about what he [child with ASD] wants to talk about, if other people with him want to discuss something else that he is not interested in, he won’t participate or he will try and bring it back to what he wants to talk about”* (Tom, parent). This tendency for the children to dominate conversation with special topics of their own interest was reported by a number of participants. Shar (parent) shared, *“His major issues with interacting with other children is that he will go off on a tangent, he will be so focused on one idea he doesn’t realize the other kids aren’t paying attention...they tend to walk away and yeah, it doesn’t really faze him”*. These quotes demonstrate the observer’s perception of the social challenges associated with the tendency to dominate conversation, the lack of insight of this tendency on the child’s behalf, and the impact this has on their interactions with others. Louise (parent) expressed her child’s tendency:

*“He [son with ASD] has particular passionate interests, and he prefers to socialize with people who share those interests, to the point where we*

*[parents] wonder how well he could do in a group of people that didn't share his interests."*

Similarly, Michael, a youth with autism, shared his strategy: *"I 'just' find people with common interests [to interact with]."* It was proposed that children with ASD may be inherently less motivated by social participation compared to children without ASD, as described by Mary (clinician): *"There's this lack of desire too. So, they're not connecting with others, they don't want to connect with others"*. Accordingly, Jade (parent) described her son's lack of interest in playing with other kids: *"He [son with autism] always plays by himself, and ...he's not interested in sharing the game, he wants to hold the game and play by himself, and have fun."* Likewise, Sharon, a teacher, said: *"Lots of the time they [children with ASD] don't look, like they don't need a friendship or they are not interested in making friends. They are happy doing what it is that they do."* This lack of interest limits their opportunity to connect with other people and communicate with them.

Maladaptive behaviour can be presented as poor impulse control and over-reaction to social events. Donna (parent) said: *"So he [son with autism] just flips. And he goes from 0 to 100, and is in tears, and you can't calm him down."* These reactions can understandably lead to negative social experiences: *"They [peers] figured out pretty early on that he [son with ASD] would react in a really entertaining way when they would push his buttons"* (Louis, parent). Similarly, Yvonne (parent) said: *He [my son] told me, at school sometimes children would tease him, so he would just scream. But now [he knows he] had to tell them [other children], 'stop it, I don't like it'."*

These inappropriate peer behaviours may further diminish positive social experiences by decreasing confidence or motivation to engage with peers: *“I find that [with] low self-esteem then, they [children with ASD] don’t want to interact with other kids.”* (Nicole, clinician). Similarly, Marie (parent) stated that her son learned to not involve and selectively decided not to talk with peers, leading to fewer social interactions.

*“He [son with ASD] found not to get in trouble by not communicating with anybody [peers]. So instead of fighting or giving opinions that sounded really rough and sometimes didn’t make sense, he decided not to talk.”*

These quotes demonstrate that, in addition to small social networks and narrow interest in connecting with others, sometimes peer rejection or an unwelcoming group limit involvement of children with ASD in social situations. This creates additional pressure on children and families, which further limits the child’s social participation.

### **Limited services: “Give them the opportunities”**

Participants identified that there is a lack of services for children with ASD related to social participation. For children under six, interventions typically focus on pre-school skills (academics) and activities of daily living. *“When you’re under 6, the parents are still trying to get their kids ready for kindergarten, trying to teach them all those fundamental skills, and the social doesn’t really come up.”* (Nicole, clinician)

Challenges may become more apparent once entering school, but there is a *“lack of services for kids over the age six, seven, eight”* (Anna, clinician). Further, social skills are not identified as a priority in schools and goals related to social development are not typically included in individualized education plans. Katrina, a clinician said: *“They [instructors]*

won't write in 'a goal around friendship' because they say that that is too much to ask of the school." In later years, social interventions diminish further: "Some of the middle school counselors have tried to do social groups and what not, but it's very marginal and superficial" (Anna, clinician). There was consensus among the clinicians that there is not enough support for social participation in schools, as illustrated by Rachel (clinician):

*"I think there isn't enough education around what is/what are social skills, and how do you teach them... I think that that is a definite barrier as well, they're in school all day, that's where they have access to peers and I still don't think there is enough understanding around that."*

Some clinicians commented that social participation is not a priority for teachers and educational assistants and children are not given the opportunity of making friends and learning from peers in the natural settings. For example, Mary (clinician) said:

*"Because in school, they're always so busy doing like their kind of one-on-one and everything, you know it's unfortunate but they don't have that many [social opportunities], like it's hard to make friends and there's not that many opportunities and there are not that many social groups out there."*

She adds that this may lead children with ASD to have more relationships with adults rather than peers, leading to lack of practical social opportunities to learn and experience how to interact with other children.

*"They end up having more of a relationship with their educators, you know, rather than with the other kids in the class. And there's not even that much time given where the kids... like in my experience, I've found that the kids don't have too much time*

*getting like, having just social fun stuff together. Giving them those opportunities.”*

Similarly, Anna (clinician) said “*the natural progression of making a friend is impaired by having an adult [instructor] standing behind you, you know, or beside you.*” This implies that, although one-on-one nature of training is a necessity, it needs to be accompanied by more social groups and activities with peers to provide children with ASD more opportunities to practice social skills in a natural context.

It was frequently reported by both clinicians and parents that children with ASD are able to learn social skills or rules, but exhibit challenges demonstrating those behaviours, as illustrated by Louis (parent):

*“We would talk about... some of the social rules that [son with autism] needs to follow and then he would say what the rule was, he would explain why it was important, and then in the moment, he wouldn’t be able to follow the rule.”*

Nicole (clinician) also described how in her social skills group, “*You can ask them [children with ASD] all the social questions and they probably know all the answers... But when it actually comes in real life, they don’t know what to do.*” This shows that children with ASD not only need to explicitly learn social skills but also implicitly display those skills in the real environment to master the learning process. The lack of practicing social skills either prior to entering or during school creates too few social learning opportunities for children with ASD. Nicole (clinician) felt that this was the greatest barrier to positive social experiences for children with ASD:

*“I think a lot of kids are not getting enough opportunity to practice it [social interactions] and I think that’s huge... if they had more opportunity... to be able to practice it and also have somebody there to just kind of guide it.”*

Geographical distance was also a factor impacting participating in social groups. For example, Michael, a youth with ASD, said:

*“If they [my friends] want to go to the seawall or something, it’s kind of hard, cause it takes up a lot of my time because I have to leave early..., and I sort of want to do something that’s close to my house, kind of makes me feel like it’s inconvenient for them, but to be far, most of the things are far for them.”*

In addition to the need for having the high quantity of practicing social skills, some participants noted the importance of the quality of training for supporting children with ASD. Participants advised that because children with ASD have delays, their involvement in play or team activities may be impeded and may compel the presence of a facilitator. Andrea (parent), for example said:

*“He [my son] doesn’t really play a lot with kids, building something. He needs an adult to help him not only introduce the social play but to keep him there... you know the other kids are usually more advanced. The other kid kind of takes control and then maybe he’ll play for a few minutes and then he’ll just start building his own tower kind of thing.”*

To meet the different abilities among children and provide children with ASD the opportunity to model and learn from peers, arranging appropriate group members and matching novice children with expert ones by a supportive facilitator might be promising.



Elise (parent), for example, said: *“So usually two kids have autism and the other kids are what they call co-experts, so there are novice players and expert players. Kids on the spectrum are novice players and regular neuro-typical kids are expert players. So, you know they try to incorporate a mix and the play guides.”* Therefore, children with ASD require an adequate amount of practice and appropriate social supports in order to solidify skills.

These quotes illustrate that, although children with ASD have a special need for additional practice of social skills and applying that training in real life settings, sometimes due to the restricted nature of training and/or inadequate social supports, they face difficulties in getting enough opportunities to practice or establish learned skills.

## **2.4 Discussion**

Social participation is one of the most important predictors of children’s physical and mental health (Lollar & Simeonsson, 2005). Although it is well evidenced that children with ASD have various social problems (Garfin & Lord, 1986), it is unclear which one(s) play a significant role in limiting children’s social participation as seen from the stakeholders’ viewpoints. This research is one of the first studies to examine barriers to social participation as perceived by youth with ASD, as well as parents of and clinicians working with individuals with ASD. The three main barriers were at the level of perception (understanding social situations), behaviour (maladaptive behaviours), and services (limited services).

Participants highlighted that perceiving social situations and viewing them from the perspectives of others would greatly contribute to the quality of social participation. Among all of the social problems observed in children with ASD, participants outlined the perspective-taking ability as one of the main challenges. This is consistent with previous

studies that have shown that performance of individuals with ASD on perspective-taking is closely related to their social competencies (Dawson & Fernald, 1987; Rehfeldt, Dillen, Ziomek, & Kowalchuk, 2007). Social skills, such as the ability to engage in symbolic or cooperative play, reciprocity in conversations, and empathy when interacting with others, require levels of perspective-taking. Because individuals with ASD are characterized by problems in forming or maintaining social reciprocity, it is assumed that this may be related to, if not the basis of, deficits in perspective-taking (Dawson & Fernald, 1987; Rehfeldt et al., 2007).

Children start demonstrating perspective-taking once they reach a developmental milestone, around ages 4-5 years; however, this ability is delayed in children with ASD (LeBlanc et al., 2003). To empathize with others, it is necessary both to understand others' mental states or emotions (cognitive part) and respond to them appropriately (affective part) (Aan Het Rot & Hogenelst, 2014; Baron-Cohen, 2009). Perspective-taking, cognitive empathy, and affective empathy are linked together (Bensalah, Caillies, & Anduze, 2016), and children with ASD show difficulty in these components, which profoundly affects their ability to empathize and to display socio-emotional reciprocity in social situations (Baron-Cohen, 2009).

Participants also indicated that children with ASD may have fixed or particular interests that interfere with interpersonal communication. Circumscribed interest or pre-occupations can cause one-sided conversations that prevent the development of interpersonal relations or may result in the rejection of children with ASD by their peer groups (Boyd, Conroy, Mancil, Nakao, & Alter, 2007; Klin, Danovitch, Merz, & Volkmar, 2007). This rejection is an undesirable experience for individuals with ASD, and functions as part of a larger cycle of decreased confidence and motivation to engage with their peers. Individuals

with ASD have difficulties in inhibiting these interest that affect their adaptability in participation in daily activities (South, Ozonoff, & McMahon, 2005).

Diminished ability in perspective-taking or empathizing skills and presence of narrow interests among children with ASD can be interpreted through the empathizing-systemizing theory (Baron-Cohen, 2010; Baron-Cohen, 2009). According to this theory, individuals with ASD have a high tendency to analyze systems and predict environments, which result in their lower performance to empathize (Baron-Cohen, 2009). Given the unpredictability of social situations, narrow interests, and resistance to environmental changes, there remains a tendency for withdrawal from social participation among individuals with ASD.

Findings in the current study align with previous literature on external supports and services as key determinants of health and development among children with ASD (Müller, Schuler, & Yates, 2008; Obrusnikova & Cavalier, 2011). Participants in our study expressed the existence of conflicting priorities in schools with the therapeutic interventions that may restrict the opportunity of learning social skills from peers. They argued that because the majority of interventions in early childhood tend to focus on preparing for school and depend on a one-to-one and high intensive approach (Orinstein et al., 2014), the opportunities of having peer interactions and building the social skills in natural settings are limited, and this may lead to lack of social participation.

Support groups can provide valuable opportunities to enhance social interactions and participation (Müller et al., 2008; Obrusnikova & Cavalier, 2011; Tobin, Drager, & Richardson, 2014). The presence of an adult moderator or peer support could facilitate social engagement among individuals with ASD (Jantz, 2011). Adequate peer training is required

(Bellini, Gardner, Hudock, & Kashima-Ellingson, 2016; Zagona & Mastergeorge, 2016) to ensure that bullying and inappropriate responses do not take place, which would further restrict social participation (Cappadocia, Weiss, & Pepler, 2012). Peer-mediated training as one example of support groups can be applied in natural settings and facilitate generalization of skills by practicing with peers (Zhang & Wheeler, 2011). This method allows teachers and adults to act as facilitators in the promotion of peer interactions rather than acting as children's playmates that could limit the natural peer-modeling process among children with ASD.

#### **2.4.1 Limitations and Future Direction**

Although this study has led to important findings from stakeholders' view point, there are some limitations. First, despite our effort to recruit a variety of stakeholders, the limited demographic variety from each group of stakeholders should be considered. For example, most youth were 13-year old males, all parents were mothers of high functioning 'sons' above 8 years, and service providers were only occupational therapists, special educators, and behaviour consultants. We recommend future studies to continue recruitment until saturation in data is achieved. Second, due to difficulty scheduling stakeholder focus groups, the sample size of each focus group was smaller than is typically recommended (5-8 participants) (Carlson & Glenton, 2011; Pearson & Vossler, 2016) and interviews were used to supplement the data. We suggest future studies consider focus groups with similar and different stakeholders in each session, as this can provide an avenue to hear a variety of perspectives and opportunity to formulate new ideas through discussion. Third, all participants were from one small urban geographic location, which gives a preliminary insight on the subject matter. Future studies can expand the findings and mitigate these

limitations by recruiting various stakeholders from rural and suburban areas, and investigate the barriers of social participation.

## **2.5 Conclusion**

Social participation is a crucial factor to promote health equity and well-being. Social participation among children with ASD is a complex phenomenon, and finding the contributing factors from perspectives of stakeholders is imperative. This study involved youth with ASD, parents of, and service providers working with, individuals with ASD to highlight barriers of social participation at the level of the perception, behaviour, and provision of services among children with ASD.

This phase of the project helped us to determine which factors contribute to social participation in children with ASD. Among all the identified factors, and based on participants' priorities and project scope, we identified perspective-taking and recognizing emotions as the concepts to target in our virtual-reality program. What still remained unknown were elements that could enhance the effectiveness of the virtual-reality game for children with ASD, informing us for the next phase.

### **3 What Makes a Virtual Reality Program Effective for Use Among Children with Autism Spectrum Disorder: Stakeholders' Viewpoints**

#### **3.1 Introduction**

Problems in communication skills and impaired social interaction, both in quality and quantity, are the core symptoms of ASD. Children with ASD have fewer social interactions and spend less time interacting with others. These deficits may create long-lasting barriers for children with ASD, preventing them from participating in interpersonal activities (Kreider et al., 2016; Tanner, Hand, O'Toole, & Lane, 2015).

As one of the established and highly effective approaches for addressing the socio-emotional symptoms of ASD, early intensive behavioural and educational interventions are applied for 20 to 40 hours per week for multiple years (Eikeseth, 2009; Matson & Smith, 2008). Such one-to-one behavioural teaching is effective but has been estimated to cost approximately \$40,000 to \$75,000 per child per year (Amendah, Grosse, Peacock, & Mandell, 2011; Lilly, Motiwala, Coyte, Ungar, & Gupta, 2006). Some families have difficulty affording this high cost for a long period of time. Therefore, the use of technology, such as virtual reality, as a complementary tool may be a suitable means of overcoming these barriers and improving communication skills in children with ASD.

Virtual reality allows individuals to experience social scenarios in a safe and controlled manner (Kandalaft, Didehbani, Krawczyk, Allen, & Chapman, 2013), while learning new rules and repeating tasks in replicable environments (Aresti-Bartolome & Garcia-Zapirain, 2014; Bartoli, Corradi, Garzotto, & Valoriani, 2013). These programs can gradually expose children with ASD to stimuli, provide consistency and stimulus control,

and give real-time feedback. Virtual reality is often highly engaging for individuals with ASD in addition to being accessible, user-friendly, and usually cost effective (Aresti-Bartolome & Garcia-Zapirain, 2014; Didehbani, Allen, Kandalaft, Krawczyk, & Chapman, 2016; Foran & Cermak, 2013).

It has been widely reported that many individuals with ASD have an affinity for computers and video games, which could increase children's motivation for virtual reality (Ferguson, Gillis, & Sevelever, 2013; Moore, Cheng, McGrath, & Powell, 2005). Virtual reality programs have repeatedly been found to have high engagement among individuals with ASD compared with other types of modalities; virtual reality takes advantage of visually stimulating environments to keep individuals with ASD interested in the intervention (Cheng & Ye, 2010; Grynszpan, Weiss, Perez-Diaz, & Gal, 2014; Ke & Im, 2013; Wainer & Ingersoll, 2011). It has also been suggested that, due to its capacity to direct attention and engage participants emotionally, virtual reality may be used as a complementary educational and therapeutic avenue (Herrera et al., 2008).

Research has demonstrated that virtual reality technologies, such as video and computer games, can be an effective intervention targeting social challenges (Aresti-Bartolome & Garcia-Zapirain, 2014; Bartoli et al., 2013; Sarah Parsons & Cobb, 2011). Virtual reality programs have the potential to improve social interaction and communication, as well as instruct users with ASD on how to recognize emotions, take others' perspectives, and respond properly (Aresti-Bartolome & Garcia-Zapirain, 2014; Bellani, Fornasari, Chittaro, & Brambilla, 2011; Bölte, Golan, Goodwin, & Zwaigenbaum, 2010). However, most previous studies have used commercially available games that did not incorporate individualized needs of clients with ASD.

Despite the rapid growth in usage of technologies and virtual reality programs among individuals with ASD, incorporation of stakeholders' views and input (i.e., service providers, parents of children with ASD, and youth with ASD) has been limited. Incorporating consumer views helps ensure programs meet the demands of the target population (Sanders & Kirby, 2012). Parsons and colleagues designed a computer program based on the advice and input from a group of adults with Asperger's syndrome (Parsons et al., 2000). However, as far as we know, no study has investigated the stakeholders' ideas on factors that may determine effectiveness of a virtual reality program to teach social skills for children with ASD. To avoid common issues of non-use or noncompliance with technologies, it is imperative that interventions be consistent with the expectations and goals of families and service providers (Sanders & Kirby, 2012).

Thus, this project aimed to identify the elements that are necessary to consider when developing a virtual reality game for children with ASD, from the perspectives of stakeholders.

## **3.2 Methods**

### **3.2.1 Research Design**

This study was a qualitative project to gather stakeholders' perspectives on the characteristics of effective virtual reality programs among individuals with ASD through conducting interviews and focus groups. We used an interpretive description approach informed by constructivism (Thorne, 2016). Please see Section 2.2.1 for the philosophical underpinning.



### **3.2.2 Participants**

Participants of this study were the same participants as in Chapter 2. Participants were key stakeholders in the field of ASD, including parents of children with ASD, high functioning youth with ASD, and service providers, such as clinicians or teachers who work with children with ASD. Recruitment criteria included: (1) parents/guardians of children diagnosed with ASD; (2) service providers with minimum one year of experience working with children with ASD; or (3) high functioning youth between the ages of 13-17 years diagnosed with ASD who are able to verbally communicate with the research team and have experience with the use of computer, video, or other virtual reality games.

Using convenience sampling, participants were recruited via email, online blogs, social media, and posters through community ASD networks. Participants were also recruited via snowballing recruitment (i.e., asking participants to send recruitment information to other potential participants). The goal of recruitment was to have an equal number of participants across the stakeholders; however, due to challenges with recruiting youth, the majority of participants were parents/guardians and service providers.

### **3.2.3 Research Procedure**

A combination of focus groups and interviews were used as an avenue for the stakeholders to share their perspectives and ideas about features of an effective virtual reality program for children with ASD. Although focus groups allow the opportunity for stakeholders to formulate new ideas through discussion, setting up focus group meetings was challenging due to scheduling conflicts. In those cases, individual interviews were conducted.

Four focus groups were completed, one with parents (n=2) and three with service providers (n=3, n=2, n=2). Eleven interviews were completed with parents of children with ASD and two interviews with service providers. All four youth with ASD attended interviews individually.

We involved participants in a 45-90 minute interview or focus group, at a time and location agreed by participants. All the interviewers were trained on how to communicate with participants and ask questions. There was no relationship between interviewers and participants prior to the study.

We interviewed three participants remotely (one by phone and two via Skype) due to travelling challenges. Prior to the meeting, we asked participants to fill out a demographic form (Appendix II, III, IV). This included: (a) for service providers, information about their age, work experience, and level of familiarity with technology on a four-point Likert scale (not at all to very familiar); (b) for parents, information about their age and their children's age, and the type and duration of using technology in the house by children; and (c) for youth with ASD, information about their age and the type and duration of using technology.

During the meeting, we used a semi-structured interview guide to facilitate discussion through open-ended questions (Appendix I). Follow-up questions and probes were also used to allow for the exploration of participants' ideas during the discussion. All focus groups and interviews were audio-recorded on a password-protected voice recorder. Interviewers also took field notes and memos to better reflect on the discussions. We replaced all participants' names with pseudonyms to maintain their confidentiality.

This study was approved by the University of British Columbia Behavioural Research Ethics Board. Prior to the focus groups and interviews, participants gave written consent to participate in the study.

#### **3.2.4 Data Analysis**

Focus group and interview audio-recordings were transcribed verbatim by four members of the team. One researcher listened to all the recorded files and double-checked transcripts for accuracy.

The data analysis of the project was informed by constructivist approach in which researchers consider that there are shared realities and perspectives on a phenomenon. Data analysis was an iterative process, and it started in the early stages of the data collection. We used thematic analysis to classify the data. First, we studied a few transcripts to understand the primary concepts identified by participants. Then, by reading and re-reading the ongoing transcripts, we looked for common ideas shared by participants. Using NVivo computer software, three members of our team coded the first few focus groups and interviews individually. Then, we discussed our codes in a meeting to resolve any disagreements, and continued to code the rest of the transcripts. Then, we came together to group the codes into categories based on similarity in concepts. Finally, we merged the categories together to come up with overarching themes (Thorne, 2000).

#### **3.2.5 Trustworthiness Strategies**

We used reflexivity and triangulation as two trustworthiness strategies, as described in Section 2.2.5 (Creswell & Miller, 2000; Morgan-Ellis et al. 2006).

### **3.3 Results**

#### **3.3.1 Demographic of Participants**

The researchers recruited 26 participants, including 13 parents, four youth, and nine service providers (4 occupational therapists, 3 behavioural consultants, and 2 special educators). Among recruited participants, 12 parents were female, all youth with ASD were male, and all clinicians were female.

The service providers' age range was 30-57 years [mean (SD): 40.1 (11.3) years], with a mean (SD) of 8.7 (6.8) years working with children with ASD (range 1-20 years). Seventy-five per cent of service providers were somewhat familiar and 25% were not too familiar with technology being used with individuals with ASD.

Parents' ages ranged between 30-65 years old, with a mean (SD) age of 46.5 (9) years. They each had a son with ASD, ranging in age from 8-17 years old [mean (SD): 12.4 (3.4) years]. Among their children, 44% did not have any co-occurring conditions, while the rest had one or multiple co-occurring conditions, including attention deficit hyperactivity disorder, anxiety, sensory processing disorder, and learning disabilities. All parents reported that their children had experience with virtual reality games and playing video games (27% between 0-4 hours; 18% between 5-9 hours; 9% between 10-14 hours; 9% between 15-19 hours; and 36% above 20 hours per week).

Youth participants with ASD had an average age of 14.1 years (SD=1.9). All youth had experience playing virtual reality games. Two of them reported to spend less than an hour, one of them between 3-5 hours, and one of them above five hours per week to play

virtual reality games. Participants had experience playing with a range of virtual reality games, including computer, motion gaming, and iPad games.

### **3.3.2 Themes**

The information gathered from the interviews and focus groups from youth with ASD and parents and clinicians of children with ASD yielded three themes with regards to essential elements that are required when considering virtual reality programs for children with ASD. These include: (a) addressing heterogeneity and diverse needs; (b) mirroring the real world; and (c) teaching strategies. These three factors are deemed to be influential in the effectiveness of virtual reality programs.

#### **Addressing heterogeneity and diverse needs: “Personalizing the program is really hard”**

Children with an ASD diagnosis may have different abilities, behaviours, and combination of symptoms. Given the diverse nature of ASD, participants felt that there should be a high degree of customization and adjustability within the game. Marni (parent) explained: *“These kids are all different, you have to have a way of customizing it, because you may have someone who is low functioning on the spectrum and then you have somebody that is very high functioning.”* Similarly, Michael, a youth with ASD, said: *“Having lots of different ways [in the game] to do the same thing is interesting, like, a lot of different unique ways to accomplish effectively the same goal.”* Having the ability to adjust the game would help cater to individual differences, address relevant social challenges, and integrate strategies that meet the learning needs of children with ASD.

Participants had suggestions to address the various sensory needs of individuals with ASD, including auditory or visual accommodations. Sharon (teacher) said: *“I would have the*

*brightness adjustable and in terms of things on the screen, I would limit that, distractions, and the tendency for kids to be overwhelmed by external stimuli, would be too much to process.”* Marni (parent) stated, *“Sometimes, auditory things can set him a bit over the edge, but if it is a game, you can turn down or have control over how loud the auditory is”*. Mandy, another parent, said, *“No background music or annoyances like blooping or little sound effects”*. Parents reported differing needs in terms of the visual stimuli of the game. For example, Shar stated that her son needs low levels of brightness: *“The lights, they can be too much for him because he is trying to focus on the game”*, but Jade expressed that her son is ok with it [brightness]: *“I don’t find, yeah, he’s okay with that [brightness].”* Another parent, Elise, mentioned that her son needs absolutely vivid levels: *“I have it like one third brightness, don’t know what it is but he always has it at max brightness, so they like bright, for him anyways, he likes vivid.”*

These comments show that the game should be adjusted to the children’s needs. The idea of individualizing interventions was a frequent point of discussion. Parent participants discussed that due to the spectrum of autism, each individual with ASD requires a different approach and families often use *“a lot of trial and error”* (e.g., Donna, parent). Louis, (parent) explained, *“Once we found the right mix of things [programs], the right fit for him... he’s really come into his own.”* This was echoed by Rachel, a clinician, who discussed her approach to interventions as pulling from a variety of programs and adapting specific programs to suit the individual needs of her clients: *“I think so much in our program, we don’t just pick one thing and go with it, we kind of pull from a wide variety of programs... depending on the client”*.

Every participant voiced the importance of incorporating the children's play interests into the game. However, this common suggestion presents itself as a potential game design challenge, as interests were vast and varied. Andrea (parent) shared, "*Certain kids with autism might be interested in some topics, but that doesn't necessarily appeal to all kids with autism.*" Similarly, Mandy (parent) stated that integrating every child's interest is "*going to be tough because their interests are so varied and the way they play is so different*". In addition to the wide range of interests, interests might change over time. For example, Pamela, a teacher, shared: "*[A child with ASD says] what are you talking about, I don't care about that. I'm so bored of trains.*" Shar (parent) explained how this complicates the situation:

*I think personalizing it [the game], which is really hard to do. If you can incorporate their name or children have things that they specifically like, one student obsessed with trains, another is transit, fans...if it could incorporate something that is completely focused to them, I think it would be an engaging thing but I know it is a hard thing to do.*

Children with ASD also might vary in the level of support they need to play the game. Children who are lower functioning need to have their own special educators present while they work on their skills, until they can play with peers. Marni (parent) said:

*I could see the level because obviously it is a spectrum right, all over the place. Somebody that was lesser functioning, their interventionist or consultant or parent or EA [educational assistant] would be the one that would be involved with playing*

*with them, but as time went on a peer definitely, or a peer that was helping out that would be great.*

**Mirroring the real world: “Some of programs are extremely cheesy and not realistic at all”**

Most participants stated the importance of staying as close as possible to real life in the game. This would potentially help to generalize skills from the game to real life.

When discussing the importance of transferring learned skills to tangible outcomes, Katrina (clinician) discussed how she ensures that generalization is built into her programs:

*“Unless the child can generalize whatever the skills are... it’s, can they do it with their parents? Can they do it at the park? At preschool? When they go to kindergarten? So, I think our approach is just making sure... whatever we pick, everyone is consistent and they can practice across environments and with different people.”*

Some stakeholders discussed the “look” of the game as affecting generalization, debating between reality, animation, and fantasy. Harvey, a youth with ASD said: *“video games blur the line between what’s real and what isn’t”*. Marni (parent) stated, *“I think I would do in between; I would do a blend between realism and a cartoon... so they recognize that as being fun and they are reinforced to keep doing it”*. Pamela (teacher) saw the benefits of both realism and fantasy:

*“I think it would be beneficial to have it [the program] be real world so they [children with ASD] could apply it to their real world, but I know that for some kids, they relate better to animations and cartoons and might respond to it better.”*



However, there is a different perspective between parents and children with ASD on the extent of the realism: *“Some parents will want that regular reality because their child is too far into the fantasy thing, so I can see parents having different buy-ins with that too”* (Sharon, teacher). Similarly, Jessica, a parent, stated: *“I just don’t like [him] playing anything that, so say it does involve zombies..., I don’t want it to look remotely realistic, at all. And the less of that the better.”* Katrina, a clinician, mentioned that some of the current virtual reality programs have not been designed well as they are not realistic enough to help apply learned skills in real life: *“Some of them [programs] are extremely cheesy and not realistic at all, like ‘follow my eyes’ or you know, those type of social teaching things, so those I’ve seen not work, not worth the 99 cents or more for some of those games.”*

Participants also felt that including familiar characters into the design of the game would increase the desire to continue to play, as well as assist in the ease of skill development. Sarah (clinician) stated, *“If you could make [characters] look like the people in their social circles, that could help them rehearse and feel more comfortable”*. Shar (parent) reiterated the need for familiar characters to increase game participation: *“[Including] something familiar, so they can be like ‘oh I really like that character, I want to make them happy, what can I do in the game to make them happy?’”* Pamela, a teacher, emphasized using familiar settings with which the child can relate: *“School playground, every kid has to go outside for recess or lunch, so I think that [school playground] is a setting almost every kid can relate to.”* Similarly, Michael, a youth with ASD said: *“Like you’d get in the [school] halls [in virtual reality] and there might be some obstacles”*. Including familiar characters or settings foster greater inclination for the child with ASD to try and understand the characters’ mood or emotion, and may subsequently promote greater game engagement.

Participants described the importance of seeing faces on the screen. Louis, a parent, stated that *“Not seeing people’s faces means that they don’t get to learn that facial referencing and how to read expressions.”* Participants also felt that avatar movements need to be natural and realistic. Sarah (clinician) said: *“[avatars’] movements, [should be] in a way that matches the real world as closely as possible.”* Elise (parent) suggested having users *“virtually walk and do things, like real life skill, so that it translates into real world at some point.”*

Some of the participants talked about the limitations of simulating real world into the virtual programs. For example, Mandy (parent) stated the challenges of communicating with a “machine”: *“I am not sure how you would put that [education] into a virtual reality. You’re teaching them [children with ASD] to interact with a computer who doesn’t have emotion right? So how do you have the emotion show, and have the child understand how they can’t actually hug them... so how do they gauge that social situation too?”* Such obstacles, which are inherent in the virtual reality programs, will impede translation of the learned skills to real life. Shar (parent) shared such a challenge with a game her child experiences: *“It’s more or less the construction of the game itself, because of the way is currently designed, it’s really hard to get the kids so close together [in front of the monitor] even when they [children] are small, bumping into each other”*. Tom (parent) emphasized the importance of having dyadic interactions so that the child learns reciprocity and improves communication.

*“If it’s definitely the singular interaction [in the program], I don’t necessarily think you get it [improvements] because all you would be seeing is your own reflection and what you’re playing with, but if there’s another individual with it certainly,*

*because then they [children with ASD] would see the other reaction or you would hope they would see the other reaction.”*

**Teaching strategies: “You would need some structure.”**

Participants identified an array of relevant and successful strategies that should be included into the design of the game. Those included modeling, repetitions, feedback, structure, and common goals.

The use of modeling was discussed multiple times. Yvonne (parent) emphasized, *“If you model [the expected behaviour or response], it is easier for [children with ASD].”* Sarah (clinician) believed that modeling strategies could be incorporated into the game by *“having the avatar respond to the [player’s] interactions and [having the player] respond in a modelling way”*. Two youth participants with ASD also suggested modelling and observing others. Andrew (youth) stated: *“You need to look, listen and watch what [others in play group] are doing.”* Gavin (youth) provided an example: *“I learn from the cartoons like what people actually feel, what makes them annoyed, by ‘watching’ Sponge Bob, I see [how he] makes people mad.”* Similarly, Donna (parent) reiterated the importance of showing the right action rather than telling it. *“Showing him [my son with ASD]. Just showing him how to do it [the task], acting it out in a group scenario. That works best for him because if you tell him, he doesn’t get it.”* Therefore, attending to, observing, and modelling the appropriate behaviours of another may facilitate the acquisition of social skills.

Repeated practice of a skill was additionally highlighted to promote social participation and emotional recognition. Mandy (parent) explained, *“You need to train enough with the video game, this is the way to process, then it [the skill] could be*

*transferable.*” Sarah (clinician) echoed that thought by stating, *“Try and focus on certain skills and repeat that exposure.”* Similarly, Yvonne (parent) reinforced the importance of repetition by stating,

*“[Children with ASD] see themselves [in the game], so if they watch it many times, their memory is like a camera. When [son with ASD] sees it, he puts it into his brain, so if [children with ASD] look at themselves many times, I think that would help with the transfer.”*

One technique that was deemed important to include in a virtual reality game was to provide feedback to enhance the user’s learning. Mary (clinician) noted the importance of including both motivating and constructive feedback: *“I think the guidance and the positive support and encouragement is huge... But also, the [constructive] feedback... So it’s both.”* The use of feedback, to inform users of their decisions and actions throughout the game, was highlighted when Marni (parent) stated, *“You definitely have to have some sort of feedback system... something visually happening on the screen”*. Brenda (clinician) stated, *“I think [feedback] would have to be immediate and very explicit.”* It was also suggested that feedback could come from game characters. Mandy (parent) proposed, *“If you could have avatars react to kids, like get angry when they don’t complete something, or have your character react this way, that would be excellent.”* Similarly, Gavin (youth) stated that feedback should be used to identify incorrect choices, *“If you don’t get enough stars, then you could have done better and that goes to show, oh I should have listened, or oops, could have done that.”*

Participants also discussed the importance of providing structure and rules within the game. Clinician and parent participants stressed that many individuals with ASD thrive within a structured learning environment. For example, Anna (clinician) said: *“If you just said ‘Here’s your avatar – have fun’! I think that would be harder for kids with autism. For typically developing kids, it would be yee-haw, but I think for kids with autism, you would need some structure.”*

Working together with the characters was suggested for the game design. Pamela, (teacher) said: *“Having characters in [the] game where you have to approach [them] and get them to do a task with you or have to use that other player to complete a task to work together.”* Incorporating such strategies would help children with ASD to practice the skills of communication as well as perspective-taking.

### **3.4 Discussion**

Virtual reality programs are getting attention as therapeutic and educational tools for improving the socio-emotional skills of children with ASD. Despite previous research showing the effects of using virtual reality, there is an absence of stakeholders’ ideas on the elements that are necessary to consider when developing a virtual reality game for children with ASD. This study is the first to examine this by involving stakeholders, including youth with ASD, parents of, and clinicians working with individuals with ASD. Our findings provide new insights into potential parameters of game design in three main areas, including addressing heterogeneity, mirroring real world, and teaching strategies.

Participants underscored the importance of developing virtual reality programs that meets individualized needs of children with ASD. According to the literature, individuals

with ASD present a broad range of symptoms and variability in the type and extent of severity (Wilczynski, Menousek, Hunter, & Mudgal, 2007). The heterogeneous nature of ASD leads to deficits in patterns of cognition, perception, emotion, communication, social, and behavioural functioning (Georgiades, Szatmari, & Boyle, 2013). Children with ASD may experience under- or over-sensitivity in sensory domains, such as auditory or visual stimuli (Talay-Ongan & Wood, 2000). These diverse symptoms and co-occurring conditions can explain why using any treatment for children with ASD, including virtual reality programs, result in mixed findings (Parsons et al., 2000).

Research has shown that an individualized therapeutic or educational regimen based on the child's needs, implementation support, and family culture will maximize the treatment outcomes for children with ASD (Schreibman, 2000). Integrating the universal design approach and customizing the program to meet the child's ongoing needs are required (Coyne, Pisha, Dalton, Zeph, & Smith, 2012). The difficulty of the program should be adjusted to avoid possible anxiety and boredom if the challenges are too much or too little (Boutsika, 2014). Participants also shared potential challenges in individualizing virtual reality programs or tailoring them for children with ASD. As this goal is hard to achieve, it is assumed that virtual reality programs cannot replace traditional one-to-one interventions, and thus they might be used as complementary programs.

Stakeholders identified the generalization of the learned behaviours from the virtual to the natural settings as critical. Although virtual reality can provide an opportunity to practice in various settings, and present a simulated 3-D of the real world, the extent of generalization remains a significant challenge (Parsons & Mitchell, 2002; Strickland, McAllister, Coles, & Osborne, 2007). This may be due to the contrived stimuli used in the

virtual settings, which may impede true representation of the natural setting (Kasari, Gulsrud, Wong, Kwon, & Locke, 2010). It is assumed that the more familiar, realistic, and believable a virtual setting or characters are, the greater the chance of translating skills (Parsons & Cobb, 2011; Pierce, Haist, Sedaghat, & Courchesne, 2004; Wages, Grünvogel, & Grützmacher, 2004).

Individuals with ASD may experience difficulty in naturally generalizing skills from one situation to similar settings. This can be interpreted via the empathizing-systemizing theory, which postulates the higher drive of individuals with ASD in analyzing systems and predicting situations (Baron-Cohen, 2009). A good systemizer is detail-oriented and attends more to find differences, rather than lumping information as a necessity to generalize (Baron-Cohen, 2009). This is aligned with the weak central coherence theory that describes difficulties of these people in integrating disparate information to extract the gist of the situation (Plaisted, 2001). Thus, the inherent nature of resistance to transfer skills among individuals with ASD highlights the importance of adequate and high amount of practice.

Participants identified the importance of incorporating behavioural strategies in the virtual reality programs to promote acquisition and maintenance of social skills training. This includes modeling, which allows learning through observation and imitating the preferred behaviour. Indeed, previous studies showed that video-modeling is an effective method of addressing social skills of children with ASD (Bellini & Akullian, 2007; Charlop, Schreibman, & Tryon, 1983). By removing irrelevant stimuli in a model, individuals with ASD can focus on essential elements of target behaviour (Bellini & Akullian, 2007). Modeling will help individuals with ASD to form the repertoire or internal model that is necessary to perceive social situations and act appropriately (Crowder & Merritte, 2013).

Using structured training and delivering social skills in a dyadic or group format can facilitate social interaction, reciprocity, and generalization (Tse, Strulovitch, Tagalakis, Meng, & Fombonne, 2007). One of the essential elements in reinforcing appropriate behaviour is giving immediate and contingent feedback (Keenan, 2006). This feedback can be gradually faded over time in the virtual reality programs as children master skills. It has been shown that virtual reality programs can allow interacting with humanoid avatars and working together on shared goals, the activity that facilitates cooperation in social situations (Hopkins et al., 2011; Tartaro & Cassell, 2007). It should be noted that because the idea is not to create overreliance of children with ASD on virtual communication or to reduce real world social interactions, the extent and duration of using virtual reality programs should be regularly monitored.

### **3.4.1 Limitations and Future Direction**

Although our study shed light on the primary elements that are required to consider in virtual reality programs for children with ASD, it has several limitations. First, the small sample size from each group of stakeholders and lack of diversity should be considered. For example, interviewing only four males with ASD limited the representation of the female with ASD and whether they have different perspectives. In addition, all guardians had a 'son' with ASD older than 8 years and the majority of service provider participants included female occupational therapists and behavioural consultants. Second, the small sample size of the focus groups with 2-3 participants might affect generating ideas and dynamic group interactions through discussions. Previous studies suggested 5-8 participants as the ideal sample size for focus groups (Carlson & Glenton, 2011; Pearson & Vossler, 2016). Third, the familiarity of stakeholders with the virtual reality programs varied. This may have affected



their awareness of what is and is not feasible with respect to the technology. Fourth, due to the difficulty in scheduling meetings, the use of skype and phone calls in some of the interviews versus face-to-face meetings may have limited the richness of the findings. We suggest that future studies gather more diverse perspectives by including more youth with ASD, parents, and service providers with varied demographic backgrounds through in-person meetings.

### **3.5 Conclusion**

The current research reflects an attempt to gather ideas from key stakeholders to delineate factors that contribute to effectiveness of a virtual reality program for children with ASD. Involving youth with ASD, parents, and service providers will help assure stakeholders' needs and ideas are met. By including these voices and considering them as a guideline for future development of virtual reality programs, it is assumed that the developed virtual reality programs may serve as user-friendly and engaging tools to potentially complement interventions when overcoming social difficulties among individuals with ASD.

This phase helped us to determine what contributes to a virtual reality program for individuals with ASD. Based on participants' ideas, we planned on giving constructive feedback, having different difficulty levels to address heterogeneity of children with ASD, and presenting real-life social situations in the virtual reality program to simulate real-life interaction. However, what still remained to determine was the content of the program.

## **4 Social Stories to Facilitate Perspective-Taking Among Children with Autism: The Content of a Virtual Reality Program**

### **4.1 Introduction**

There have been various forms of social skills training for children with ASD. Social stories as a method of teaching can facilitate the understanding of social contexts that a child might find difficult to interpret (Delano & Snell, 2006; Kokina & Kern, 2010; Scattone, 2007). These stories include descriptive sentences (i.e., describing the context), perspective sentences (i.e., feeling of characters), and directive sentences (i.e., appropriate responses) (Gray & Garand, 1993; Reinhout & Carter, 2006). Previous studies have shown that social stories can improve understanding social situations, inferring perspectives of others, and demonstrating appropriate behaviour (Balakrishnan & Alias, 2017; Marshall et al., 2016; Sansosti, Powell-Smith, & Kincaid, 2004). This is aligned with the theory of mind, which suggests that understanding other people's thought will improve interpersonal skills. Social stories can help children with ASD find the social cues and enhance their communication skills. Using written stories, or stories in a form of pictorial cuing or videos, can increase frequency and length of positive interactions and modify inappropriate behaviours (Thiemann & Goldstein, 2001). Since children with ASD are usually visual thinkers and rely more on visual features of the situations, taking advantage of using visual cues and digital media may expedite the process of learning and increase their motivation (Kunda & Goel, 2011; More, 2008).

Virtual reality programs, as a type of three-dimensional computer programs, have been widely used to serve as a teaching modality for children with ASD (Parsons & Cobb,

2011; Volioti, Tsiatsos, Mavropoulou, & Karagiannidis, 2016). These tools can create a dynamic environment for learning, enhance children's motivation and engagement, and provide visual feedback during repetitive practices (More, 2008). Previous studies have shown that children with ASD enhance their social skills via a virtual environment that represents a virtual café or a bus (Mitchell, Parsons, & Leonard, 2007), and demonstrate some improvements in perspective-taking, emotion recognition, and social perception (Kandalaf, Didehbani, Krawczyk, Allen, & Chapman, 2013). However, the majority of previous studies did not integrate social stories within their program, nor did they incorporate the character's feelings and emotions in relevant daily social situations for children with ASD (Golan & Baron-Cohen, 2006; Ploog, Scharf, Nelson, & Brooks, 2013). For example, these studies only used facial expressions or facial images without contexts or social stories thus making them difficult to be interpreted by children with ASD (Golan & Baron-Cohen, 2006; Ploog, Scharf, Nelson, & Brooks, 2013). This might affect the degree of transferability of the learned skills from virtual environment to real life.

Previous studies suggest that to enhance generalization of learned skills, the “general case training” method can be used (Chezan, Drasgow, & Marshall, 2012; Day & Horner, 1986; Horner, Sprague, & Wilcox, 2005). This method identifies natural variations of stimuli seen in real environments (such as various types of feelings or emotions) and then selects an adequate number of stimuli based on their natural variation to teach the skill (e.g., a portion of the stimuli from each variation), which may result in correct responses to all of the stimuli of its type (e.g., the untrained stimuli) (Horner et al., 2005). By applying general case training that targets perspective-taking through social stories in the content of the virtual reality program, we can potentially improve the generalization of the learned skills. To

develop the content of the program, we considered a group of stimuli that was representative of a variety of social contexts and emotional responses within various social situations. The stimulus variations were types of feeling or emotion (i.e., happy, sad, angry, scared) and intensity of emotion (i.e., slight, moderate, extreme) in three social contexts (i.e., home, school, community). The aim of this project was to involve stakeholders in modifying and validating these various social stories to ensure that they were representative of the situations the children with ASD might encounter; these social stories would then be used as the content of the virtual reality program to help children with ASD increase emotion recognition and perspective-taking.

Involving stakeholders, including parents of and clinicians working with individuals with ASD, will strengthen the quality, relevance, and effectiveness of the stories and assure they can meet end-users' needs (Sanders & Kirby, 2012). Incorporating consumers' views help to create valid and meaningful products (Sanders & Kirby, 2012). Due to frequent issues with non-use or noncompliance with technologies, it is imperative that these programs not only appeal to young users, but also are consistent with the expectations and goals of families and clinicians.

As far as we know, no previous study has incorporated stakeholders' input in validating the socio-emotional stories as the content of a virtual reality program. Using a panel of experts, including parents of children with ASD and clinicians working with this population, this study aimed to prepare a validated library of social stories with various levels of difficulty and emotion intensity to target perspective-taking of children with ASD.

## **4.2 Method**

### **4.2.1 Study Design**

We used the modified Delphi method via online surveys as a structured and iterative process of refining a group's judgement to validate scenarios (Dalkey, Brown, & Cochran, 1969; Jorm, 2015). This method has the advantage of reducing the possible dominant opinion often seen in focus groups, leading to more autonomous and reliable responses (Dalkey, 1972). We used an online platform as it reduces the substantial time commitment during the multiple rounds of the validating process and increases the likelihood of receiving higher response rates (Wright, 2005). Through this iterative and controlled feedback process, we developed and validated the scenarios until consensus was reached (Hsu & Sandford, 2007). The modified Delphi method for this study consisted of two main rounds (Round 1 and Round 2) with each containing two iterations (a/b).

### **4.2.2 Participants**

Due to the possibility of attrition during the iterative process and multiple rounds, we aimed to recruit a large sample size of stakeholders from the initial stage of the project. The participants in this study were naive to the project and had not participated in previous stages of the project. We targeted parents of and clinicians working with individuals with ASD. This study consisted of 63 participants in Round 1a (39 parents and 24 clinicians), 48 participants in Round 1b and 2a (26 parents and 22 clinicians), and 38 participants in Round 2b (20 parents and 18 clinicians).

Inclusion criteria were as follows: (1) clinicians had at least one year of work experience with individuals with ASD and were certified in one of the relevant disciplines

(e.g., speech language pathology, occupational therapy, behavioural therapy); or (2) parents had at least one child diagnosed with ASD. In addition, all participants were required to comprehend written English.

Participants were recruited via email, online blogs, social media, and posters through health organizations and community ASD networks across Canada. Participants were also recruited via snowballing recruitment (i.e., asking participants to send recruitment information to other potential participants).

Informed consent was obtained from all participants prior to the study. This study was approved by the University of British Columbia Behavioural Research Ethics Board.

#### **4.2.3 Procedure**

Participants were asked to fill out a demographic form describing their age and background (Appendix II, III). Then, they were invited to participate in two rounds of an online survey. Round 1 aimed to investigate whether the story represents a situation in which children with ASD would have difficulty understanding or responding to appropriately. Round 2 aimed to investigate the emotion type and emotion intensity related to the validated scenarios from round 1. We asked participants to rate their level of agreement on the content, type of emotion, and intensity using a 4-point Likert scale, in which 1 denotes “disagree” and 4 denotes “agree” (Kirkwood, Wales, & Wilson, 2003). Participants had the opportunity to give reasons for their level of agreement/disagreement.

Round 1: Validating Scenarios. The purpose of the first round was to obtain consensus of participants on the content of socio-emotional scenarios that can be used for a gaming program. First, we shared with our steering committee the scenarios we developed

according to the ideas gathered from focus groups with stakeholders held in previous phases of the study and based on the previous literature (Golan et al., 2010). Any comments related to rephrasing the stories or changing the terms were addressed prior to the validation process. Next, participants were provided with those scenarios in the online survey.

Round 1a: In Round 1a, the scenarios were presented by emotions including: angry (18 scenarios), scared (21 scenarios), sad (17 scenarios), and happy (17 scenarios). Because children with ASD usually experience anxiety and have difficulty understanding the emotion of fear, this category had the largest number of stories (Uljarevic & Hamilton 2013).

Each scenario consisted of describing a short emotional story involving two or three characters (avatars), depending on the content. The scenarios varied in complexity and included avatars of different ages to encourage children with ASD to take various perspectives. Each scenario also had a directional sentence or corresponding action. The corresponding action was a fun, fine or gross motor activity that focused on helping the avatar resolve the issue raised in the scenario. For instance, below is a scenario from the angry category and the corresponding player action:

*The avatar was putting together a puzzle. As soon as she finished it, her dog ran over the puzzle and kicked some of the pieces [descriptive sentence]. The avatar got angry [perspective sentence]. Action: Help the avatar find the pieces and put the puzzle back together [directive sentence].*

Participants were asked to rate their level of agreement with the following statement: “This scenario represents a situation that a child with ASD might have difficulty in understanding or responding to appropriately.” If the participant marked any level of

disagreement (i.e., either disagree or somewhat disagree), there was an open-ended question to give participants the opportunity to provide feedback and explain why the scenario may not be relevant to children with ASD. At the end of the survey, there was also a section for the participant to provide ideas for additional scenarios.

Round 1b: In Round 1b, participants were presented with the summary of the results from Round 1a. We also presented the revised scenarios from Round 1a that did not reach agreement. These revised scenarios incorporated the comments received from participants in Round 1a. We also included new scenarios that were suggested by participants in Round 1a. Participants were asked to re-validate the scenarios by rating their level of agreement with the same statement from Round 1a for each scenario.

Round 2: Validating Emotion Type & Intensity. The purpose of Round 2 was to obtain consensus on the type of feeling or emotion and the intensity of that emotion for each scenario.

Round 2a: The participants were presented with scenarios from Round 1 that reached agreement. Each scenario was presented with a proposed targeted emotion (i.e., angry, scared/anxious, sad, or happy) as well as proposed intensity of the emotion (i.e., slight, moderate, or extreme). The participants were asked to state their level of agreement with the proposed emotion and the intensity of the emotion for each scenario. If participants selected an answer with any level of disagreement (i.e., disagree, somewhat disagree), they were asked to comment on which emotion or level of intensity they think it should be.

Round 2b: The summary of results, including number of scenarios that reached agreement for both the identified emotion and emotion intensity in Round 2a, was provided



to participants. For scenarios that did not reach agreement in Round 2a, we either revised the scenario and/or changed the emotion type or intensity based on participants' comments and then presented them to participants again to validate. Participants were asked to rate their level of agreement for each variable (i.e., emotion and intensity level) on the same Likert scale.

#### **4.2.4 Data Analysis**

During data analysis, the options “agree” or “somewhat agree” were considered as in agreement and the options “disagree” or “somewhat disagree” were considered as in disagreement. We used descriptive statistical analysis that included the percentage of agreement for each scenario. For all rounds, agreement (consensus) was set *a priori* as  $\geq 75\%$  agreement. For each item, percentage of agreement was calculated by summing the number of participants who selected either agreement levels (i.e., somewhat agree, agree) and dividing that number by the total number of participants. We did not separate clinicians from parents and we considered each vote as having equal value. If this total calculation was 75% or greater, agreement was reached. This level of agreement was consistent with other studies that used the Delphi method (Keeney, Hasson, & McKenna, 2006).

We used a content analysis to summarize written comments that participants provided (Hsieh & Shannon, 2005). For the scenarios that did not reach agreement, these comments were used to revise and revalidate the content and/or the emotion type or intensity level.

## 4.3 Results

### 4.3.1 Demographic Information

**Clinicians.** Based on Round 1a, clinicians were primarily female (91.6%) and the age range was between 25-65 years old with the average of 42 years. Among clinicians, 79% resided in the province of British Columbia and the rest were from other provinces of Canada, including Ontario (4%), Alberta (4%), and Saskatchewan (13%). Ten clinicians were speech language pathologists, eight were behavioural consultants, two were occupational therapists, and four were psychologists. They worked for 1-40 years with children with ASD for a mean (SD) of 16.3 (9.2) years. Eighty-six per cent of clinicians were somewhat familiar, 4% were very familiar, and 9% were not too familiar with technology being used with individuals with ASD, on a four-point Likert scale (not at all to very familiar).

**Parents.** Based on Round 1a, parents were primarily female (94.8%), ranging in age from 30-59 years; mean (SD) age was 43.8 (7.8) years. Among parents, 74% resided in the province of British Columbia and the rest were from other provinces of Canada, including Ontario (3%), Alberta (8%), Newfoundland and Labrador (2%), Saskatchewan (5%), Prince Edward Island (5%), and Nova Scotia (3%). Among those, 84% had one child with a diagnosis of ASD, four families (13%) had two children on the spectrum, and one family (3%) had three children with ASD. The sex of the child with ASD was mostly male except two families (7%) who had a daughter with ASD. The age range of participants' children with ASD was between 2.5-18 years old [mean (SD): 12.2 (5.7) years]. Half of the children had no co-occurring conditions, but 33% of participants' children also had attention deficit

hyperactivity disorder, 13% had anxiety, and 3% had auditory processing disorder; 17% had more than one co-occurring condition.

#### **4.3.2 Results of Each Round**

**Results from Round 1a – Validating Scenarios.** In Round 1a, of the 73 total scenarios, three scenarios did not reach agreement (two from the angry category and one from the scared/anxious category (see Table 4.1). The scenario of the scared/anxious category was eliminated and was not re-validated in Round 1b, based on participants' recommendations, to avoid reinforcing fear of bees. The two scenarios that did not reach agreement for the angry category were revised based on participants' comments. Researchers also reviewed new scenarios suggested by participants and presented five relevant ones to be validated in Round 1b.

Some of the participants' comments were related to the content of the scenarios and the structure of the game. These included incorporating elements of cognitive behavioural therapy and calming strategies, in particular for the scared/anxious scenarios. For example, a clinician commented, "*[You] need to add more CBT [cognitive behaviour therapy]/calming strategies to actions in addition to the specific solution for that specific problem*". A parent stated, "*I think there needs to be a bit more focus on deep breathing and other calming strategies before moving into the scenario [actions]*". Based on these comments, we revised some action items for scenarios to incorporate calming strategies. For instance, we revised the previously described scenario to have the character takes three deep breaths prior to getting helps to put the puzzle back together.

Participants also suggested to use action items as teaching moments by explaining to the player what was wrong in a scenario, what action needed to happen and why, and teaching children with ASD safety concepts related to challenging social situations. For instance, a parent said: *“First you must give an explanation [in the story]”* prior to completing the directing action. Another parent commented, *“The action should also include calling for help and finding a way to safety”*. Stakeholders also commented about the age appropriateness and level of complexity of the scenarios. For example, a clinician stated, *“The scenarios are quite good, although the responses would depend very much on the level of functioning and learning history”*.

The comments have been addressed in the multiple iterations of the revisions. These suggestions could help us not only to target emotion recognition and perspective-taking, but also to include the understanding of the ‘why’ – why others feel this way, and the ‘how’ – what needs to be done to rectify the situation.

Table 4.1: Number and Percentage of Scenarios that Reached Agreement in Each Round

Scenarios	Round 1a	Round 1b	Round 2a		Round 2b		Final Numbers
			Emotion Type	Emotion Intensity	Emotion Type	Emotion Intensity	
Angry	16/18 (88.8%)	3/3 (100%)	18/19 (94.7%)	15/19 (78.9%)	1/1 (100%)	4/4 (100%)	19
Scared	20/21 (95.2%)	2/2 (100%)	22/22 (100%)	19/22 (86.3%)	-	2/3 (66.6%)	21
Sad	17/17 (100%)	2/2 (100%)	19/19 (100%)	15/19 (78.9%)	-	3/4 (75%)	18
Happy	17/17 (100%)	-	17/17 (100%)	15/17 (88.2%)	-	2/2 (100%)	17

Round 1b includes revised scenarios that did not reach agreement in Round 1a and new scenarios that participants suggested in Round 1a.

Round 2b includes scenarios that did not reach agreement in Round 2a

**Results from Round 1b.** In Round 1b, all new scenarios suggested by participants (one in the angry category, two in the scared category, and two in the sad category) and revised scenarios (two in angry category) reached agreement (Table 4.1).

**Results from Round 2a - Validating Emotion Type & Intensity.** In Round 2a, one scenario did not reach agreement for emotion type and 13 scenarios did not reach agreement for emotion intensity (Table 1). Researchers revised scenarios that did not reach agreement based on participants' comments to match the emotion type or intensity level. The one

scenario that did not reach agreement for emotion type (72% agreement) was revised to emphasize the intended emotion type. Scenarios that did not reach agreement for the emotion intensity were also revised based on participants' comments. For example, a scenario that was intended to be slightly sad and reached only 71% agreement was revised from stating *"When she took the cake out of the oven it was burnt"* to *"the cake was lightly burnt on the edges"*. We then revalidated the revised scenarios in Round 2b.

**Results from Round 2b.** In Round 2b, we re-validated the one scenario for emotion type and 13 scenarios for emotion intensity that did not reach agreement from the previous round. Of these, two scenarios did not reach agreement for emotion intensity, one in the scared category and one in the sad category (Table 4.1). Subsequently, both these scenarios were eliminated, as we did not conduct subsequent rounds of surveys. The result of all rounds produced a library of 75 validated scenarios (see Appendix V).

A few participants highlighted that scenarios sometimes might have more than one associated emotion (i.e., frustration and anger) and the intensity level of emotion was difficult to determine for some scenarios as the experience of emotions is individual. For example, a parent commented: *"Anger is a secondary emotion [in this scenario], [it is not clear] how to identify the primary emotion"*.

#### **4.4 Discussion**

Using social story as a teaching method has been widely adopted for children with ASD to help them understand social situations. Social stories can be read to children or be presented in virtual reality programs. Although evidence shows positive outcomes when using a social story, developing social stories and identifying appropriate responses might be

interpretative and thus challenging. To this end, this project developed and validated a library of 75 short social stories for the content of a virtual reality program by involving parents and clinicians of individuals with ASD to improve perspective-taking among children with ASD.

Using the general case training method and integrating it into the social stories, we considered various types and intensities of emotion in three social contexts of home, school, and community. General case training focuses on a range of discriminative stimuli (in this study, we examined contexts and the type and intensity of emotions) with relevant features in which a response should occur (Horner et al., 2005; McDonnell & Ferguson, 1988; Petursdottir, McComas, McMaster, & Horner, 2007). Previous studies showed that using sufficient and various stimuli during the training resulted in acquisition and generalisation of the functional behaviours among individuals with severe disorders (Horner & Albin, 1988). The current project is the first study to use this approach in developing the content of a virtual reality program that targets perspective-taking in emotional situations of children with ASD.

Presenting social stories in a virtual reality setting may motivate children with ASD to participate and make the learning more enjoyable. Previous studies have shown that combining pictorial cuing or presenting social stories in a virtual learning environment could facilitate communication among children with ASD (Thiemann & Goldstein, 2001; Volioti et al., 2016). In addition to capitalizing motivation, virtual programs can provide a versatile learning platform to reduce the cost and increase the accessibility for users (Goldsmith & LeBlanc, 2004). Moreover, engagement of end-users in the design, selection, and development of the stories will help meet the clients' needs and maximize the outcome

(Sanders & Kirby, 2012; Volioti et al., 2016; Walsh & Barry, 2008). This potentially increases the sustainability and adherence to the program.

During the iterative process, stakeholders provided a benchmark for levels of difficulty of stories and intensity of emotions. The majority of stakeholders' comments were on the action items of the stories, such as using calming strategies to better reflect the adaptive strategies and appropriate responses in emotional situations. This is consistent with the literature, indicating the positive effects of cognitive behavioural therapy in emotion regulation and anxiety control for children with ASD (Conaughton, Donovan, & March, 2017; Weston, Hodgekins, & Langdon, 2016). It has been shown that effective social stories can enhance children's abilities to stay calm under stressful situations and increase communication skills (Lau & Win, 2017). This can facilitate socio-emotional reciprocity among children with ASD.

In addition to calming strategies, participants noted the importance of explaining why the behaviour is appropriate or why the character feels a specific type of emotion. Explaining the reasons that govern a feeling or behaviour gives information about what is expected to happen (Smith, 2017; Ying, Sah, & Abdullah, 2016). It is assumed that illustrating the context, expected feelings, appropriate behaviours, and consequences in social stories can help children with ASD to make social inferences (Smith, 2017; Ying, Sah, & Abdullah, 2016). This is consistent with the theory of mind because understanding affective states (e.g., others' feeling or emotions) and cognitive components (e.g., why s/he feels that way) is essential in selecting the appropriate behaviour (e.g., how to help if in that situation) (Bensalah, Caillies, & Anduze, 2016; Dziobek et al., 2008). Previous studies showed the



positive effects of social stories on social inference and acquisition of communication skills among individuals with ASD (Balakrishnan & Alias, 2017; Marshall et al., 2016).

Stakeholders mentioned that integrating the safety concept is a critical element of the scenarios. Previous research found that teaching safety skills in the educational programs usually can not satisfy parents' expectation (Agran & Krupp, 2010). The lack of sensitivity to danger and risky situations, and presence of impulsive behaviours among children with ASD, call for safety management training. Recent studies have shown that children with ASD benefited from social stories and virtual reality programs that focused on safety skills (Self, Scudder, Weheba, & Crumrine, 2007; Ying et al., 2016; Josman, Ben-Chaim, Friedrich, Weiss, 2008). The majority of research, however, has been on street walking skills and road safety. Therefore, it is suggested to incorporate the safety concepts in other areas within social stories.

The current project provides a uniquely validated library of social stories focused on perspective-taking, with diverse difficulty and intensity levels. The strength of this library lies not only on the diverse stories and stimuli, but mostly on the fact that the library was created in close collaboration with end-users. This library can reduce a significant burden on clinicians and special educators, allowing them to more quickly and easily adjust the stories based on the unique needs of each child. Wide representation of how ASD is presented and its heterogeneity reflect a need for tailoring individualized programs based on children's symptoms (Wilczynski, Menousek, Hunter, & Mudgal, 2007). For those who have severe problems in perspective-taking, these stories in varying difficulty levels can offer adequate stimuli based on general case training. Of particular usefulness, this library can be used as validated content for any virtual reality program, presenting the stories in a gradual level of

emotion intensity and difficulty to help children improve perspective-taking and socio-emotional reciprocity. This study completed the first step in general case training— defining the instructional universe. The next step of this process would be the identification of the scenarios that represent the general case, which will be described in the next chapter.

#### **4.4.1 Limitations and Future Direction**

There are some limitations of the project. First, those who participated in validating the scenarios may not represent the diversity of the stakeholders. Participants of the study consisted mostly of women between the ages of 40 and 44 years old and majority of the clinicians had backgrounds in either speech language pathology or behavioral intervention. The sample was from one country that may affect transferability of the scenarios. Furthermore, due to the multiple rounds of the Delphi method study, there was an attrition rate in the sample size. A typical attrition rate is estimated to be about 30% in the Delphi method (Keeney, Hasson, & McKenna, 2006). In this study, the attrition rate from round 1a to round 1b was 23.8%, from round 1a to round 2a was 23.8%, and from round 1a to round 2b was 39.6% amongst all participants. We did not involve children and youth in this phase of the project due to their ability in reading stories and abstract thinking skills. Further research needs to include a wider population, larger sample size, and involve children and youth with ASD to include their ideas and reflect on their lived experiences. Second, this project only considered four basic emotions with three intensities and contexts as a starting point to develop the program. Future studies are warranted to include emotions other than the four included in this study, such as disappointment, frustration, surprise, and excitement, as well as include other intensities and other contexts. Third, we included only two rounds for each Delphi, and eliminated two scenarios that did not reach agreement at the end of the

study to avoid conducting subsequent rounds. It should be noted that adding additional rounds could shift participants' responses. It is suggested that these validated socio-emotional scenarios be tested with children with ASD in different formats, such as a virtual reality, to investigate the outcomes in future projects.

#### **4.5 Conclusion**

This study is the first attempt to develop and validate the content of a virtual reality program using general case training and social stories by involving parents of and clinicians working with individuals with ASD. The feedback provided by stakeholders allowed the researchers to gain insight into what scenarios and strategies are useful for targeting perspective-taking. The developed library of validated social stories in various contexts and with varied emotions may help to improve socio-emotional skills among children with ASD.

This phase of the project helped us to validate the content of the program and improve the socio-emotional scenarios that our program presents. We adjusted the scenarios based on participants' feedback, including having an explanation of the scenario, adding calming strategies, and rephrasing some of the stories. This phase was the first step in general case training framework. The next step was involving stakeholders to actively co-design and provide feedback during the development of the program.

## **5 Co-Development of An Interactive Kinect Game for Children with Autism: A Participatory Design Approach**

### **5.1 Introduction**

The ability to attribute behaviours to various intentions and emotions, and understanding what is in the mind of others are parts of empathy (Baron-Cohen, 2009). Children with ASD show difficulty in empathizing with others and perspective-taking (Baron-Cohen & Wheelwright, 2004), which profoundly affects their ability to participate socially and display socio-emotional reciprocity.

Video gaming programs have been increasingly used to support individuals with ASD to improve their social skills (Parsons & Mitchell, 2002). These programs can offer a simulation of the real world, maintain motivation, and immerse users in an interactive virtual environment through the use of multiple sensory channels (Parsons & Cobb, 2011). Virtual reality programs can provide a safe learning environment for individuals with ASD, as it allows users the opportunity of having control over the stimuli and work at their own ability level (Ke & Im, 2013; Parsons & Mitchell, 2002). Increased communication skills and a higher level of social interaction after using these programs show that these technologies can be potentially useful for individuals with ASD (Hughes, 2014; Moore, McGrath, & Thorpe, 2000; Parsons & Mitchell, 2002; Wainer & Ingersoll, 2011).

Despite the increasing interest and development of gaming programs, most technological modalities are computer-based, where the user controls the play with a keyboard, mouse or joystick. Motion gaming programs, however, can be more engaging and can support learning among users through body movements and embodied learning (Crowder

& Merritte, 2013; Pasch, Bianchi-Berthouze, van Dijk, & Nijholt, 2009). The Kinect platform offers players the opportunities to interact via body movements or verbal speech. These types of technologies enhance children's engagement in the activity by allowing them to move their body naturally, while learning new skills (Boutsika, 2014). Given the higher resemblance of interactions seen in these programs to real life compared to computer programs, Kinect-based gaming programs have recently been used to improve social skills in children with ASD (Bartoli, Corradi, Garzotto, & Valoriani, 2013; Garzotto, Valoriani, & Bartoli, 2014).

Previous studies that used motion gaming among individuals with ASD demonstrated learning benefits and improvements in attentional skills (Bartoli et al., 2013; Chia et al., 2013). However, these papers used commercial programs that did not focus on perspective taking skills as one of the main areas for children with ASD. Commercially available games have not been specially designed for individuals with ASD, and thus may not completely meet their needs or address the challenges from participants' viewpoints around social skills. This may result in difficulties in adoption of the program or continuation of using it among stakeholders.

A review of the literature suggests that there has been limited incorporation of the view and input of key stakeholders, such as children and youth with ASD and their parents, in regards to the design of the gaming programs (Jivraj, Sacrey, Newton, Nicholas, & Zwaigenbaum, 2014). Involving different stakeholders in the design process has been recently used to allow developers to integrate the preferences of children with special needs (Malinverni et al., 2017; Mora Guiard, Malinverni, & Pares, 2014). Previous studies emphasized the importance of user-centred approach and stakeholders' engagement during

design and development (Gillespie-Lynch et al., 2011; Keay-Bright, 2007). However, involvement of children with ASD in the development of games designed for them is still rare and relatively limited to later stages of the development in refining the design (Frauenberger, Good, & Keay-Bright, 2011; Jivraj et al., 2014).

Participatory design involves a collaborative process where children's interests can be combined with parents' knowledge and experience in order to strengthen the quality and effectiveness of the intervention, and thus improve outcomes (Millen, Cobb, & Patel, 2010; Parsons, Millen, Garib-Penna, & Cobb, 2011). Consumers as informants or design partners, not only just testers, act as equal stakeholders during the whole process of design and development (Druin, 2002). Involving children during the design process would create a product that more likely meets their needs and thus be used by them (Frauenberger, Good, Alcorn, & Pain, 2012). For children with disabilities such as ASD, their restricted abilities in verbalizing abstract concepts may require involvement of their parents alongside their participation. Due to frequent issues with non-use or noncompliance with technologies, it is imperative that novel interventions not only appeal to clinicians' ideas, but they must also be consistent with the interests of children and expectations of families.

As far as we know, no previous study developed a motion gaming platform for children with ASD with the participatory design approach to address perspective taking in socio-emotional scenarios.

This study aimed to involve children and youth with high functioning ASD (i.e., those with verbal abilities), and their parents, in collaboration with game developers, to develop an interactive motion gaming program that focuses on perspective-taking.

## **5.2 Method**

### **5.2.1 Research Design**

This study adopted a participatory design approach, using a think-aloud method, during the usability testing of the product design and development, where we collected data by involving stakeholders and in collaboration with developers (Millen, Cobb, & Patel, 2010; Parsons, Millen, Garib-Penna, & Cobb, 2011). Based on the international standards for user-centred design (Earthy, Jones, & Bevan, 2012), this phase of the project focused on creating design solutions and evaluating it to troubleshoot the system.

### **5.2.2 Participants**

The inclusion criteria for children/youth with ASD were: (a) having a clinical diagnosis of ASD based on parents' reports; (b) having previous experience of playing with virtual reality games; and (c) being high functioning and able to verbally communicate with the research team in order to respond to questions and provide feedback on the prototype of the game. The exclusion criteria for children was having uncontrolled epilepsy or seizures. Parents also needed to be able to communicate in English.

We recruited 20 participants through convenience sampling via emailing community networks, and public and private ASD organizations across BC. We also used snowball sampling (i.e., asking participants to pass along recruitment information to other potential participants).

Informed assents or consents were obtained from children and youth respectively, as well as asking their parents to give consent prior to their participation in the study. If any of

youth had problems in reading the consent, we provided them with the assent form. The project was approved by the University of British Columbia Behavioural Research Ethics Board.

### **5.2.3 Description of the Program**

The proposed game was built on the Kinect device that could track players' body movements and project it on the screen. The device also allowed players to communicate and talk with the characters shown on the screen. The user was represented by an avatar, which faced to other characters in the virtual setting, that is, their back is facing the player. Users were able to communicate with characters and select objects on the screen according to the instructions of the game, in order to get a score.

The content of the game was scenario-based (Sansosti, Powell-Smith, & Kincaid, 2004). The program included 25 emotional stories with varieties in emotion intensity (severe, moderate, slight), type (happy, angry, sad, scared), setting (home, school, community), characters' age (child, youth, adult), and gender (male, female). This allowed us to have 216 various stimuli based on the 3 (emotion intensity) X 4 (type of emotions) X 3 (settings) X 3 (age groups) X (2 gender groups). We selected stories of the game from the library of stories developed and validated by the different stakeholders in the previous phase of the project. The selection process of stories was conducted in consultation with the steering committee and our game developers to make sure the stories are feasible to develop in addition to maintaining the variation. This selection is considered as the second step for general case training (Appendix V). A map of scenarios is provided in Appendix VI.



The player observed an interaction between two or more characters shown on the screen. Then, one of the characters asked the player a question regarding the emotion inherent in the story. For example, one of the stories takes place around the dinner table, with an interaction between a child and his mom. The child avatar is asking his mom to take him to a movie. The mom explains that she is not available to take him right now, as she needs to finish washing the dishes and clean the house. Then, the child character shows sadness on his face, and asks the player how the character is feeling in this context using the relevant tone of voice or emotion in voice (Golan, Baron-Cohen, Hill, & Rutherford, 2007). The player needs to infer the emotion and communicate either by selecting the appropriate image out of possible four (emotive faces) displayed on the screen (recognition) or by articulating the answer aloud (recall). As selecting the option (recognition) is easier than articulating it (recall), this allows adjusting the program to the player's level of function (Figure 5.1).

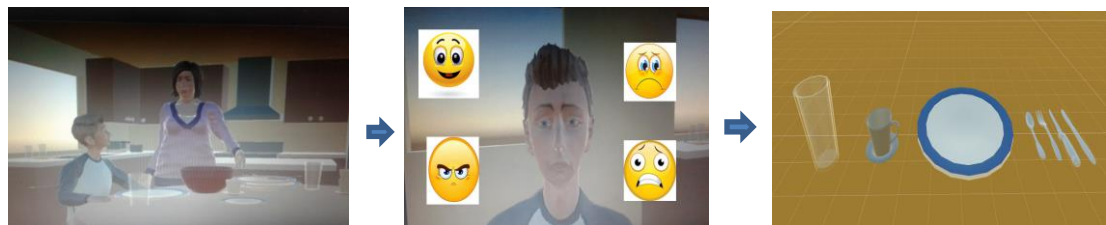


Figure 5.1 Few Screenshots of the Game

Visual and auditory feedback were given based on the correct or incorrect responses. In the case of an incorrect response, visual feedback was presented in the form of the character shaking the head to illustrate “No”. This was followed by an auditory feedback and

request for the player to “please review and try again”. Then the story was replayed for the second time and the player was given another opportunity to respond correctly. In the case of a correct response, one of the characters invited the player to help in solving the problem that has been presented. For example, the character says, “I am sad. Unfortunately, we cannot always do things exactly when we want. However, if I help clean up, then we can have time to watch a movie at home instead. Can you help me clean the dirty dishes quickly while I wash the pan?” The player then had the opportunity to manipulate objects and select the items relevant to the context (e.g., selecting dirty dishes) within two minutes. This potentially helps the child to better understand what is being discussed in the social context, as a necessity for perspective-taking (Fonagy, Allison, Midgley, & Vrouva, 2012; Symons, 2004). Then, the character says, “give me a high five” and once the player responded appropriately, the scene ends. The sequence of presenting the stimuli can be seen in Figure 5.2.

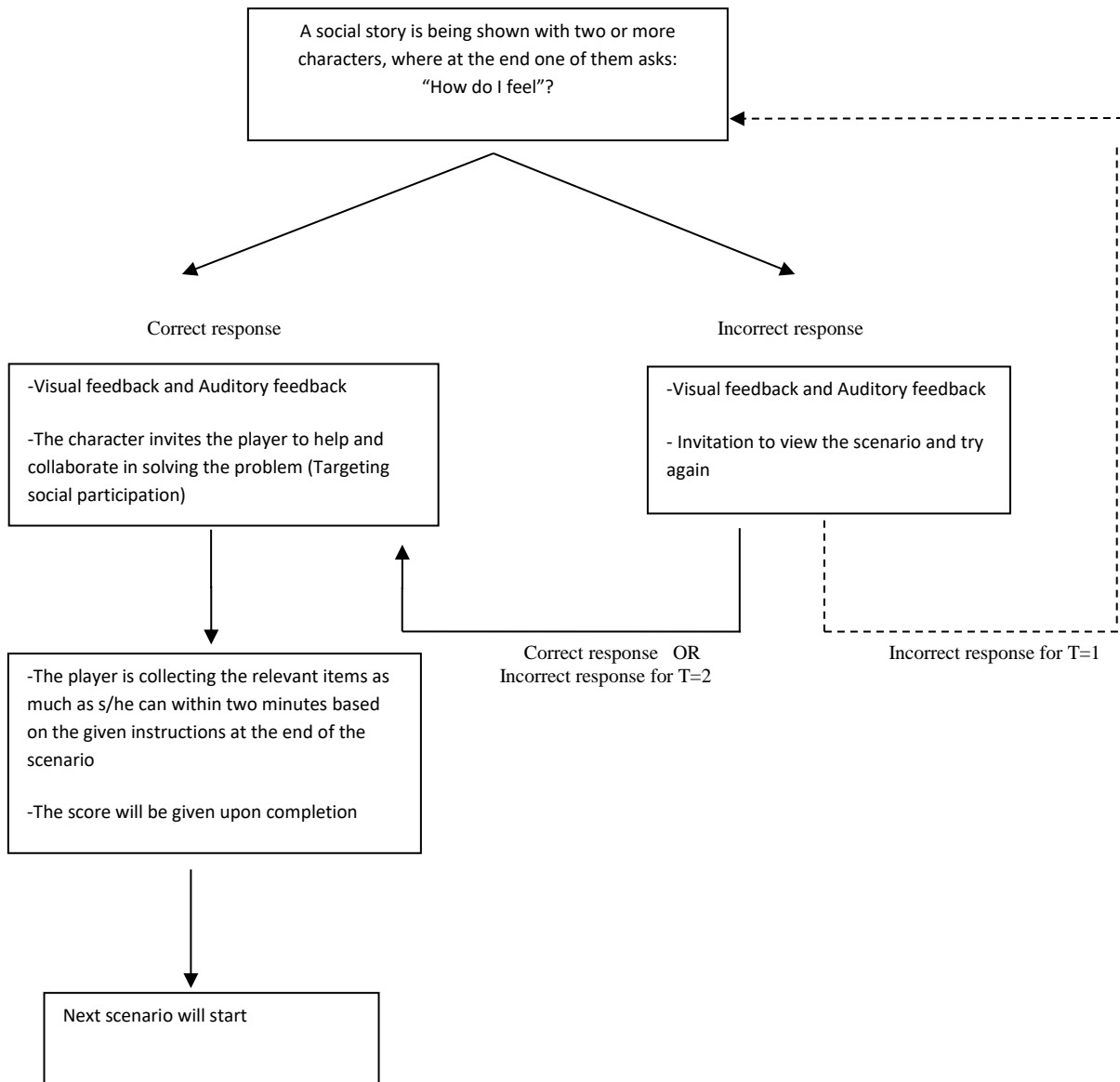


Figure 5.2 The Sequence of Each Trial of the Game.

Note: We defined “T” as the trial where the child is given an opportunity to respond. The incorrect response for T=2 is defined when the child gives an incorrect response for the second time.

#### **5.2.4 Procedure of Development**

We asked participants to attend a 45-90-minute session, at a time and location agreed by the participants, to share their feedback and impression about the developed program. Participants were invited to participate throughout the process of the development of the game, thus some were involved when only a few scenes were ready and others after the whole system had been developed. Each session was audio-recorded, with field notes taken by the researchers, allowing data analysis afterwards.

After developing the first five scenes of the game in the virtual settings, we involved 12 participants, including two children and four youth with high-functioning ASD and their parents, each family in separate sessions. Using the “think aloud” method (Valdés, Hilderman, Hung, Shirzad, & Van der Loos, 2014), we asked participants to say out loud what they are thinking about the developed scenes, graphical design and interface features of the game, while they are playing it. After participants played the game, we asked both the children/youth and their parents questions about the game features to further gather feedback and suggestions for improvement (Appendix VII). We resolved the bugs, adapted scenes, and moved forward to build the rest of the program.

After developing the whole program, we tested the system involving two children and two youth with high-functioning ASD and their parents who were naive to the project scope. We asked participants and their parents to give us feedback about the program and what needed to be improved (Appendix VII). This user test step helped us to identify potential problems that may arise when new users play with the system. Identified problems were

addressed, and the program was further viewed by researchers prior to launching the system and the release of the prototype program.

### **5.2.5 Data Analysis**

All audio files were transcribed verbatim and then reviewed by a researcher carefully to ensure the accuracy for both verbal and non-verbal information, such as pauses. We used summative content analysis to accumulate participants' comments and summarize comments. We replaced all participants' names with pseudonyms to maintain confidentiality.

### **5.2.6 Trustworthiness Strategies**

We used two methods of trustworthiness strategies, namely reflexivity and triangulation, to ensure credibility of findings as described in Section 2.2.5 (Creswell & Miller, 2000; Morgan-Ellis et al. 2006).

## **5.3 Result**

### **5.3.1 Demographic of Participants**

Participants were four children and six youth with high functioning ASD and their parents (20 in total). Twelve of the participants were Caucasian, four were Asian, and four were Hispanic. The mean (SD) age of children was 10 (1.8) years, and the mean age of youth with ASD was 15.16 (1.8) years. All children and youth were male, and only two reported having a co-occurring condition - one with an attention deficit hyperactivity disorder and another with developmental coordination disorder. All of them had previous experience of playing with games including computer games (70%), PlayStation (60%), motion games (60%), and iPhones or iPads (90%). Half of them reported spending 1-2 hours per week to

play video games, 40% about 3-5 hours, and 10% above 5 hours. They play for various purposes or multiple purposes, including education (50%), therapy (20%), and entertainment (100%).

### 5.3.2 Themes

Participants commented on three main areas: design of the game, level of engagement, and feedback provided to the player.

#### **Design– How it looks and sounds**

All the participants provided comments related to the design of the game, including visual design, animation, and sound.

a) Visual design: Some participants spoke about the colour and background. The most prevalent theme raised included the need for a vibrant and realistic look to the objects, size, and perspectives. The following comments from participants are some examples that illustrate these points:

- *“The visual needs more colouring, something interesting, and more background. It’s more natural, more realistic”.* (Catherine, mother)
- *“I think too many greys [are in the game]. The kids usually prefer the life colors, red, green, orange, warm, light. That is too grey.”* (Michael, father)
- *“Maybe the dish should be a little bit smaller.”* (Jared, youth with ASD)
- *“I think that the area to clean was a big rectangle, but the plate was a big circle inside that. So, you clean the plate but it doesn’t seem to be done.”* (Tony, father)

b) Animation: All participants stressed that the way the characters move, how they look, and how they express emotions should be improved. Most of them talked about intensifying the

expressive level of emotions to better reflect the feelings. One parent suggested adding body gestures to better illustrate characters' feelings.

- *“Instead of walking, it’ll [the characters] glide.”* (Loren, youth with ASD)
- *“The faces don’t have any expression. It doesn’t matter if it looks fun, the faces don’t have expressions, they don’t give you any communication about what’s the feeling. Even with arms, because if you feel mad you do this with your arms. But there is nothing, no gestures. We need information about what’s the feeling. Lower functioning kids won’t have that information.”* (Michael, father)

c) Sound: In addition to the visual elements, some participants expressed the importance of improving the tone of voices while characters are talking. Using expressive language rather than a computerized version of the recorded talks would make the feelings sound more natural. Participants elaborated on the extent to which natural and informal dialogues compared with the formal ones should be used. It was also stated that adding sound effects and audio features relevant to each scenario would be helpful.

- *“In some cases, the inflections for the emotions seemed a bit harder to pick up with the computerized dialogue. Just based on the computerized dialogue it seemed unnaturally slow a bit. I think the tone of voice is going to go a long way.”* (Tony, father)
- *“Maybe you can make the dialogue a little bit better. Like, what they’re saying, how they’re saying it.”* (Jared, youth with ASD) *“I think the gap between the characters’ [mouth movements] is just a bit too big when they’re talking.”* (Loren, youth with ASD)

- *“The sound of the waves, ..., [having it] more rich. Make them [kids with ASD] feel it’s real”.* (Suzy, mother)

### **Maintaining engagement – How it feels**

All the participants addressed ways to impact the sense of engagement of the player. Those included the use of full body movements, the comfort level of using the game, external motivators, and ways to increase clarity of use.

a) Movement: Almost all the participants acknowledged that the way the game incorporates body movements helps to keep children interested and engaged. Parents also pointed out that body movements might help with the co-occurring conditions that a child with ASD experiences, and promote physical and mental engagement.

- *“I liked seeing my movements and also I liked it [avatar] copying me.”* (Cody, a child with ASD)
- *“It’s hard to get his [my son’s] attention, you got his attention [by body movements], and that was really cool to see.”* (Eric, father)
- *“I like the body movement parts. I think it’s a good idea to keep the kids active, and the kids are more interested as well I think rather than just sitting there with a controller. It’s more real life as well, if they’re actually getting up to do something. Also, my son’s got DCD, Developmental Coordination Disorder, and I think the game might help with the coordination.”* (Alissa, mother)
- *“It’s good to keep kids moving, because it’s something that makes him do exercise, [and be involved] mentally, too.”* (Rose, mother)



b) Comfort: Despite the potential benefits of using body movements in the game, capturing movements with high precision and sensitivity, and providing easy navigations, are critical to keep children engaged. Some of the participants experienced a lack of sensitivity in the sensor or an awkward hand-positioning in order to navigate through the system that might interfere with the natural flow. They also noticed that some of the play icons might not be reachable for shorter children, making navigation in the system difficult.

- *“Sometimes the sensor doesn’t move so effective, so I think for younger kids they might feel frustrated if the sensor does not easily get it, so make it more sensitive and easier”* (Susy, parent).
- *The most awkward part of those seemed to be having to hold your hand in certain spots to get the key. So, when you picked up something he would have to hold his arm in the same spot for a very long time, and then when he moved it, [he] had to reset, and that seemed a bit annoying. I don’t know if there’s a way to make that shorter or something to make it more realistic.* (Loren, youth with ASD)
- *“I was like doing on my tippy toes and reaching with one hand... I’ll try reaching, but if I cannot reach.”* (Bryan, child with ASD)

c) External motivators: Some parents expressed the ideas of incorporating external motivators, such as images that children might like or background music. However, this idea contradicted what all children and youth with ASD participated in the study shared. They thought that there was no need to add music, because it should feel like the real environment.

- *“He [my kid] always loves dinosaurs and trains, so if there is some train racing games or some adventure to find dinosaurs, he would love that”.* (Susy, mother)

- *When the characters are talking, you can think about music, and when they are trying to resolve things, like collect all the apples, usually the games will have 'challenge' music because that makes the kids more, oh, I need to go, I need to do..."*  
(Michael, father)
- *"I wouldn't say add music because you want it to be a realistic feel and not just an animated feel."* (Loren, youth with ASD)

d) Clarity - Manual / instructions: Participants unanimously stated that instructions or a manual on how to play would be helpful for children and keep them engaged.

- *"Yeah [having some instruction in the game]. It was like the paddles were held in a certain placement, and you have to know where to place those paddles to catch them...If you know this, it's fine, but if you're just an average kid that's playing the game, that's used to playing other games...[that is difficult]"* (Eric, father)
- *"There could be a map in the corner that just shows kids what to do, I think some kids could be confused initially."* (Tony, father)
- *"I think some [children] don't know how to play so if you make something like [the virtual character], it can talk to them how to play the game."* (Catherine, mother)

### **Fine-tuned feedback**

Participants stressed that providing adequate and efficient feedback to children with ASD is necessary. Their comments addressed the format, content, and amount of feedback.

a) Format: Stakeholders shared that it is important to provide various forms of feedback so children with ASD with diverse functional levels can understand. Most parents stated that taking advantage of concrete and visual forms of feedback would be helpful for children with

ASD. While few parents mentioned quantitative methods to show scores visually, almost all children/youth preferred receiving qualitative feedback (i.e., excellent, very good, and good).

Here are some examples:

- *“I think it depends on the kid, because for low functioning kids, the visual is more important, green bars are more effective than numbers.”* (Michael, father)
- *“I think it’s just remembering that these guys [children with ASD] are very visual, so if you have visual support like for timers or percentages, it’s really helpful, even if they don’t know that, it’s just that extra visual support.”* (Mary, parent)
- *“I think Excellent would be better [than a score].”* (Jerad, youth with ASD)
- *“Both [time and score], because it introduces, like for him [my son], he’s just picking up that kind of stuff, so it’s kind of an offshoot, where it’s another skill you’re developing, maybe not intentionally, but they are building that other skill.”* (Mary, parent)

b) Content: All participants recommended providing constructive feedback to help the children to be informed about why it was the right or wrong response, without getting emotionally hurt. Participants negated the idea of seeing responses through the lens of binary right or wrong, suggesting how to word the feedback in a way that will facilitate the child learning. Some examples included:

- *“I don’t think the way they say that [the feedback] would make the kids happy. Say something positive, like if you make it wrong, it says, ‘Oh, why don’t you take another chance or pick another answer?’ Or, ‘Oh, I think this one might be okay but find a*

*better one!’ Something positive... Yeah, positive is better, because if it makes them upset they don’t want to play anymore.” (Catherine, mother)*

- *“Where it says, ‘Correct Response’, I would probably put in someone [character] saying, ‘Wow, that’s what I think too!’ or something like that to validate that it’s the right response, a bit more natural..., so if someone picks ‘angry’ instead of ‘sad’, I would have someone [a character] say, ‘Really? I felt sad about that... verbalizing how they felt, and how they would feel, just to sort of get the idea... Yeah, you could sort of say, ‘Really? Well, I felt differently, try again.’” (Alissa, mother)*

c) Amount: Participants also pointed out that the amount and frequency of feedback plays a vital role during the game. Providing adequate amount of feedback will encourage kids to take a second chance and keep trying.

- *“I could say more information, more feedback on what they’re doing right or wrong, a lot more feedback definitely.” (Alissa, parent)*
- *“We all make mistakes, so even though I got one wrong, I can watch it [the game] again.” (Alex, youth with ASD)*
- *“I think that when the kids failed, you can give them second chance to help them to achieve” (Susy, parent)*

These quotes illustrate that providing adequate and well-tuned feedback will reinforce positive behaviors and help children with ASD to nurture new skills.

## **5.4 Discussion**

Participatory design and co-creating technology ensure stakeholders are meaningfully involved in the research and can reduce the possibility of non-use of the program. Given the

paucity of participatory research to create a motion gaming program that meets end-users' needs, this project is one of the first studies that involved children, youth, and their parents to contribute as design partners during development of an interactive Kinect game. Participants gave ideas and feedback in three main areas, including audio-visual design, maintaining engagement, and fine-tuning feedback.

Stakeholders identified the importance of the design, and they pointed out that animations should be improved. This is consistent with the previous study that found visual and audio features play a pivotal role in virtual environments (Gillespie-Lynch et al., 2011). Enhancing graphics and sound effects can contribute to the sense of presence and help with perceiving the virtual setting as if it is similar to real world (Slater, 2003; Witmer & Singer, 1998). Displaying relative depth, realistic perspectives of objects, and spatial cues can optimize reconstruction of a scene (Bowman & McMahan, 2007). Increasing the sense of immersion and presence through 3-D audio and visual features would render a more realistic experience for individuals with ASD. Such coherency in simulated sensory and perceptual processing potentially activates the nervous system to produce a behaviour similar to the ones shown in the real life (Slater, 2003). Although our developed game could represent users in the form of an avatar and project users' movements on the screen to allow users to interact with objects and other characters in the virtual setting, the level of immersion is low. As the game had components of interaction with avatars and manipulation of objects, it can be considered as a low-level immersive virtual reality.

Participants also stated that characters in virtual environments should better demonstrate emotions through their facial expressions, gestures, and speech. Emotion, as a cornerstone in communication, is usually expressed in a multi-modal way among typically

developing people but not individuals with ASD (Scherer & Ellgring, 2007). To be able to empathize with others, both cognitive and affective elements should be considered (Aan Het Rot & Hogenelst, 2014). Blunt faces and computerized recorded conversations would not portray affection or the tone of voice felt in humanoid speech. High resemblance of virtual settings to real environments would help represent internal models or repertoire, which in turn generate ongoing experiences (Crowder & Merritte, 2013; Pierce, Haist, Sedaghat, & Courchesne, 2004; Wages, Grünvogel, & Grützmacher, 2004; Wolpert, Miall, & Kawato, 1998). This interplay would likely facilitate transferring learned skills to real life contexts.

It is challenging to maintain players' engagement while adhering to the reality elements. The point is how much virtual settings should be real or fantasy-driven in order to secure potential positive outcomes (Wages et al., 2004). There were contradictory ideas between children and their parents on how to engage players in the virtual environment. Some stakeholders asked to include music and various fantasy agents, such as dinosaurs, that make children with ASD attentive to the game; however, some did not agree with these ideas. This might be derived from the diversity of preferences that can be seen in the participatory design (Bruno & Muzzupappa, 2010; Kensing & Blomberg, 1998). Having various ideas can be attributed to previous experiences or backgrounds that complicate the design process. Reconciling different points by negotiating with stakeholders or offering some alternatives would help prioritize the ideas and design a user-friendly system (Kensing & Blomberg, 1998).

Stakeholders unanimously expressed the benefits of interacting with the system through movements to highly engage users. According to embodiment theory, there is a close interaction between the sensory-motor system and cognitive system, leading to more

effective learning (Kiefer & Trumpp, 2012). However, to capture the subtle movements during the program, the sensors of the system should be sensitive enough (Gillespie-Lynch et al., 2011). Considering system limitations, unnecessary lag between users' movements and projected outcome may cause frustration, resulting in discontinuation of the program. Providing a manual or demos for children, their parents, and clinicians showing how to use the program may help users or those who have difficulty configuring its procedure. Through integrating the inclusive design, users of different ages and capabilities can comfortably navigate through the system and be engaged in the program (Clarkson, Coleman, Keates, & Lebbon, 2013).

Providing feedback to children with ASD, or giving the opportunity of reflecting on their performance, is one of the vital elements in learning new skills. Participants recommended using various forms of feedback to help players with ASD to understand their progress. This is aligned with a previous study that indicated pictorial feedback or concrete cues would be preferred over numeric systems that carry abstract concepts (Gillespie-Lynch et al., 2011). As most individuals with ASD are visual learners, their abilities excel when visually-cued instructions are present (Grandin, 2006; Quill, 1995).

Stakeholders suggested that continuous and constructive feedback is a critical factor, not only to maintain using the program, but also to enhance the learning of the players. The constructive feedback should not create feelings of frustration; rather, it should encourage users to keep working towards the desired goal. Providing adequate amounts of contingent and immediate feedback that are faded over time would reinforce the behaviour (Keenan, 2006; Whyte, Smyth, & Scherf, 2015).

One of the significant strengths of this project was the iterative process of development with involvement of stakeholders as knowledge producers in the design process. Inclusion of both parents and their children/youth with ASD helped us to obtain ideas from different viewpoints. According to family-centred care, the family plays a significant role in implementation of a program and maintaining its usage (Prelock & Hutchins, 2008). Therefore, parents' views and concerns should be considered. In general, there was agreement between parents and their child/youth with ASD, but there were also some differences in their voices, in particular for selecting the motivating factors and forms of the feedback. Being aware of the range of preferences and ideas that might be used during the design process enriched the design of the game.

#### **5.4.1 Limitations and Future Direction**

This study has a number of limitations. First, we only included parents and their high functioning verbal children or youth, and they might not reflect the ideas of those who are on the lower level of the spectrum. We recommend future studies to add other methods of data collection such as videotaping the player to later analyze their reactions, for example, their level of enjoyment. Second, gender differences and ideas for external motivators (e.g., trains, music) might affect how the game should look. Despite considerable effort to include females with ASD, data are devoid of their perspectives. This might be due to higher prevalence of disorder in males compared with females, and/or potentially males' interest in attending the project and using virtual reality games. Third, although we recruited all participants from one western country, future studies should consider stakeholders from various ethnic or cultural backgrounds. Fourth, our study included more youth than children with ASD who were all familiar with motion gaming systems. As both knowledge and age



affect viewpoints, having a population with various ages in the design process would be helpful.

## **5.5 Conclusion**

The current research reflects an attempt to gather ideas from key stakeholders to design a motion-based video game to improve perspective-taking in children with ASD. By including children and youth with ASD and their parents as equal partners in the design process, it is assumed that the proposed development of this motion-based game may serve as a user-friendly and engaging tool to complement interventions when overcoming social participation difficulties in individuals with ASD. In particular, the results of this study enhanced the design of the game, allowed us to improve features related to level of engagement, and enriched the feedback provided to the player in order to improve their learning.

This chapter helped us to co-design the game and enhance the user-friendliness of the system. During this phase, audio-visual features were improved. This included improving facial expressions and creating more background presentations in the scenes. Furthermore, we recorded human voices and removed all computerized versions of the voices to better represent emotional voices. We included sound effects relevant to each scenario to increase the feeling of real-life interactions. As for the engagement, we adjusted sensitivity of the sensor and prepared some demoes to show children how to play the game. We also modified the feedback mechanisms by incorporating the qualitative feedback and adding a barcode to represent a visual form of feedback. This could help children at younger ages to better understand how well they performed while using the

program. However, we wanted to know how to potentially improve the uptake of the novel technologies such as our developed program. Therefore, we conducted another project, prior to launching our system, to identify potential barriers that impede adoption of technologies among stakeholders.

## **6 Uptake of Technologies among Individuals with Autism Spectrum Disorders: An Exploratory Study of Barriers and Challenges**

### **6.1 Introduction**

There has been a dramatic advancement in the development of technologies to help end users with daily-life tasks during recent years. The explosion of software applications, gamification, and virtual and augmented realities in pedagogy or medicine demonstrate the utility of these electronic devices (Schultheis & Rizzo, 2001; Wainer & Ingersoll, 2011). The technology revolution has not only affected the daily living of individuals without disabilities, but it also has had a tremendous effect on the lives of individuals with disabilities, such as people with autism spectrum disorder (ASD) (Goodwin, 2008).

Using educational interventions has been widely considered among individuals with ASD (De Boer-Ott et al., 2004). These intensive and long-term interventions are often geared towards addressing social and communication problems in populations with ASD. Implementation of these programs requires the family's motivation and monetary support, which sometimes make it difficult to continue for those with limited resources (Croen, Najjar, Ray, Lotspeich, & Bernal, 2006; Jacobson & Mulick, 2000). Taking advantage of technologies can help support the delivery of services.

Individuals with ASD have a special interest in computerized-learning programs (Cobb et al., 2002; Moore, Cheng, McGrath, & Powell, 2005). In addition to easy access to these programs in order to reduce the cost of therapy, they can offer advantages with respect to the core deficits of ASD. These virtual environments do not require high cognitive efforts,

which are evident in real world, and can provide consistent and predictable stimuli to teach social skills (Grynszpan, Weiss, Perez-Diaz, & Gal, 2014). Reducing distractors and displaying visual or auditory cues to direct attention on a specific task can help individuals with ASD build skills at their own pace (Golan & Baron-Cohen, 2006; Moore, McGrath, & Thorpe, 2000). These programs allow individuals with ASD to bypass the complexity of real social contexts and gradually learn skills in a controlled environment.

Previous studies have shown that technology-based programs can address diverse needs of individuals with ASD, such as academic skills, functional behaviours, initiating conversations, emotion recognition, and daily skills (Bölte, Golan, Goodwin, & Zwaigenbaum, 2010; Grynszpan et al., 2014). In addition to a platform for building skills, these technologies can help those individuals with ASD who require augmentative and alternative communication (McNaughton & Light, 2013). Speech generating devices or using picture exchange communication systems allow those with little or no communication abilities to communicate independently and to scaffold their skills. While the acceptance of technologies has increased among practitioners and families, still after few decades of emerging technologies, they have not yet been considered as an established complementary method of intervention among individuals with ASD (National Autism Center, 2009). This raises the importance of identifying the barriers which are inherent in adoption or continuation of using technologies.

Lack of usage or discontinuation of a technology can be due to inefficiency of the program (Riemer-Reiss & Wacker, 2000; Rogers, 1995), or concerns about the degree of transferability of learned skills in virtual environments to real-life settings and dependency of children with ASD in using these technologies (Bölte et al., 2010; Pennington, 2010). While

some technologies have shown effectiveness in skill acquisition among children with ASD (Moore et al., 2000; Pennington, 2010), what is not clear yet is what elements play pivotal roles in making decisions for the uptake of a technology-based intervention in children with ASD (Moore et al., 2000; Ploog, Scharf, Nelson, & Brooks, 2013; Riemer-Reiss & Wacker, 2000). As the development of technology is expanding, understanding the elements that govern the uptake of novel devices or developed software among stakeholders in the field of ASD is warranted. We wanted to know how to potentially improve the implementation of technologies in general and our developed program in particular. This is the first step in planning the end-of-grant knowledge translation and to understand what methods should be used in the future.

As far as we know, no study has investigated existing barriers in adopting novel technologies among children with ASD. The current study aimed to uncover attitudes and perspectives in adopting technology-based interventions among stakeholders in the field of ASD. Such information could help researchers and professionals to gain a better understanding of factors contributing to the acceptance of using technology-based programs in the field of ASD.

## **6.2 Methods**

### **6.2.1 Research Design**

This project was a qualitative study using interviews and focus groups with stakeholders in the field of ASD, including administrators of ASD associations, parents of individuals with ASD, educators, and clinicians working with people with ASD. We used an

interpretive description approach informed by constructivism as described in Section 2.2.1 (Thorne, 2016).

### **6.2.2 Participants**

We involved 17 stakeholders, including parents of children with ASD, service providers, and administrators of ASD organizations, in interviews or focus groups to understand their perspectives on factors that impede up take of the technologies in clinical settings.

All participants had to be able to understand written and spoken English. The inclusion criterion for parents was having a child diagnosed with ASD. Inclusion criteria for clinicians/educators were: (a) having worked at least one year with children with ASD; and (b) belonging to a licensed/recognized profession working with children with ASD, such as occupational therapy, special education, speech language pathology, or behavioural consultant. Inclusion criterion for managers was having worked at least one year in managing an ASD organization or being involved in the therapy decision-making process.

Participants were selected through convenience sampling via email and printed posters sent by public or private community-based organizations, health organizations, and networks supporting families of children with ASD across BC. They were also recruited via snowballing recruitment (i.e., asking participants to pass along information to other potential participants).

### **6.2.3 Research Procedure**

We conducted meetings either face-to-face, over the telephone, or via Skype, at the time and place agreed by participants. Overall, two focus groups (each with two participants)

and 13 interviews were conducted. Of all the meetings, six were conducted face-to-face, eight by phone, and three via Skype.

As the term ‘technology’ is wide, and people may have different ways of understanding it, in this study we shared with the participants our definition of the term prior to the interview. We defined it as the products that may be used in therapy for children with ASD. This includes any types of gaming programs such as computer-based games, virtual realities, robots, and augmented realities. We used a semi-structured interview guide, including open-ended questions and related probes to facilitate discussion (Appendix VIII). The interviewer was trained on how to communicate with participants and ask questions. There was no relationship between the interviewer and participants prior to the study. Each interview or focus group lasted around 1-1.5 hours. The interviews and focus groups were audio-recorded, with additional field notes taken by the interviewer. We replaced all participants’ names with pseudonyms to maintain confidentiality.

This study was approved by the University of British Columbia Behavioural Research Ethics Board. Informed consent was obtained prior to participation in the study.

#### **6.2.4 Data Analysis**

Interview or focus group audio-recordings were transcribed verbatim. One researcher listened to all the recorded files and double-checked transcripts to make sure of their accuracy. The data analysis and data collection were based on a constructivist approach, in which researchers believe that there are shared realities and co-construction of the knowledge.

We started data analysis during the early stages of the data collection. Using thematic analysis, we classified data based on similarity in meaning. First, we studied the first transcripts to have a better understanding of the main concepts. Then, by reading and re-reading the rest of the transcripts, we looked for common concepts shared by participants. We used NVivo computer software to code data. Two members of the team individually coded and analyzed the first few transcripts. Then, we discussed the codes in a meeting to resolve any disagreements, and proceeded to code the remaining transcripts. Consequently, we came together to group the codes into categories based on similarities in concepts and merged the categories together to come up with overarching themes (Thorne, 2000).

#### **6.2.5 Trustworthiness Strategies**

Reflexivity and triangulation were used to ensure credibility and transparency of the findings (Creswell & Miller, 2000; Morgan-Ellis et al. 2006). These methods are described in Section 2.2.5.

### **6.3 Results**

#### **6.3.1 Demographic of Participants**

Participants included 17 key stakeholders, who self-identified as four parents of individuals with ASD, 10 service providers (seven clinicians and three special educators), and three managers of ASD organizations. Among clinicians, there were five speech language pathologists, one occupational therapist, and one psychologist. One of the self-identified parents worked as a clinician and one of the self-identified managers had a son



with ASD. Of all 17 stakeholders, three were male, including one manager, one psychologist, and one special educator.

The clinicians' age range was between 28 and 68 years [mean (SD): 47.4 (15) years]. The average clinical experience of clinicians was between 5 and 43 years [mean (SD): 20.3 (14.4) years].

The average age of managers was 51 (11.5) years old. They worked for about 10 years as a manager (Mean=10.5, SD=13.4). The age range of parents was between 38 and 52 years [mean (SD): 45 (7) years], and all had one son with ASD ranging from 4 to 16 years old.

Of all 17 participants, 12 reported to use technology for children with ASD about 0-4 hours per week and two participants (i.e., one parent and one clinician) spend about 5-9 hours per week. The remaining three participants (i.e., one parent and two clinicians) reported to use the technology for 10-14 hours, 15-19 hours, or above 20 hours per week.

### **6.3.2 Themes**

Information gathered from the interviews or focus groups with families of individuals with ASD, clinicians working in the field, and managers of ASD organizations yielded three themes with regards to factors contributing to technology adoption. These entail: (a) choices to be made; (b) apprehension and concerns; and (c) external obstacles to implementation.

## Choices to be made

Participants reflected on the reasons for selecting a particular technology, including being evidence-based, being effective in meeting the treatment goals, and having reliable and easily accessible information about the technology.

The majority of stakeholders stated that one of the main factors in selecting a product is making sure it is evidence-based, with research supporting the benefits among the population with ASD. For example, Gina, a clinician, stated: *“I think first of all, the foundation of it [technology] has to be research-based, has to be evidence-based with reliable research.”* However, the problem is that research process is slow and quite behind the current needs. This can be illustrated in Shandra’s quote, as a parent, when she stated: *“I think that as a parent you see the time running out, you see? Okay we don’t have all the time in the world to wait for this research, we need to start doing [things], so the research is going to have to catch up.”* This aspect may result in trying out some technology devices that are still in research and testing stages. Brook (clinician) said: *“I know of a number of private clinics and clinicians that don’t, that they’ll use various assistive technologies, I guess, that aren’t evidence based.”*

Participants emphasized the importance of an effective technology that meets the therapeutic goals. Tiffany, a clinician described: *“I have to see that it [technology] actually is targeting what I need to target with the student, so I don’t give technology for the sake of giving technology, or I don’t recommend technology just because it’s technology.”* Similarly, Gordon, an administrator of an autism organization, claimed that the efficiency of a technology is the critical point in making the decision to use and purchase it. He shared: *“If*

*someone's going to buy something, it has to be useful, or they're not going to buy it. So, if you want to translate knowledge, you're going to have to give me something that I can use."*

One participant highlighted values in effectiveness of a product compared with its innovative aspects. Rachelle, a clinician stated: *"It's like going to a doctor's office and getting a medicine that's not really going to work, only because it's the new medicine and everyone thinks it's great, it's super affordable, but if it doesn't work, then why are you taking it?"*

Another main factor in selecting a suitable technology among stakeholders is having reliable and easily accessible knowledge or information about the technology. Sophia, a clinician stated: *"The biggest thing is they [stakeholders] would need to find the app. Do they hear about it and try it?"* Similarly, Tiffany, a clinician, reflected on her role in informing families. She said: *"I know where to go to get the information I need, but maybe helping parents and people outside institutional settings, how do you help them understand what the assistive technology can do."* This demonstrates that disseminating information about the possible applications of technology among individuals with ASD would facilitate the selection process. Rachelle, a clinician, identified some selection biases related to high-tech versus low-tech devices due to advertisement. She stated:

*"Stakeholders, administrators, or parents don't often understand what a low-tech device is, because it's not marketable, it's not in the media, it's not covered, it's not mainstream....Because of that, people will probably gravitate towards the high-tech device."*

This illustrates that increasing awareness and knowledge of alternatives would mediate the selection process. Sharing reliable and valid information about novel technologies and their effects among families and clinicians can facilitate the uptake of a suitable product.

### **Apprehension and concerns**

Participants described elements related to their concerns that might take part in making the decision to use a technology. These include potential fear, getting the child dependent on the device, and concerns about power of technology and generalisation of skills.

Lack of interest in using technologies can be due to existing fears among stakeholders on whether using these devices is safe. Zoha, a clinician, compared technologies to vaccination:

*“I think that some of the people who are afraid of technology would want to avoid that further exposure in their children. So, there’s that side of things, just how some people are not immunizing their children because they read a research study once upon a time that links the MMR vaccine and autism. So, because the cause of autism is unknown there’s still so much fear around the cause of it, and so families are having the belief and then potentially avoiding technology because of that.”*

Barbara, a clinician, who is also a parent of a child with ASD, explained that a lack of knowledge or presence of false beliefs among some of the stakeholders can prevent them from approaching the technology: *“It is just not even knowing how, come on people! It’s science (laughs), we have some people who are afraid of the radio waves, I’m like, really? How did you get that Bachelor’s degree?”*

She later pointed out that the existing fear might be because stakeholders try to control the child, rather than letting technology control him/her. She said: *“I guess, the fear of not being in control. The fear of somebody else controlling your child, especially some non-human.... Yeah, fear of not being in control, and its illusion anyway.”* Similarly, Gerald, a special educator, mentioned:

*“I think they [stakeholders] feel threatened, they’re human. We feel threatened by the fact that you [technology] know more than I do, and there I’m going to look like a dummy, so I’d rather not have you in my class. It’s human nature. We need to suspend our egos, that silly ego of ours really does get in the way, doesn’t it?”*

Tiffany (clinician) explained that the fear of moving outside of one’s comfort zone can lead to lack of usage of technology among some stakeholders:

*“But I think even like a real simple technology for some people who are not that oriented to technology, I think it’s a little scary. I think that there’s a fear thing in there because we’re asking them to step out of their comfort zone and use something that they’re not that comfortable or familiar with. [If] you ask me to walk along the cliff with a river down below, I’m really going to be scared. That [technology usage] could generate the same kind of reaction.”*

This demonstrates that a personal sense of security might be involved during the decision-making process of using a technology among stakeholders.

Most stakeholders identified some concerns about getting the child with ASD to become too dependent on technology. For example, Zoha, a clinician, said: *“Kids with autism love technology, actually too much. They spend a lot of time on screens, yet there are*

*many great tools out there, that it's a fine line, because some kids are becoming addicted to screens."* Similarly, Tiffany, a clinician, pointed out that *"I think for some families, there is also a concern that the child will become dependent on the technology."* Gina, a special educator, while acknowledging the technology, was reluctant to use it with clients:

*"I personally believe this [technology], and I use technology even for myself, but for my students, I feel like I kind of want to steer away from technology because I feel like we're too dependent on technology in terms of, I mean I haven't done a whole lot of research on this, but in terms of knowing what they're talking about now in terms of social media, and technology addiction and video game addiction, so I can see that that could be a problem especially."*

Stakeholders identified the need to verify the right amount of technology usage. Gerald, a special educator, brought up this uncertainty in the discussion when he queried that: *"How much technology do I use? How much is enough, how much is too much?"* These questions show that uncertainty in the adequate amount of using a technology may affect its adoption .

Another factor in being reluctant to use a technology is attitude towards the technology and whether it can solve all existing problems of individuals with ASD. Denise, an administrator of an ASD organization, stated, *"Some things are hyped, you know, this particular technology or medication or special inserts for your shoes will be the answer to all of the problems that one faces in autism."* Setting reasonable expectations during taking up a technology were stated by Lucas, a clinician: *"They're [some stakeholders are] hoping it's [the technology is] basically a panacea for everything, but they need to know exactly*

*what it can do, and what it can't do.*" He later discussed the diversity among individuals with ASD:

*"What product works for everybody? Air [laughs]. Not a product yet. Water's getting to be a product [laughs]! No, but, so which of the devices are we talking about that's good for everybody and good under all circumstances? For whatever it is that ails you, right? There isn't anything."*

Stakeholders also mentioned that there are doubts and ambiguity in whether children with ASD can generalize learned skills from the technology to real life. Rachelle mentioned: *"I know that sometimes with colleagues, they're not fond of certain programs that districts are using. Even if there is research to support that it works, they don't like it, they think it doesn't generalize to natural settings, so they're almost questioning why we're doing it at all"*. Similarly, Gina (clinician) explained:

*"If you're talking about virtual reality..., it can be really great and it could teach them [children with ASD] something, but at the end of the day, it's not real life, and if you can only learn that way or you can only generalize your skill in that situation, then that wouldn't be effective. Because if you're not able to connect with people in real life versus through virtual reality or versus online gaming or texting or social media, then you're still not able to function in society the way that we're trying to teach students to do."*

Likewise, Tiffany, a clinician, focused on communication: *"My job is to teach kids communication, and I really struggle with that concept of technology being part of that process, because communication is face-to-face between two people. So, when it comes to*

*technology, that's the piece that I really struggle with....You can't replace the face-to-face contact with the kids, and I'm teaching them the kids face-to-face."*

### **External obstacles to implementation**

Stakeholders identified the external factors that might impede utilization of a technology. These include financial burden, time to invest, and technical support during implementation process.

Many of the barriers experienced by stakeholders to adopting a technology had external origins. Financial burden incurred by the stakeholders might overshadow other existing hurdles. For example, Tiffany, a clinician, said: *"In school systems, everything is about money, everything. Because there's never enough to go around. If there was lots and lots of money for school systems, we would have all the technology we ever wanted. Truly, money is the first and biggest barrier in public schools."* Shandra, a parent, stated that because the budget might be a barrier, school staff might not be transparent with families. However, families are willing to cover the cost if the program is useful:

*"I think a lot of it has to do with money, maybe not the funding, and not [school staff] wanting people to ask, because then it'll have to be funded, and there's no funding for it, so it's a lot of funding I would say. Whereas, I think many parents would say I'm willing to pay for that, if it costs money, we'll pay for it, if we need it. For 'us', it's not money, it's [that] we just need to have it, we need to do it. That seems to be a barrier, hiding things because it costs money."*



Sophia, a clinician, reflected on how this cost changed in the last few years: *“There is the cost, but the cost is actually much lower than what augmentative communication was before, so that’s not a barrier.”*

Stakeholders explained that to implement a technology, they need to invest time, which may be another obstacle. Rachelle, a clinician, described that usually clinicians have a lot on their plate: *“Educators don’t have a lot of time to reflect on their practices, and what that does is [it] creates kind of a loop where they’re short for time so they’ll do what they can to get their work done, or in a clinical perspective to do whatever practice there is that’s been going on.”* Zoha (clinician) described how her own practice in which she asks clients to bring their iPads becomes time consuming:

*“It is amazing how many times I tell families to bring their iPad to the session so that I can upload an app for them and help them in that way, and they forget, so I have to remind them, I’ll text them, I’ll email them, and they show up to the appointment, ‘Oh we forgot the iPad!’ So, it’ll take me like a month of seeing their kid weekly until I can get a hand on their iPad.”*

Sophia, a clinician, pointed out that she prefers to use a technology that takes less time for her to figure out how it works. She stated:

*“I find that, for instance, all the new apps that are out [there] are fairly overwhelming, especially more complex apps that you have to spend time learning how to use them. I find I download a lot of them onto my iPad, and I don’t use them because I don’t have time or motivation to figure them out.”*

As another factor, participants stated that having the technical support to enable them to use the technology is critical. Barbara, a parent who is also a clinician, said:

*“The keeping up with the technology, technology changes so fast, and what do you mean I have to wait three months until the technology people can come in and fix it or just download the program to my computer, right?”*

Similarly, Tiffany, a clinician, stated: *“This year my boss ordered the SLPs [speech language pathologists] in our district, we each got a brand new iPad, but they sat on her desk for 6 months, we didn’t get them until about two weeks ago, because the IT guys couldn’t come to set them up. So, have I been able to use that iPad to work with children? Absolutely not!”*

Lucas, a special educator, elaborated:

*“I think the understanding of how much or type of support somebody who is using assistive technology might need in order to actually keep it functioning properly is huge. Most of the guys that I work with by themselves can use the technology, but can’t manage the technology, like putting new items into, reorganizing things, and things like this that they would need to have somebody fix it, I mean some of them even when the batteries go out don’t know what to do.”*

## **6.4 Discussion**

Technology can serve as a powerful tool, potentially to enhance social skills and function among individuals with ASD. Despite the rapid growth in development of technology-based programs, its implementation in educational and therapeutic settings among individuals with ASD is slow. This suggests that there might be a number of significant challenges that hinder technology adoption or its continued usage. The current

project is the first study to investigate stakeholders' perceptions on potential barriers they confront in the uptake of a technology in the field of ASD. Our findings provide some insight into contributing factors and perceived barriers in the usage of technology for individuals with ASD in three main areas, including choices to be made, apprehension and concerns, and external obstacles to implementation. These barriers are intertwined together and affect the decision-making process in adoption, continuation, or discarding of a technology in the field of ASD.

Participants highlighted the importance of selecting the right technology for individuals with ASD. Knowledge of the available resources and accessibility to the information would create an environment where stakeholders can explore, identify, and select the best options that fulfill the clients' needs (Gamble, Dowler, & Orslene, 2006). With the advancement of technology, it is challenging to keep resources updated and reliable to help stakeholders with the process of decision-making. Interpreting evidence and research findings is required for selecting a suitable technology in practice. However, not every stakeholder, parent, or clinician is equipped with the skills to critically appraise the literature (Straus, Tetroe, & Graham, 2009). Thus, disseminating knowledge by knowledge brokers or researchers, using lay language in communication, and making the information accessible for stakeholders would facilitate the process of identifying the suitable option. Knowledge translation strategies, such as educational materials, meetings, or mass media, might help disseminating the information (Scott et al., 2012).

In addition to the availability of the information, stakeholders underlined the necessity of quality of evidence and existing research as a critical step in the uptake of technology. Perceived usefulness is considered as a key determinant to implement the

technology (Davis, 1985). While there is some evidence demonstrating the positive effects of technology among individuals with ASD, the sample size is relatively small (McNaughton & Light, 2013; Golan et al., 2010). Due to diverse symptoms and a wide range of functionality among individuals with ASD, the extent to which potential benefits can be achieved through using various technology-based interventions is unclear. This uncertainty would make the process of identifying the best option difficult among stakeholders working in the field of ASD. Thus, research is required to investigate the effectiveness and relative cost-benefit analysis of using various technology-based interventions, compared with other therapeutic approaches among individuals with ASD (Jacobson & Mulick, 2000).

Stakeholders indicated that their concern and fear of potential side effects might contribute to being reluctant in the uptake of technology in the field of ASD. According to the social learning theory, personal beliefs and attitudes might be influenced by the society (Rosenstock, Strecher, & Becker, 1988). People learn from one another by observing and modeling a behaviour. Despite previous studies that refuted some concerns (e.g., that using technology such as gaming programs offers the opportunity of practicing in a safe and controlled environment, or that individuals with ASD do not show negative sensory experiences when using these games), some issues still remain (Parsons & Mitchell, 2002; Wallace et al., 2010). On the one hand, some stakeholders presume that technology-based approaches intensify the social disability of individuals with ASD as they would over-rely on the simulated interaction, which would consequently decrease real-life communication and lead to further isolation. On the other hand, taking advantage of using technology that motivates individuals with ASD and offers an active control over the interaction may help increase their confidence and enhance outcomes (Parsons & Cobb, 2011). Previous studies

have shown that technology-based programs can offer flexibility to gradually increase the cognitive demand of the learning tasks and to allow collaboration between multiple users at the same time (Parsons & Cobb, 2011). Individuals with ASD can learn concepts through technology-based programs and can apply the learned skills in real life situations to the extent that they are similar to the program (Parsons & Cobb, 2011; Parsons & Mitchell, 2002). While technology indeed has its own limitation, these concerns or unwillingness can be in part due to insufficient evidence and/or not feeling the necessity of having technology in place when the common behavioural approach is working.

If technology is considered as a novel tool, it should be consistent with the values and needs of end-users to be adopted. Based on the diffusion of innovation theory, the relative advantage, complexity of the device, and compatibility with users' experiences play a pivotal role in using a technology (Kaminski, 2011; Rogers, 2003). Considering the sensitive role and responsibility of stakeholders in the education and therapy of individuals with ASD, technologies should be tested prior to any commitment to use it. Lack of information about tangible outcomes and personal attitudes would influence the decision whether or not to use technology. However, the changes in end users' attitudes do not necessarily facilitate the uptake of technology (Scott et al., 2009).

Participants stated that successful implementation of technology is also influenced by external factors. They emphasized the necessity of having the support to help them with technical issues and trouble-shooting the systems, because they do not necessarily have the required skills and expertise. Consistent with the unified theory of acceptance and use of technology, effort expectancy and perceived ease of use would facilitate technology adoption (Venkatesh, Morris, Davis, & Davis, 2003; Venkatesh & Davis, 2000). Stakeholders outlined

few other obstacles including monetary resources to purchase the technology and time to use it. When talking about the finances and time, the relative values should be considered (Jacobson & Mulick, 2000). Some countries such as Canada have federal policies and offer funding to support stakeholders who work with individuals with ASD in purchasing technology. However, the time required to learn and implement the technology is still a potential barrier. Thus, access to technical support to install the software, upgrade the system, and configure and solve potential problems can facilitate the process.

#### **6.4.1 Limitations and Future Direction**

Several limitations should be considered when interpreting the findings. First, the sample size from each group of stakeholders such as administrators was relatively small. We recommend future studies to continue recruitment until saturation in data is achieved. Second, we were limited in our ability to schedule all meeting face-to-face due to distance and/or participants' preference in meeting remotely to save time. Face-to-face meetings would help facilitate communication and enrich the study. Third, the sample size of each focus group in our study was small due to scheduling challenges, and interviews were used to supplement the data. Focus groups can help participants to generate ideas and exchange information through discussion, whereas interviews allow researchers to obtain richer information. Although some studies reporting focus groups with two participants, the ideal sample size for focus groups vary in the literature and it is ranging between 5-8 (Carlson & Glenton, 2011; Pearson & Vossler, 2016). Fourth, there was some overlap among stakeholders' roles that make distinguishing perspectives difficult. It is suggested that future studies be conducted to recruit larger sample size, diverse demographic backgrounds for each stakeholder, as well as using further focus group meetings.

## 6.5 Conclusion

The recent revolution of technology and its accelerating development affect everyday life. Despite the proliferation of technology, not all stakeholders gravitated towards using technology for individuals with ASD. The gap between the research and practice calls for the necessity of delineating potential factors that contribute to decision-making process. This project was the first study to involve key stakeholders to determine components that take place in utilization and adoption of a technology in the field of ASD.

This chapter helped us to identify elements that affect the implementation of novel developed technologies in order to guide the implementation activities related to our developed game. Being aware of these factors helped us plan our knowledge translation activities efficiently and successfully. This phase informed us to consider various methods of knowledge dissemination and information sharing. We used knowledge brokers, conferences, publications, posters, media, educational materials, and developing a website to disseminate findings. Using lay language, we tailored the content of each material and adjusted it based on the audiences' needs and their level of interest. We also prepared several executive summaries and demonstrations showing how to use the program to facilitate its uptake.

## **7. Discussion**

### **7.1 Overview**

Children with ASD may experience difficulties in perspective-taking, language, and communication, which affect their daily functioning (American Psychiatric Association, 2013; Baron-Cohen, Wheelwright, Hill, Raste, & Plumb, 2001; Simonoff et al., 2008). As children get older and gain insights about these significant deficits, their self-esteem in communicating with their peers may suffer (Lopata, Volker, Putnam, Thomeer, & Nida, 2008). This may act as a vicious cycle that precludes children from acquiring social skills to interact appropriately with peers.

The delivery of early and effective therapeutic services is crucial to enhance the outcomes and functioning of clients with ASD (Eikeseth, 2009; Matson & Smith, 2008). Selecting an appropriate intervention aligned to the clients' needs, and performing it with high amount of repetitions, are indispensable parts in achieving optimal outcomes (Eldevik et al., 2009; Matson & Smith, 2008). Clients usually need additional practice at home to meet the necessity of high dosage of an intervention. This continual and repetitive intervention may reduce clients' motivation, which may consequently affect the quality and quantity of adherence to the therapeutic program. Implementing technologies, as adjuncts to traditional interventions, can create motivating contexts and bring advantage of remotely monitoring of therapeutic outcomes during long-term interventions.

Gaming programs have been widely used in the fields of education and rehabilitation to address a diverse range of clients' needs. These programs provide an opportunity for practicing in a safe environment with gradual exposure to stimuli, providing consistency and



stimulus control, giving real-time feedback, and augmenting attention to performance (Parsons & Cobb, 2011). They can provide a simulated environment in which the intensity of training, level of difficulty, and amount of feedback can be adjusted. This allows for the creation of an individualized program and keeping clients motivated to endure the program.

Recently, there have been rapid advancements in developing low-cost technologies in rehabilitation, including computer-based programs, virtual reality games, motion-tracking games, and video games (Anderson-Hanley, Tureck, & Schneiderman, 2011; Parsons & Cobb, 2011). Depending on the type of device, the user receives specific sensory information that affects the type of interaction. Shifting away from using touch-based systems (such as devices with a mouse, joystick, or keyboard) towards systems that offer interaction through natural user interfaces (such as body movements) may better resemble real-world interactions (Francese, Passero, & Tortora, 2012; Teófilo, Nogueira, & Silva, 2013). Motion gaming systems, such as Kinect, track body movements and project them on a screen. This allows body movements to be simulated in a virtual world that provides simultaneous feedback.

However, developing an appropriate program for children with ASD is a complex task due to the heterogeneity of the disorder and co-occurring conditions (Wilczynski, Menousek, Hunter, & Mudgal, 2007). Not every program can fit the broad range of needs that may be observed in individuals on the spectrum. It is necessary to tailor each program to address the symptoms and deficits that a child with ASD demonstrates. In addition to the importance of individualised programs, the involvement of clients in making decisions about the program to suit their family style and preferences would maximise outcomes (Elwyn, Edwards, Kinnersley, & Grol, 2000; Guadagnoli & Ward, 1998). Using a client-centred

approach, valuing clients' autonomy, and giving clients the power to engage, share ideas, and discuss their preferences as equal partners with researchers are all pivotal factors in maintaining a therapeutic program (Law, Baptiste, & Mills, 1995).

However, integrating clients' ideas adds more complexity to the development of unique programs. Not involving stakeholders during the development or not considering an iterative procedure for refining the product will result in spending time, money, and human resources to develop devices that may not be able to meet expected outcomes. Therefore, there is a risk that the product might not be adopted, or its usage might be discontinued after a short period of time. Although we acknowledge the advantages and limitations of using technology, working in a multidisciplinary team of stakeholders that consists of researchers, patients and their families, engineers, and clinicians should be valued and considered as a guideline for developing technology-based programs in rehabilitation settings.

## **7.2 Key Findings and Implications**

This project used a participatory design approach to develop a client-centred virtual reality program for children with ASD. Across five steps, we identified the main focus of the virtual reality program, highlighted features of the game, created the game content, designed and developed the game, and identified barriers to implementing it.

In our first study (Chapter 2), we showed that there are several parameters contributing to social participation of children with ASD. These include factors associated with the perception of social situations, demonstrating appropriate behaviours, and provision of services. Being socially isolated due to the ASD and having fewer social networks affect children's self-confidence and well-being (Kawachi & Berkman, 2001; Orsmond, Shattuck,

Cooper, Sterzing, & Anderson, 2013; Valkenburg, Peter, & Schouten, 2006). Subsequently, the perceived low self-confidence acts in a negative feedback loop to further restrict children with ASD in attending social situations (Valkenburg et al., 2006). Given the increasing prevalence of individuals with ASD, it is necessary to uncover patterns of social participation and highlight the barriers in place (Shattuck, Orsmond, Wagner, & Cooper, 2011). Although there is a body of literature to highlight the social impairments of children with ASD, most studies used questionnaires or objective assessments compared with interviews that we used in the study to identify core issues. Using qualitative methods, our study allowed participants to elaborate on the ideas and provide richer insight about barriers in social participation of children with ASD.

*Implication:* Health care providers, policy makers, funding agencies, families, and researchers should be informed about these barriers to implement strategic planning and build the infrastructure to support social participation of individuals with ASD. Improving perspective-taking and behavioural skills can help facilitate social participation of children with ASD. This could also directly and indirectly promote the health-related quality of life of children and their families.

Our second study (Chapter 3) sheds light on the parameters that can make virtual reality programs effective for use with children with ASD. Through involving youth with ASD, their parents, and clinicians, the elements of addressing heterogeneity and diverse needs, mirroring real world, and potential teaching strategies were identified as priorities to be integrated into the virtual reality programs. This is consistent with previous studies that emphasized an individualized regimen and adequate amount of practice for children with ASD (Schreibman, 2000). Virtual reality programs can be customized to meet the ongoing

needs of a child with ASD and to provide a high dosage of simulated contexts in a motivating environment (Parsons & Cobb, 2011; Parsons & Mitchell, 2002). Taking advantage of high interests of children with ASD in using these virtual reality programs will potentially help meet the goal of continual therapy and overcome its discontinuation due to frustration over repetitive practice. Training a wide range of appropriate behaviors in various contexts will give children with ASD the chance of properly selecting appropriate behaviours, and help prevent children from acting as a robot in social situations. Virtual reality can simulate the real world and help overcome concerns related to lack of transferring learned skills (Parsons & Mitchell, 2002). The similarity of virtual situations to the real world alongside the reinforcement of appropriate behaviors may facilitate transferring skills from one setting to another, and from virtual environments to real life.

*Implication:* Due to an upsurge in interest in developing technology-based interventions for children with ASD, it is important to know which factors contribute to efficacy and efficiency of the virtual reality programs. Although clinicians working with individuals with ASD may understand these required components, engineers, and computer scientists should be informed about these factors well in advance prior to the development. This would help prevent investing time and financial resources on developing tools that are innovative only in appearance, but cannot meet the expected outcomes or be used by children with ASD. Making sure that the program is not only fun, but also meaningful and relevant to real-life situations, is vital for individuals with ASD.

In the third study (Chapter 4), we developed and validated a library of social stories related to emotional situations. This query was informed by general case training to provide a variety of stimuli and contexts that a child with ASD may experience in life when interacting

with others. It has been shown that general case training can accelerate the acquisition and generalisation of learned skills among individuals with developmental disorders (Chezan, Drasgow, & Marshall, 2012; Day & Horner, 1986; Horner, Sprague, & Wilcox, 2005). Using this approach, intertwined with social stories, the content of our virtual reality program offers a broad range of exemplars, including types and intensity of emotions within different social contexts. However, due to subjectivity of the social situations and potential biases in attributing appropriate responses, this required a consensus-building technique to enhance the likelihood of precision and to achieve convergence in opinions (Hsu & Sandford, 2007; Thangaratinam & Redman, 2005). Involving a panel of experts and stakeholders in the field of ASD helped us to refine the socio-emotional stories and to establish their credibility. Stakeholders outlined the necessity of integrating safety concepts and explaining the reasons that a particular feeling or behaviour might happen. Such strategies will help children with ASD better infer meanings from social situations and demonstrate appropriate responses (Balakrishnan & Alias, 2017; Ying, Sah, & Abdullah, 2016).

*Implication:* Most previous virtual reality programs lack in incorporating social stories with valid content. This is important when dealing with socio-emotional situations that the individuals' subjective interpretation about appropriate social behaviour is primarily in place. The validated library of social stories can be used during therapeutic interventions or monitoring effects of intervention. In addition, these social stories can be used as content for other types of virtual reality platforms for children with ASD or other developmental disorders involving difficulty in perspective-taking.

In the fourth study (Chapter 5), we developed a gaming program in close collaboration with children and youth with ASD and their parents. Trialing the program and

using an iterative process during the development assisted users to make their tacit knowledge active and to express their opinions explicitly. Input taken from stakeholders helped us to refine the system and maximized its quality. The co-design of the program with key informants ensures their needs are integrated and the product is more easily adopted (Kujala, 2003; van Gemert-Pijnen et al., 2011). Stakeholders emphasized the importance of audio-visual features, maintaining engagement, and fine-tuned feedback. Enhanced graphical design and user experiences reinforce motivation and facilitate a more intuitive interaction with characters on the screen (Madsen et al., 2009). Accommodating the cognitive needs of users and giving them constructive feedback during the program will excel acquisition of the skills (Gillespie-Lynch et al., 2011; Madsen et al., 2009). Sometimes the design process can be challenging due to the diversity of opinions and, in particular, contradictory ideas in the area of users' preferences and engagement (Bruno & Muzzupappa, 2010; Kensing & Blomberg, 1998). We found that these different opinions could be resolved by prioritizing them and further discussing them with stakeholders.

*Implication:* The developed novel home-based program has the potential to improve socio-emotional function, with lower costs than current programs. As this program saves data online and allows clinician to remotely monitor data, it can be used at homes or in clinics as an adjunct for therapeutic interventions. This program can potentially be used by other children with developmental delays experiencing difficulties in perspective-taking skills. As children with ASD present a broad range of cognitive and emotional impairments, many ideas shared by stakeholders and the lessons learned through this participatory design can be used when developing programs for children with other developmental disorders with similar disabilities.

In our final, fifth study (Chapter 6), we identified factors that are associated with the uptake of technologies among different stakeholders, including health care providers working with individuals with ASD, parents of children with ASD, and administrators of ASD organisations. Using interviews and focus groups, we uncovered stakeholders' ideas on elements that are involved during the decision-making process. These consisted of making the right choice, apprehension and concerns, and external obstacles to implementation. Previous studies have shown that accessibility to information and dissemination of evidence-based research affects the continuation of using a technology as a therapeutic medium (Gamble, Dowler, & Orslene, 2006). Although research in the field of ASD is rapidly expanding, we should acknowledge that due to multi-faceted nature of the disorder, there is still a lack of understanding on cost-effective analysis of therapies for each ASD phenotype. In addition, due to varieties of information sharing platforms, distinguishing legitimate information might be challenging. This might create a fear related to potential side effects or unconscious beliefs associated with the ineffectiveness of the technology. Having support in place and removing external barriers such as time and money in selecting, implementing, and troubleshooting the systems would facilitate the process (Jacobson & Mulick, 2000).

*Implication:* Because of profound distribution of technology and its potential effects in various settings, it is important to know how to support parents, therapists, and administrators in making the best choice. Researchers can provide clear and accessible information to facilitate the selection process. Administrators and policy makers in the field of ASD should be aware of unconscious and conscious biases that might affect the decision-making process during the technology uptake in health care settings. The identified factors

have implications during commercialising effective programs and/or facilitating the uptake of novel technologies in the field of ASD and other related domains.

### **7.3 Strengths of the Research**

This multi-disciplinary study has multiple strengths and conceptual novelty that makes it unique from previous studies.

First, *this study used a community-based participatory approach to design and develop a gaming program to address perspective-taking of children with ASD*. Establishing and maintaining close partnerships with different stakeholders in the ASD community and engineers were weaved throughout this project. We involved over 120 stakeholders, including children and youth with ASD, their parents, and clinicians to develop this novel program (26 stakeholders in Chapters 2/3, 63 stakeholders in Chapter 4, 20 stakeholders in Chapter 5, and 17 stakeholders in Chapter 6). Participants in all chapters were unique except Chapters 2 and 3. As integral elements of this multi-phase project, we followed an iterative process of refining stakeholders' ideas, selected the most feasible ones in consultation with stakeholders, and integrated them within the project's time and financial limitations.

Second, *this query was informed by an integrated knowledge translation approach to reconcile the 'gap' usually seen in research and the utilization of findings*. The previous literature in the field of ASD primarily relied on the dissemination strategies at the final stages of the project. In this project, we employed an integrated knowledge translation approach by involving stakeholders as knowledge users and producers, to unravel the principal tensions that result in the know-do gap and under-utilization of the findings (Bowen & Graham, 2013; Graham, 2007). With the help of a clinical partner, we engaged



stakeholders from initial stages of the project, and we considered knowledge exchange and brokering throughout the project to potentially facilitate clinical implementation and translation of the research into practice.

Third, *this study involved children and youth with ASD during the design process*. To overcome some of the challenges associated with communicating with youth or children with ASD who participated in the study, we incorporated different strategies, such as the option of drawing their ideas, and asked their parents to be present to facilitate the communication. Involving children and youth with ASD in the design process will potentially help maintain the motivation of children with ASD to use the program (Benton, Johnson, Ashwin, Brosnan, & Grawemeyer, 2012). Being engaged to provide feedback to the team during the design process helped participants to feel ownership over the product and to consider it as a meaningful activity.

Fourth, *each phase of the project informed the following phase and was led by the knowledge users*. The first phase of the project clarified the issue that we, as researchers, needed to address. Stakeholders prioritised ‘perspective-taking’ or ‘ability to understand social situations’ as the pivotal element to be targeted in the virtual reality program that can increase social participation and well-being of children with ASD (Lollar & Simeonsson, 2005). In the second phase, we gathered ideas on factors that can enhance the efficacy of a virtual reality program for children with ASD. This helped us to be informed on the concepts of ‘addressing heterogeneity and diverse needs’, ‘mirroring real world’, and ‘teaching strategies’ that should be integrated into the program. Therefore, we considered the game in a way that resembled real-world social interaction scenarios in various contexts. Because we could not find valid content for such a virtual reality program in the previous studies, in the

third phase, we validated our proposed content by involving various stakeholders across Canada. This helped us to incorporate broader perspectives and to potentially build valid content. In the fourth phase, we used a participatory design to develop the game through an iterative process in collaboration with youth and children with ASD. Subsequently, in preparation of dissemination of the results, we investigated what are the perceptions towards the use of technology-based interventions among stakeholders in the field of ASD.

Fifth, *the program, was novel in both 'content' and 'interface design'*. We used general case training as an established method of teaching new skills to facilitate generalisation (Horner et al., 2005). We considered various types of emotions, intensity levels, and social contexts to provide an adequate number of stimulus representations. To our knowledge, this was the first study to integrate such an approach into developing a virtual reality program for children with ASD.

In addition to the novelty in content, we used the Kinect motion gaming platform to provide a natural user interface to interact with the system. This allowed children with ASD to communicate with gestures and speech rather than pressing buttons on the keyboard, a feature less appropriate when attempting to simulate real-life interactions. If we presume that children with ASD might take advantage of using technology-based programs, it is best to approximate it to real life as much as possible. Gradual exposure to social stimuli and controlled cues that are offered in these virtual reality programs may help overcome social anxiety seen in some children with ASD.

Furthermore, the developed program will provide the opportunity of being used at children's homes, and it offers clinicians the ability to remotely monitor children's progress

and their compliance to the therapy. This tele-rehabilitation component of the program decreases cost associated with commuting to clinics and provides greater accessibility for those who live in far distances or have financial difficulties. It should be noted that, although common one-on-one educational interventions are necessary for children with ASD, sometimes families will not be able to continue or lose their motivation due to affordability (Motiwala, Gupta, Lilly, Ungar, & Coyte, 2006). Therefore, having complementary programs to further support them would be helpful.

#### **7.4 Limitations of the Research**

There were several limitations associated with this project. One of them is related to the sample and whether it could provide diversity of perspectives among stakeholders. Despite the fact that various stakeholders with a broad range of backgrounds are connected to children with ASD (such as parents, behavioural interventionists, occupational therapists, speech language pathologists, physicians, psychologists, and special educators), the sample recruited in Chapters 2, 3, 4, and 6 did not reflect the variety of expertise among clinicians or different sex among participants. Most clinicians were females with the expertise of speech language pathologists, behavioural consultants, or occupational therapists. The narrow sample distribution in terms of demographic background might affect the richness of findings.

In Chapters 2, 3, and 5, we structured the research plan and aimed to recruit children and youth with high-functioning ASD through convenience sampling, to provide a preliminary understanding of their ideas during the design process. It should be noted that the project was limited to one geographical location. Furthermore, despite our effort to include

voices of females with ASD, their ideas are absent in this project potentially due to the low female-to-male ratio in ASD prevalence. As the design process is influenced by stereotypical behaviours or norms of a culture, the findings might be cautiously used nationally and/or internationally.

Another limitation relates to the developed program per se. The proposed program primarily focused on perspective-taking of emotions as one of the critical aspects in social functioning among children with ASD. It also targeted the sense of collaboration with avatars during participation in a joint-task. We selected these behaviours because they were identified by stakeholders, and could be represented in the virtual reality program. However, there are additional skills and behaviours that should be addressed when working with children with ASD. Therefore, our program might be suitable for a specific group of children with ASD who experience difficulties to some extent in perspective-taking of emotional situations. However, due to the timeline of the project, the extent to which the program should be used to see the potential effects or to identify the subgroups of ASD that might benefit more from the program were not investigated.

Another limitation has to do with the facial stimuli that we used in the program. We targeted only four types of basic emotions that are universally recognised, including happiness, anger, fear, and sadness. However, there are more ambiguities with recognising surprise, or complex emotions such as guilt, pride, and shame (Capps, Yirmiya, & Sigman, 1992; Golan & Baron-Cohen, 2006). There is still lack of information on how children with ASD understand and respond to these complex facial expressions. Furthermore, we graded the intensity of emotions into three categories of slight, moderate, and exaggerated to be able to develop the various types of scenarios. However, it should be noted that the intensity of

emotion is a continuous, not discrete, entity, and considering a wider spectrum of intensity of emotions for children is warranted.

Finally, integrating all stakeholders' perspectives during the design process was quite challenging and not possible to be covered in one project due to financial and human support during the restricted timeline. Furthermore, some of the ideas, such as allowing multi-players or individualising the program by giving children some choices to select avatars, required programming resources that went beyond the scope of the study. Therefore, all of the factors and elements identified in this project can be considered as a guideline and framework for upcoming studies to further develop technologies in the field of ASD.

## **7.5 Future Directions**

The goal of this project was to develop the first prototype of this novel virtual reality program. Future studies need to examine the effects of using this program on socio-emotional skill development in children with ASD, and whether the learned skills generalise to other settings. Conducting a case-control feasibility study will assist with gathering preliminary data to form a larger sample size for a randomized controlled trial. This will help to identify the potential effects of the program and to generate new ideas to further refine it. It is also recommended to determine the dose of intervention needed to make positive gains (e.g., frequency, duration, and intensity of using the game). Furthermore, future functional and structural neuro-imaging studies will be helpful to distinguish the underlying mechanisms involved during playing the program and/or after its usage for a period of time. Cost-effective analysis and comparing the effects of the program with other interventions are

recommended for future studies to help with clinical decision-making and to prepare a clinical guideline for children with ASD.

Upcoming virtual reality projects can take advantage of integrating other features, such as selecting the multi-player option and allowing two children to play together while they are connected remotely. This may help to maintain social interaction and build friendship. Furthermore, family can be involved in playing with the child to increase motivation and enhance adherence to using the program. Providing more choices and variations for emotions, implementing basic and complex emotions, static and dynamic stimuli, and various emotional voices are further suggestions for upcoming studies.

We suggest that the developed library of social stories be evaluated to investigate the potential to create an evaluation tool for perspective-taking related to emotions in children with ASD. Although there are a few existing assessment tools that evaluate perspective-taking as a subtest component of a larger assessment (Brooks, Sherman, & Strauss, 2009; Korkman, Kirk, & Kemp, 1998; Stevens, Dudek, Nash, Koren, & Rovet, 2015), none of them is a stand-alone tool. It is suggested to examine the sensitivity and usability of the developed library with respect to age or severity of ASD among children for upcoming studies.

Although we narrowed down the scope to perspective-taking in emotional situations, future virtual reality programs should target various social skills, such as conflict resolution, problem-solving, initiation in making friends, turn-taking, using appropriate words in greetings, distinguishing genuine expressions from fake ones, inferring others' intentions, and communication strategies to deal with teasing or bullying. Such a broad focus would

potentially contribute to further improvements in the social functioning of children with ASD.

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## Appendices

### Appendix I: Interview Guide for Social Participation and Virtual Reality

#### *Interview guide for service providers working with children with ASD*

- 1- What challenges does a child with autism face in the social world? (Probe: Emotion recognition, social participation)
- 2- How would you describe a typical scenario when a child with ASD you were working with experienced difficulty with social participation and/or emotion recognition?
- 3- Can you give several examples to demonstrate those challenges?
- 4- Can you please prioritise issues from the most important to the least important?
- 5- What facilitates the social participation of a child with ASD? Probe: Are there situations that might enhance children's social performance? (Probe: For example, show less irritation, agitation, anxiety, and demonstrate more social attention?)
- 6- What strategies have you used in the past to enhance children's socio-emotional skills?
- 7- What worked well and what didn't work well? What do you think was the reason for that outcome?
- 8- What do you think are barriers to learning and facilitating socio-emotional skills?

#### *Based on your previous experience with children with ASD and/or virtual reality interventions\_*

- 9- If you were to imagine a video game, what social scenarios would you suggest to best target social participation and emotion recognition? (Probe: Can you give us multiple examples? For e.g., a setting within a school hallway, at home, outside on the playground?)
- 10- What features of the video game would a child with ASD find more interesting?
- 11- What features of video games need to be considered in order to make the game more effective? (e.g., visual, auditory, two players, adjustable parameters, levels of difficulty, etc.).
- 12- What features should be avoided that might be irritating or challenging for a child with ASD? (e.g., loud noises, multiple distractions, number of players, specific colours/sounds)
- 13- How long do you think that children with ASD would be attentive in playing a video game? (Why? How can we maintain the children's interests for longer periods of time to play with the video game?)
- 14- How can we enhance the transferability of the skills to real-life situations?

### ***Interview guide for parents of children with ASD***

- 1- What challenges does your child with autism face in the social world? (Probe: Emotion recognition, social participation)
- 2- Can you describe a typical scenario when your child experienced difficulty with social participation and /or emotion recognition?
- 3- Can you give several examples to demonstrate those challenges?
- 4- Can you please prioritise issues from the most important to the least important?
- 5- Can you tell us about a scenario that illustrates the challenges your child has with social participation, either at school or at home?
- 6- What strategies have you used with your children to enhance child's socio-emotional skills? (Probe: which one was the most effective?)
- 7- What do you think are barriers to learning and facilitating socio-emotional skills? (Probe: Why? How can we solve them?)
- 8- What should interventions for socio-emotional skills aim to include?

*Based on your previous experience with virtual reality interventions\_*

- 9- If you were to imagine a video game, what social scenarios would you suggest to best target social participation and emotion recognition? (Probe: Can you give us multiple examples? e.g., a setting within a school hallway, at home, outside on the playground?)
- 10- What features of the video game would a child with ASD find more interesting?
- 11- What features of video games need to be considered in order to make the game more effective? (for e.g., visual, auditory, two player, adjustable parameters, levels of difficulty, etc).
- 12- What features should be avoided that might be irritating or challenging for a child with ASD? (e.g., loud noises, multiple distractions, number of players, specific colours/sounds)
- 13- How long do you think that children with ASD would be attentive in playing a video game? (Why? How can we maintain the children's interests for longer periods of time to play with the video game?)
- 14- How can we enhance the transferability of the skills to real-life situations?
- 15- Would you encourage your child's use of a gaming program for emotion recognition and social participation? Why or why not?



### ***Interview guide for youth with ASD***

- 1- What challenges does a child with autism face in the social world? (Probe: Emotion recognition, social participation)
- 2- Can you give several examples to demonstrate those challenges?
- 3- Can you please prioritise issues from the most important to the least important?
- 4- Do you have any challenges participating in activities with other youth? (Probe: At school, or after school/weekends? (Give us an example)
- 5- What strategies, interventions, and tools have you used to increase socio-emotional skills?
- 6- Can you tell us about how you make friends with youth your age?
- 7- What do you think is helpful in increasing social participation of kids with Autism? (Probe: Can you let us know the reasons?)

*Based on your previous experience with virtual reality interventions\_*

- 8- Can you think of examples or situations that you had some difficulty with social participation and /or perspective taking? (Prompt: if you find it easier to draw out these scenarios, we have some paper and crayons you are welcome to use)
- 9- What social scenarios would you suggest to best target social participation, perspective-taking or emotion recognition? (Prompt: Can you give us multiple examples?)
- 10- What would make the games interesting and fun for kids?
- 11- What features should we include that you like the most? (How do you advance to the next level? What could be used for a reward for completing a challenge? Can you change how easy or hard it is?)
- 12- What features should be avoided that are irritating, not interesting, or challenging? (e.g., loud noises, many distractions, the number of players, colours and sounds.)
- 13- How long do you think you would play the game for? (Why? What would make you want to play it for longer?)

## Appendix II: Demographic Form for Service Providers

Age: \_\_\_\_\_

Sex:

- ☐ Male
- ☐ Female

Ethnicity:

- ☐ Caucasian
- ☐ Asian
- ☐ African-Canadian
- ☐ East-Indian
- ☐ Hispanic
- ☐ Other (please specify):  
\_\_\_\_\_

Profession:

- ☐ Occupational Therapist
- ☐ Physiotherapist
- ☐ Recreation Therapist
- ☐ Speech Language Pathologist
- ☐ Behavioural Consultant
- ☐ Education Assistant
- ☐ Other (please specify):  
\_\_\_\_\_

Workplace:

- ☐ Hospital
- ☐ Child development centre
- ☐ Community
- ☐ Private practice
- ☐ School
- ☐ Other (please specify):  
\_\_\_\_\_

-Years working as a clinician: \_\_\_\_\_

-Years working with children with Autism Spectrum Disorder: \_\_\_\_\_

-Have you used any of the following technology for therapy or teaching purposes with a child with Autism Spectrum Disorder?

- ☐ Computer games
- ☐ Video games
- ☐ Motion games (Nintendo Wii, Xbox Kinect)
- ☐ Handheld games (Nintendo DS)
- ☐ iPhone/iPad
- ☐ Other (please specify): \_\_\_\_\_

-To what extent are you familiar with the technology that is being used for individuals with Autism Spectrum Disorder?

- ☐ Not at all familiar
- ☐ Not too familiar
- ☐ Somewhat familiar
- ☐ Very familiar

-What is your personal level of experience with motion gaming systems (e.g., Nintendo Wii, Xbox Kinect)?

- ☐ No experience – *I have never used or observed a motion gaming system.*
- ☐ Limited experience – *I have tried or have seen motion gaming systems in use.*
- ☐ Moderate experience – *I have played multiple times or am familiar with motion gaming systems.*
- ☐ Very familiar – *I frequently use or observe motion games.*

### Appendix III: Demographic Form for Parents/Guardians

#### ABOUT YOU:

Age: \_\_\_\_\_

Sex: ☐ Male ☐ Female

Marital status:

- ☐ Single
- ☐ Common Law
- ☐ Married
- ☐ Divorced
- ☐ Other (specify): \_\_\_\_\_

Ethnicity:

- ☐ Caucasian
- ☐ Asian
- ☐ African-Canadian
- ☐ East-Indian
- ☐ Hispanic
- ☐ Other (please specify): \_\_\_\_\_

-Number of children in household: \_\_\_\_\_

-Professions of Parents/Guardians: \_\_\_\_\_

#### ABOUT YOUR CHILD:

-Age of your child with Autism Spectrum Disorder: \_\_\_\_\_ Grade: \_\_\_\_\_

-What is your child's diagnosis on the autism spectrum?

- ☐ Autistic disorder
- ☐ Asperger's syndrome
- ☐ Rett syndrome
- ☐ Childhood disintegrative disorder
- ☐ Other (please specify): \_\_\_\_\_

-Does your child have any other current diagnosed conditions?

- ☐ Attention Deficit Hyperactivity Disorder / Attention Deficit Disorder
- ☐ Learning Disability
- ☐ Fetal Alcohol Syndrome
- ☐ Metabolic Disorders
- ☐ Mental health disorder (e.g., depression, anxiety)
- ☐ Neurological Disorder
- ☐ Other (please specify): \_\_\_\_\_

-Does your child have experience with any virtual reality games (e.g., computer, video, iPad games)?

- ☐ Yes
- ☐ No

*If you answered "Yes" to the above question, please move on to the next questions.*

*If you answered "No", this is the end of the form for you,*

ABOUT YOUR CHILD& VIRTUAL REALITY:

-What kind of virtual reality games does your child use? *Please check all that apply.*

- |                                                                   |                                                           |
|-------------------------------------------------------------------|-----------------------------------------------------------|
| <input type="checkbox"/> Computer games                           | <input type="checkbox"/> Video games (Playstation)        |
| <input type="checkbox"/> Motion games (Nintendo Wii, Xbox Kinect) | <input type="checkbox"/> Handheld games (Nintendo DS)     |
| <input type="checkbox"/> iPhone/iPad games                        | <input type="checkbox"/> Other (please specify):<br>_____ |

-What type of games does your child play the most?

*Please check all that apply, and put a star (\*) next to the type of game that your child plays most frequently.*

- |                                    |                                        |                                       |
|------------------------------------|----------------------------------------|---------------------------------------|
| <input type="checkbox"/> Adventure | <input type="checkbox"/> Dance         | <input type="checkbox"/> Fantasy      |
| <input type="checkbox"/> Racing    | <input type="checkbox"/> Shooting/ war | <input type="checkbox"/> Sports       |
| <input type="checkbox"/> Strategy  | <input type="checkbox"/> Yoga          | <input type="checkbox"/> Other: _____ |

-With whom does your child play virtual reality games?

*Please check all that apply, and put a star (\*) next to the option that is most common for your child.*

- ☐ Alone
- ☐ With family
- ☐ With peers in person
- ☐ With peers online (internet games, Xbox live, etc.)
- ☐ With a teacher or education assistant
- ☐ With a therapist (speech language pathologist, occupational therapist, behavioural consultant, etc.)

-For what reasons does your child use virtual reality games? *Please check all that apply.*

- ☐ For fun
- ☐ For therapy
- ☐ For school/learning
- ☐ Other, such as \_\_\_\_\_

-On average, how much time does your child spend using virtual reality games per week:

- ☐ 0-4hours /week
- ☐ 5-9 hours /week
- ☐ 10-14 hours /week
- ☐ 15-19 hours /week
- ☐ 20+ hours /week

## Appendix IV: Demographic Form for Youth with ASD

Age: \_\_\_\_\_ Grade: \_\_\_\_\_ Sex: ☐ Male ☐ Female

Ethnicity:

☐ Caucasian ☐ Asian ☐ African-Canadian ☐ East-Indian ☐ Hispanic ☐ Other: \_\_\_\_\_

What is your diagnosis on the autism spectrum?

- ☐ Autistic disorder
- ☐ Asperger's syndrome
- ☐ Rett syndrome
- ☐ Childhood disintegrative disorder
- ☐ Other: \_\_\_\_\_

Do you have any other current diagnosed conditions?

- ☐ Attention Deficit Hyperactivity Disorder / Attention Deficit Disorder
- ☐ Learning Disability
- ☐ Fetal Alcohol Syndrome
- ☐ Metabolic Disorder
- ☐ Mental health disorder (e.g., depression, anxiety)
- ☐ Neurological Disorder
- ☐ Other (please specify): \_\_\_\_\_

-I have played the following types of virtual reality games (*please check all that apply to you*):

- |                                                                   |                                                        |
|-------------------------------------------------------------------|--------------------------------------------------------|
| <input type="checkbox"/> Computer games                           | <input type="checkbox"/> Video games (Playstation)     |
| <input type="checkbox"/> Motion games (Nintendo Wii, Xbox Kinect) | <input type="checkbox"/> Handheld games (Nintendo DS)  |
| <input type="checkbox"/> iPhone/iPad games                        | <input type="checkbox"/> Other (please specify): _____ |

-My favourite types of games are (*please check all that apply to you and put a star \* next to your favourite*):

- |                                    |                                        |                                                |
|------------------------------------|----------------------------------------|------------------------------------------------|
| <input type="checkbox"/> Adventure | <input type="checkbox"/> Dance         | <input type="checkbox"/> Fantasy               |
| <input type="checkbox"/> Racing    | <input type="checkbox"/> Shooting/ war | <input type="checkbox"/> Sports                |
| <input type="checkbox"/> Strategy  | <input type="checkbox"/> Yoga          | <input type="checkbox"/> Other, such as: _____ |

-I use virtual reality games..... (*please check all that apply to you*)

- ☐ For fun
- ☐ For therapy
- ☐ For school / learning
- ☐ Other, such as: \_\_\_\_\_

-I play virtual reality games.... (Please check all that apply to you)

- ☐ Alone
- ☐ With family
- ☐ With friends in person

- ☐ With friends online
- ☐ With my teacher / education assistant
- ☐ With my therapist
- ☐ Other, such as: \_\_\_\_\_

-I usually spend \_\_\_\_\_ hours a day playing virtual reality games:

- ☐ Less than 1 hour a day    ☐ 1-2 hours a day    ☐ 3-5 hours a day    ☐ 5+ hours a day

## Appendix V: Social Stories

**\*: Indicates stories that were used in the gaming program**

### Angry

	Setting	Scenario Example- Angry	Action (Player)	Level of emotion intensity
*1	School	Avatar is having fun playing games with his friends at school when the teacher, in the middle of the game, says they only have two minutes left then it is time to clean up and do some school work.	Take five deep breaths and help the avatars clean up.	Slight
2	School	The avatar's teacher says the students can choose a book to read from the shelf. Avatar told his friend which book he was going to pick. However, when it was time to get the book, the avatar noticed his friend took the book he wanted.	Take five deep breaths and help the avatar write his name on the waitlist for his favourite book, then choose another book.	Slight
3	School	The avatar is playing catch with some kids at school. They are all taking turns throwing the ball to each other. When the ball is passed to the avatar, he keeps it to himself and will not pass to any of the other kids.	Take five deep breaths and wave your arms at the avatar and say "I'm ready!" to show him you are ready to catch the ball.	Moderate
4	School	The avatar is at gym class and asks his friend to pass him a skipping rope. His friend is currently engaged in a conversation with another classmate and doesn't answer him. The avatar asks 2 more times but his friend ignores him and doesn't pass the rope.	Take five deep breaths and help the avatar get the other avatar's attention.	Moderate
*5	School	The avatar brought his favourite Lego structure to school for show and tell. Some kids started playing with it. The avatar asked them to stop but they did not listen. The	Take five deep breaths and help the avatar gather the Lego and rebuild the structure.	Extreme

	Setting	Scenario Example- Angry	Action (Player)	Level of emotion intensity
		kids dropped the structure and broke it.		
6	Community	Avatar 1 and Avatar 2 played three games of Go Fish. Avatar 2 won all three games and Avatar 1 does not like losing.	Take five deep breaths and help Avatar 1 and Avatar 2 choose a new game to play.	Slight
7	Community	It is raining outside. The avatar has been waiting at the bus stop for over 30 minutes but the bus has still not come. This is the second day in a row that there have been bus delays.	Take five deep breaths and help the avatar call for a taxi/look for alternate transportation	Moderate
8	Community	The avatar was waiting in the long line at the ice cream truck when some older kids budged in front of him and shoved him aside.	Take five deep breaths and help the avatar to buy an ice cream and ignore the older kids. Help the avatar find an adult to tell about the kids budging.	Extreme
*9	Community	The neighborhood children were playing outside. Their ball hit the avatar's window and broke it.	Take five deep breaths. After the kids apologize, help the children find an adult to help them clean up.	Extreme
*10	Home	The avatar loves the snow. He was having fun building a snowman when his dad suddenly told him that first he needs to help shovel the snow off the pathway, then he can continue building the snowman.	Take five deep breaths and help the avatar shovel the snow.	Slight
11	Home	The avatar bought a new bike but when he got home, he suddenly realized that there was a flat tire.	Take five deep breaths and help the avatar take the bike back to the store and exchange the it.	Slight
12	Home	The avatar was working on putting together a puzzle. As soon as she finished it, her dog ran over the puzzle and kicked some of the pieces.	Take five deep breaths with the avatar and then help her find the pieces and put the puzzle back together.	Moderate



	<b>Setting</b>	<b>Scenario Example- Angry</b>	<b>Action (Player)</b>	<b>Level of emotion intensity</b>
*13	Home	It is 6pm and the children have not done their chores today. So, there are toys all over the living room and Mom avatar cannot do all the housework by herself.	Take five deep breaths and find the avatar's children and help pick up the toys in the living room.	Moderate
*14	Home	The avatar was happy that her tomatoes have finally grown and look ready to eat. She was going to pick them the next day; however, when she went outside, she noticed that the birds have eaten almost all the tomatoes.	Take five deep breaths and help the avatar pick up the remaining tomatoes and put a net over her plant.	Moderate
*15	Community	The avatar always asks the neighbor's son to stop picking up the flowers in her garden but he doesn't listen.	Take five deep breaths and help the neighbor's son build his own garden so he can pick the flowers when they have grown.	Moderate
16	Home	After the avatar cooked his lunch, he placed it on a plate. He realized he forgot to get cutlery. When he returned from the kitchen, he saw the dog was eating the lunch.	Help the avatar take 5 deep breaths, take the dog outside, and prepare a new sandwich.	Moderate
17	Home	The avatar started studying. The dog was barking too much and the avatar could not do his homework.	Take five deep breaths and help the avatar feed the dog first or let the dog outside.	Moderate
18	Home	The avatar's young sister always likes to play with the avatar's laptop. The avatar keeps the laptop away from her but suddenly he sees she is playing with the keyboard.	Take five deep breaths and help the avatar find other toys for his sister.	Moderate
19	Home	The avatar's car was just serviced yesterday. The avatar tried to start the engine of his car but it wouldn't start. Since he is in a hurry to get to work on time, he needs to cycle to work now.	Take five deep breaths and help the avatar find his bike so he can cycle to work.	Extreme

## Scared

	Setting	Scenario Example- Scared	Action (Player)	Level of emotion intensity
1	School	It is demonstration day in the avatar's class. She is going to show her class how to make origami cranes. The avatar doesn't do presentations in front of her class very often.	Take five deep breaths and help the avatar fold the paper cranes.	Slight
*2	School	It was the teacher's birthday at school and she brought cupcakes for the class. However, there wasn't enough for everyone and the avatar thought she might not get one.	Take five deep breaths and help the avatar cut the cupcakes and help give them out.	Slight
3	School	The avatar's friend climbed up to the top of the monkey bars for the very first time but then she didn't know how to get down.	Take five deep breaths and help the avatar find a teacher and bring the teacher over to help the friend.	Moderate
4	School	The avatar and his friend are working on a school project to build a Lego structure. Time is flying and they are behind the plan. They need to finish building this tower in the next 10 minutes.	Take five deep breaths and help the avatars build a Lego structure before the timer goes off.	Moderate
5	School	The local firefighters are visiting the avatar's class today. As part of their demonstration, the firefighter turns on the fire alarm. The avatar doesn't like loud sounds and was startled.	Take five deep breaths and help the avatar put on his head phones before the alarm goes off, then follow the teacher and other students out of the building.	Extreme
6	Community	The avatar and his family went out for a walk at the park. It started pouring rain, the road got slippery, and the stroller with the baby inside got stuck in the mud.	Take five deep breaths and help the avatar push the stroller safely	Slight
*7	Community	The avatar and his sister were picking mushrooms with their uncle who knows which ones are safe. The uncle said "only pick the white mushrooms and be careful not to touch the red ones because they are poisonous!"	Take five deep breaths and help the avatars collect only the white mushrooms and don't touch the red mushrooms.	Slight

	<b>Setting</b>	<b>Scenario Example- Scared</b>	<b>Action (Player)</b>	<b>Level of emotion intensity</b>
8	Community	The avatar was playing at the park in the afternoon when she heard a growling sound from a bush nearby. She knew her dad was nearby but could not find him.	Take five deep breaths and help the avatar find her dad.	Moderate
9	Community	The avatar was the first to arrive at the park/playground for a playdate with his friends. He and his mom waited for a while but suddenly saw that something huge was moving behind bushes.	Take five deep breaths and help the avatar and his mom follow signs and get back to the car safely.	Moderate
10	Community	The avatar was shopping at the mall when she noticed that her wallet was missing. She thought she may have left it in a store change room or may have accidentally dropped it somewhere.	Take five deep breaths and help the avatar find her wallet and calm her down.	Moderate
11	Community	Child avatar and her mom went swimming in the community pool. This was child avatar's first-time swimming. She did not know how to swim and didn't know whether she could jump into the water.	Take five deep breaths and help the avatars find a life jacket and look for the shallow end of the pool.	Moderate
*12	Community	The avatar is camping with his brothers and his dad. It is really dark outside and after going to the outhouse, the avatar couldn't find the campsite. Every campsite looked the same and he was unsure of which way to turn.	Take five deep breaths and help the avatar turn on his flash light and find his campsite.	Extreme
13	Community	The avatar and his mom are taking the airplane to go see his grandparents. The avatar has never been on an airplane before. When he enters the airplane, he is startled by the shaking and the loud engine sounds.	Take five deep breaths and help the avatar find his ear plugs/earphones.	Extreme
14	Community	The avatar and his friends are on a boat. The avatar sees that there is a hole in the boat which is quickly filling with water.	Take five deep breaths. While the avatars are calling for help, help them plug up the hole.	Extreme
15	Community	The avatar is in the elevator/train with his dad when all the sudden it stops.	Take five deep breaths and help the avatar and his dad find the phone and press the button to call for help.	Extreme

	Setting	Scenario Example- Scared	Action (Player)	Level of emotion intensity
16	Home	The avatar was playing in the living room when he heard the sound of something dropping on the ground outside. It startled him.	Take five deep breaths and help the avatar pick up the cans from the toppled recycle bin.	Slight
17	Home	It is time to sleep and the avatar doesn't like the dark.	Take five deep breaths and help the avatar find her nightlight and turn it on.	Moderate
*18	Home	The avatar heard loud thunder outside. He was studying when suddenly the power/lights went out.	Take five deep breaths and help the avatar find a flashlight and turn it on.	Moderate
19	Home	After sewing the dress, mom avatar dropped the box of pins and they scattered all over the floor. Mom avatar started picking up the pins but saw that her baby was getting close to that area.	Pick up the baby and put her in the playpen, then help the Mom avatar collect the pins promptly.	Moderate
*20	Home	The avatar returned to her apartment after work. She realized the door was unlocked and her belongings were scattered all on the floor.	Take five deep breaths and help the avatar find the phone to call a police officer	Extreme
*21	School	The avatar loves her favourite toy. She couldn't find it and thought it was lost and has been searching in the room for a while.	Take five deep breaths and help the avatar ask a friend for help then find her toy in the room.	Moderate

## SAD

	Setting	Scenario Example- SAD	Action (Player)	Level of emotion intensity
*1	School	The avatar's brother is in high-school, and he usually gets good marks. He got his weekly spelling quiz back and discovered he got a bad mark on the test.	Help the avatar's brother practice spelling by playing a quick game of Hangman.	Slight
2	School	The avatar is painting in art class. He just started the painting when he spilled water on it, ruining the painting. He needs to start over.	Help the avatar find a new canvas so he can re-do his painting.	Slight
3	School	The avatar's best friend said she cannot play with her today.	Please help her find other kids to play with.	Slight
4	School	The avatar went to school on the first day and realized none of her friends from last year were in her class. She missed her friends and wanted to play with them.	Help the avatar find her friends at recess.	Moderate
5	School	The avatar is quietly building a small house with Lego in one corner of the classroom. The teacher then asks the students to form groups of four to build the tallest tower. The avatar looks around and sees that everyone seems to already have started forming a group.	Help the avatar join a group with less than 4 members.	Moderate
*6	School	The avatar made a special bowl for her mom in art class. The avatar accidentally dropped the bowl and it broke. She began to cry.	Help the avatar take five deep breaths then clean up and glue the broken pieces of the bowl together.	Extreme
7	Community	The avatar was at the beach with her family and was building a sand castle. Suddenly, a big wave destroyed part of the castle.	Help the avatar take a deep breath, then find a shovel and rebuild the castle.	Slight
8	Community	The avatar waited all summer to watch the sequel to her favourite movie. It was opening day and she waited in line to buy tickets but found out that the tickets were all sold out.	Help the avatar take a deep breath, then buy the next possible ticket (online/at the counter) or drive the avatar to another theater.	Moderate
*9	Community	The avatar's teacher told the class that some families are unable to buy enough food for their family and are hungry. The avatar felt bad when he heard about this and wanted to help by buying them some food.	Help the avatar buy some canned food items from the store.	Moderate

	Setting	Scenario Example- SAD	Action (Player)	Level of emotion intensity
10	Community	The avatar just started learning how to ride a bicycle and she always falls down. All of her friends ride their bikes around the neighbourhood together and the avatar wants to join them.	Please help the avatar find his balance bike.	Moderate
11	Community	The avatar was playing with his favourite stuffed bear when he accidentally ripped off the bear's ear.	Please help the avatar sew the ear back on to the bear with help from his mom.	Moderate
*12	Community	The avatar went skiing with his friends yesterday and had a bad fall. He went to the hospital and found out he had broken his leg. The doctor told him he will not be able to ski for the rest of the season and that he needs to strengthen his leg.	Help the avatar choose some different activities he can do while his leg heals.	Extreme
*13	Home	The avatar is so excited to bake an apple pie with his grandma. She asks him to find the apples. The avatar looked around but he couldn't find any apples in the house. Her grandma says "it's okay because can pick some from the tree in the backyard."	Please help the avatar pick the apples from the backyard.	Slight
14	Home	The avatar loves to bake cakes for her family. She is baking a cake for her aunt's birthday. When she takes the cake out of the oven, it is lightly burnt on the edges.	Help the avatar make a new cake.	Slight
*15	Home	Child avatar and mom avatar are at the dinner table. Child avatar asks mom to take him to the movie sometime today. Mom tells him she cannot as she has to wash the dishes.	Help mom avatar to wash the dishes so there is time to take child avatar to the theater.	Moderate
16	Home	Yesterday, the avatar was cooking with his mom and burned his finger. His friends were coming over to play with playdough but he couldn't do it because his finger was too sore.	Help the avatar choose some other fun activities he can do.	Moderate
17	Home	The avatar bought his mom flowers for Mother's Day using the money he had saved. He hid the flowers in his closet. After coming home from school, the flowers were all wilted and looked like they were dying.	Help the avatar pick up red and yellow flowers from the garden and find a vase in which to put the flowers.	Moderate
18	Home	The avatar and his neighbor have been best friends for 3 years, but his neighbor is moving to another city.	Help the avatar copy down each other's email addresses, then help pack and move boxes or choose toys to swap.	Extreme

## Happy

	Setting	Scenario Example- Happy	Action (Player)	Level of emotion intensity
1	School	When the avatar walked into his classroom after lunch, he noticed a TV in the room. The teacher announced that the class will be watching a movie about polar bears for science class today. The students are all excited.	Help the avatar find the polar bear movie to play for the class.	Slight
*2	School	The teacher in the avatar's class is partnering up the students for a tower-building activity. Avatar is partnered with avatar2. He enjoys working with avatar2.	Help avatar and avatar2 find the pieces to build the tower.	Slight
3	School	The avatar's class just got a new class pet, a hamster, for the science unit. He's always had an interest in pets and the teacher assigned him to feed the hamster every morning.	Help the avatar find food to feed the hamster.	Moderate
4	School	The avatar just found out that her class has won a pizza party. Since she is the class representative, she gets to survey the class about what toppings they like.	Help the avatar select three favourite toppings and put them on the pizza.	Extreme
5	Community	The avatar was on a whale watching tour with her family. She was told that she may not see any whales today. Suddenly, a couple whales peered out of the waves next to the boat.	Help the avatar take pictures of the whale as it surfaces.	Moderate
6	Community	The community centre near the avatar's house built a new playground for kids. She is so excited.	Help the avatar find the playground by following signs to the playground.	Moderate
*7	Community	Mom avatar's son performed at the concert and she was proud of him. Her son loves to play guitar so she is going to buy him a new one.	Help Mom avatar choose a guitar for him	Moderate
8	Community	The avatar has been bowling for 2 years. She just scored 2 strikes in a row!	Put your arms up to cheer, then find the avatar and give her a high-five.	Extreme
9	Community	Avatar's friend trained for a long time to run the 10 km race. Avatar is very excited and looking forward to this run. Yesterday, he successfully achieved his personal best.	Give avatar his gold medal.	Extreme

	Setting	Scenario Example- Happy	Action (Player)	Level of emotion intensity
10	Community	The avatar wanted a pet dog for a long time. The avatar just got a puppy from his dad.	Please help the avatar play fetch with the puppy.	Extreme
*11	Community	The avatar graduated from high school today. His family is going to have a party to celebrate. They are going to the store to choose a dress.	Help the avatar choose the appropriate dress.	Extreme
*12	Home	The avatar finished washing the dishes. The avatar can now do something fun.	Play a catching game/dance with the avatar.	Slight
13	Home	The avatar is excited to go walking in the woods with a group of friends tomorrow. She is in charge of making some sandwiches for the picnic.	Help the avatar pick up the ingredients for preparing the sandwiches.	Slight
14	Home	The avatar received a birthday card from her granny in Ireland. She was also surprised to find \$20 tucked in the card with which to buy a present.	Help the avatar buy/choose a present at the toy store that is \$20 or less (or write a thank you note to granny).	Moderate
15	Home	The avatar's friends are over to play and they are doing their favourite activity, jumping on the trampoline. Everyone is smiling and laughing.	Jump with the avatars as high as you can and reach your hands in the air.	Moderate
*16	School	For the graduation ceremony, the avatars are decorating their house with balloons and streamers. They invited friends to come over and are excited.	Help the avatars put up decorations.	Moderate
*17	Home	The avatar is listening to music in her room. Her mom enters and tells the avatar that they are leaving for a surprise vacation to the avatar's favourite place.	Help the avatar pack for the trip.	Extreme



## Appendix VI: Scenarios Map

Emotion & Intensity Context	Angry			Scared			Sad			Happy			Total
	Slight	Moderate	Extreme	Slight	Moderate	Extreme	Slight	Moderate	Extreme	Slight	Moderate	Extreme	
Home	Snow shovelling	-Tomatoes -Toys all over			Thunder	Broke into apartment	Apple pie	No movie		Finish dishes		Surprise vacation	9
School	No time to play		Lego structure	Cupcake for all	Show & tell		Bad mark		Broken bowl	Partner to build a tower	Decoration for grad		8
Community		Neighbour's flowers	Ball hit window	Mushrooms		Camping		Unable to buy food	Ski accident		Play guitar	Graduation	8
Total	2	3	2	2	2	2	2	2	2	2	2	2	25

## **Appendix VII: Think Aloud Questions**

1. What do you think about the visual design of the game? (ideal/ currently)
2. What do you think about the speed of the dialogues? (ideal/ currently)
3. What is your impression from the content of the game – the different stories/scenarios? (ideal/ currently)
4. What do you think about the feedback (visual and auditory) that is given at the end of each scenario? (ideal/ currently)
5. Currently we have the scores as time, or number of items, or %. There is also an option to provide the scores in more of a general term, such as ‘excellent’, ‘very good’, etc. What are your thoughts on this? (ideal/ currently)
6. The mini games are meant not only to show ways of collaboration and solving situations, but also to be fun. What do you think about them? Any ideas for other fun games we can include?
7. How comfortable are you in navigation and gestural tracking of the system? (ideal/ currently)
8. How can we improve the game? Do you have any suggestions? (probe: which aspects)
9. In general, what types of games do you like?
10. Here are some images for the emotions – which set do you prefer?

## **Appendix VIII: Interview Guide for Barriers in Technology Adoption**

In this study, the term ‘technology’ was defined as any types of devices, systems, and programs such as computer-based games, virtual realities, robots, and augmented realities.

1. What are the barriers in adopting novel technologies in the field of ASD? (Probe: Which one is more important?)
2. What factors can determine know-do gap among stakeholders with ASD in adopting new technologies?
3. What do you think or perceive about tensions that exist in adopting assistive technologies among stakeholders with ASD? (Probe: How can we remove these tensions)
4. Which stakeholders are in charge of making decisions in using assistive technologies in population with ASD? (Probe: Which ones do you think is more influential that we need to speak to first? What is the hierarchy?)
5. Could you describe a “process” of how a researcher can target all these stakeholders and disseminate findings effectively?
6. Which strategies do you think are effective to increase uptake of new technologies among stakeholders with ASD?
7. As there are multiple stakeholders in making decisions in adopting assistive technologies (i.e., “families”, “organization manages”, “clinicians”, “decision makers”), how do you think disseminating strategies should be used/adapted for each of them?
8. Do you think low use of assistive technologies among stakeholders of ASD is because of lack of awareness/ineffective knowledge dissemination or because of doubts in usage or effects of using technologies among stakeholders? (Probe: Why, can you please explain? How can we address this?)
9. Do you have anything else related to use of technologies among individuals with ASD that we did not cover and you like to share?